School of Public Health

Quality of Life for Adolescents

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Statement

This thesis is my own work and has not been submitted previously, in whole or in part, in respect of any other academic award.

Lynn Meuleners

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Abstract

Assessments of quality of life (QOL) for adolescents have received relatively little attention in the literature. Although there is no consensus on the definition of adolescent QOL and what aspects should be measured, it is generally accepted that QOL is a multi-dimensional construct. Issues related to adolescent QOL bear special considerations since experiences of adolescents are substantially different from those of adults.

The aim of this study is to provide a better understanding of adolescent QOL by assessing the impact of determinants of QOL over a six-month period. The study will also evaluate the measurement properties of the latent factors underlying adolescent QOL based on a second-order confirmatory factor analysis. A recursive structural equation model is then proposed to determine the direction and magnitude of the interdependent effects among the latent factors.

The Quality of Life Profile Adolescent Version (QOLPAV), a generic 54-item questionnaire was utilised. It was administered to 251 adolescents without a chronic condition and 112 adolescents with a chronic condition at baseline and the cohort of 204 adolescent without a chronic condition and 96 adolescents with a chronic condition at six months. Stratified sampling was used to recruit the adolescents from high schools in the Perth metropolitan area. Subjects were aged 10 to 19. A non-categorical approach was utilised to recruit adolescents with a chronic condition. To account for the hierarchical effects of the adolescents nested within schools multilevel modelling was undertaken to explore the potential determinants of adolescent QOL. The results of the baseline questionnaire found no significant difference in the overall QOL scores between adolescents with and without a chronic condition with the majority of both groups reporting a positive QOL. Age, perception of physical health, the amount of control perceived in his/her life and the opportunities available were found to be significant predictors for adolescent QOL. However, as expected, health was rated poorer, with more sick days reported by chronically ill adolescents.

The results of the second-order confirmatory factor analysis suggested that adolescent QOL may be measured by five underlying constructs namely *social*, *environment*, *psychological*, *physical health*, and *opportunities for growth and development*. The interdependent relations among these constructs identified the *environment* factor as primary, exerting both direct and indirect effects on the other four factors. A multivariate analysis of variance (MANOVA) also revealed no difference between chronically ill and healthy adolescents in their perceptions of the five constructs.

Multilevel longitudinal analysis was performed to explore and quantify the variations in QOL over the six-month period. Although a large proportion of the variation can be accounted for by the covariates perceptions of physical health, age, control and opportunities, 38% of the variability in QOL scores was actually due to time. Similar to the baseline results, there was again no significant difference in the overall QOL scores between chronic and non-chronic adolescents at six months. Health was again rated poorer, with more sick days reported by chronically ill adolescents. The majority of both groups reported a positive QOL. Only 1% of the adolescents (non-chronic) reported a problematic QOL at baseline, which increased to 2.5% (non-chronic) at six months. There was also no significant change between the baseline QOL scores and those at six months. However, the *social*, *physical health* and *opportunities for growth and development* composite factor scores showed a decrease for both groups over the six months.

The findings indicated that adolescents with a chronic condition do not view themselves different from their healthy counterparts in terms of QOL. The study enhanced our understanding of the effects of the broader determinants of adolescent health through a QOL perspective.

The perceptions that teachers, parents and health professionals have on the relative importance of different aspects of QOL for the adolescent with a chronic illness were separately explored using a three round Delphi study. The first round questionnaire identified the level of importance each of the three panels attached to sixteen aspects relating to QOL. Panelists were also encouraged to provide additional comments on why they felt a particular item was important to the chronically ill adolescent's QOL. In round two, panelists were asked to prioritise the items in order of importance whereas round three attempted to achieve consensus within each of the panels. Differences between and within each of the panels in the prioritisation of item importance in round one and round two were evident. However, consensus was achieved in round three except for the prioritisation of very important items by the panel of teachers. Items identified by all three panels as extremely important included the *adolescent's attitude*, *family relationships* and *friendships with the same age group*. Themes to emerge from the qualitative responses to the open-ended questions included the adolescent "*not wanting to be different*" and the importance of a "*positive attitude*". The majority of the three panels also perceived the QOL for the adolescent with a chronic illness to be worse than their healthy counterparts.

Table of Contents

Chapter 1: Introduction

Chapter 2: Literature Review: Quality of Life

Chapter 3: Methodology

Chapter 4: Assessing Measurement Properties

Chapter 5: Determinants for Adolescent Quality of Life

Chapter 6: A Longitudinal Assessment for Adolescent Quality of Life

Chapter 7: A Delphi Study

Chapter 8: Conclusions, Implications and Recommendations

List of Tables

List of Figures

List of Appendices

List of Abbreviations

Confirmatory Factor Analysis	CFA
Exploratory Factor Analysis	EFA
Quality of Life	QOL
Socio-Economic Status	SES
Structural Equation Models	SEM

CHAPTER 1

INTRODUCTION

CHAPTER 1

Introduction

"The world can function without it (quality), but life would be so dull as to be hardly worth living. In fact, it would not be worth living. The term worth is a Quality term. Life would just be living without any values or purpose at all."
Pirsig, 1974.

1.1. Adolescence – "A Period of Stress and Storm"

Adolescence is a period of transition that is based on childhood experiences and accomplishments, with the individual ultimately aspiring to become a mature, independent and responsible person. Additionally, it is a preparatory period requiring the accomplishment of defined developmental tasks in order to attain satisfactory adjustment to adulthood (Blum, 1992).

Adolescence begins at puberty, with the associated physiological changes having psychological and social significance for adolescent boys and girls (Blum, 1992). There is considerable variation in the onset of puberty and the manner in which each individual copes with the multiple developmental events associated with pubertal changes.

The chronically ill adolescent also experiences the same developmental tasks and challenges experienced by the healthy adolescent. However, the ability to master these tasks and cope with the typical stresses of adolescence can be made more difficult by the presence of a chronic illness. Physiological aspects of the disease itself, medications and other forms of treatment, frequent hospitalisation, disruptions in daily activities and alterations in family relationships are some of the potential factors that may restrict normal development in the chronically ill adolescent (Midence, 1994; Newacheck, 1991; Zani et al, 1995; Blum, 1992; Pless, 1989; Garrison et al, 1989).

1.2. Adolescent Health in Australia

Adolescent health concerns in Australia have shifted markedly in the past decade. Prior to 1990, adolescent health was confined largely to clinical areas of activity in small adolescent medicine units in paediatric departments. However the emphasis on a public health perspective has been one important step in changing the profile of adolescent health. This shift has come about in part, as a result of the growing number of young people surviving to adulthood with diseases that in the past carried a very high mortality in childhood (Australian Institute for Health and Welfare, 1999). Other important health problems such as asthma and mental illness also appear to have become more common (Australian Institute for Health and Welfare, 2000). This growing burden on the health care system has brought a reconsideration of earlier strategies for health improvement.

One of the major responses to the population's shifting health profile has been to emphasize preventive and health promotion interventions. Current evidence suggests that the levels of many lifestyle-related risk factors for major causes of disease burden are higher in youth than in other age groups. The continued poor, or worsening health risk profile of youth, suggests that future population-wide morbidity and mortality patterns are unlikely to shift in a favourable direction as successive cohorts enter adulthood (Australian Institute for Health and Welfare, 2000). This recognition underlies the growing public health interest in the scope for preventive interventions during adolescence.

It is well established that a high standard of living, ready access to health care, and programs to encourage healthy living, all contribute to a healthy lifestyle (Australian Institute of Health and Welfare, 2000). However, the stress and demands of adolescence can put many young people at risk of physical, developmental, psychological and behavioural problems. The challenges faced by today's youth are reflected in a host of problems including suicide, depression, alcohol and substance use problems (Australian Institute of Health and Welfare, 2000). The 1995 Western Australian Child Health Survey provided further evidence of increasing emotional and behavioural problems for adolescents over the last ten years. Indeed, almost one out of five children/adolescents suffer from a mental problem or disorder within any six-month period (Zubrick et al., 1995). Furthermore, the rate of completed suicide for young Australians (16.4 deaths per 100,000 young people 15 to 24 years of age) is among the highest in the world (Australian Institute of Health and Welfare, 2000). While the onset of most mental disorders occurs in mid-to-late adolescence, if these problems become chronic they can affect the future psychosocial development of the adolescent (Raphael et al., 1996).

1.3 Quality of Life Perspective

Adolescent quality of life (QOL) is fast becoming an important focus for public health researchers and practitioners. Traditional definitions of health focus on illness and direct attention towards mortality and morbidity indicators. However, examining adolescent health and its determinants within a QOL perspective achieves various aims that go beyond other approaches. A QOL approach draws attention to determinants of health at a range of levels including psychological, social and physical domains (Raphael et al., 1996). It can include structural factors such as educational and employment opportunities, personal factors such as attitudes and beliefs, and community factors. It can encompass other aspects of life such as the importance of peers, family, educational and employment opportunities (Raphael et al., 1996). Quality of life measures can also help identify individuals at risk for poor health outcomes, even in the absence of diagnosable illness or other health problems.

One can trace the modern conceptual basis of QOL to the World Health Organization's definition of health as a "...state of complete physical, mental and social well-being and not merely the absence of disease and infirmity" (WHO, 1947). Since then it has assumed heightened awareness with the rapid evolution in both social and medical programs. Despite its growing popularity, QOL research continues to be hampered by a lack of conceptual clarity regarding precisely what is meant by quality of life. The lack of agreement results from the fact that QOL is a complex concept and can be interpreted in any number of ways. Often QOL has been used for an assortment of physical functioning and psychosocial variables (Spieth & Harris, 1996), while other definitions have emphasized components of happiness and satisfaction with life (Raphael et al., 1996).

QOL assessment for the adolescent, has received little attention in the literature. The problem of conceptualisation and determining what aspects of QOL to assess for adolescents is difficult, since life experiences and daily activities of adolescents differ substantially from those of adults. The lack of appropriate validated instruments to measure adolescent QOL, has also limited study for this group. Many established QOL instruments have been developed for highly selected groups, which make them unsuitable for the general adolescent population. Due to the complex nature of the QOL construct, there is also no standard form of measurement. Therefore, the use of a single instrument or a combination of instruments that capture the multidimensional nature of QOL is essential. It is also generally acknowledged that research should be directed toward understanding the QOL experienced by the individual, rather than making assumptions about its nature and patterns (Pal, 1996; Eiser, 1997). Sensitivity to developmental milestones and an awareness of the impact of cognitive development is necessary to increase both the accuracy and validity of QOL evaluations (Eiser, 1997; Spieth & Harris, 1996). For example, it is well documented that adolescents' concerns about their appearance and body image are paramount (Jenney & Campbell, 1997). A QOL instrument should take such aspects into account since problems from a minor ailment (e.g. acne) can cause more distress than it would for another age group.

1.4. Determinants for Adolescent Quality of Life

Current evidence has suggested that demographic variables, environmental characteristics and family composition are all potential risk factors influencing adolescent health (Eiser, 1997; Raphael, 1996). The literature has also identified selected factors such as age, gender and social economic status that influence adolescent QOL (Lindstrom & Kohler, 1991). Advocates of an expanded concept of QOL encourage research into the physical environment of individuals as important predictors for both physical and mental health and well-being (Bowling, 1995; Raphael et al., 1996). Findings from social epidemiological studies have also identified factors such as social support (Berkman & Breslow, 1983), employment, and leisure opportunities to be supportive of health (Raphael et al., 1996). In addition, coping strategies have been implicated in affecting QOL outcomes (Brown et al., 2000; Grey et al., 1998). However, little is known about the associations between QOL and other factors, or the complex interplay of these variables with respect to the QOL domains (Raphael et al., 1996). Furthermore, the majority of investigations have adopted cross-sectional designs that often lead to inconsistent findings (Fayers & Machin, 2000).

The aforementioned literature highlights the complex interplay between environmental, biological and behavioural influences that impact upon the physical and mental health of adolescents. The cultural and social context, within which adolescent development takes place, is also another important aspect of concern and warrants further research.

1.5 Statement of the Problem

It is imperative that good mental and physical health enables the adolescent to enjoy the period that lays the foundation for adulthood. The lifestyles adopted by adolescents often continue into later years and influence long term prospects for health and well-being. There is a need for research that will enhance our understanding of QOL for adolescents with and without a chronic condition. Identification of relevant protective and risk factors will facilitate the implementation of potential intervention policies. The broader view of health determinants from a QOL perspective directs attention to these factors and appears to be promising for enhancing the physical and mental health of adolescents with and without a chronic condition.

1.6 Research Objectives

The aim of this study is to provide a better understanding of adolescent QOL. The study will attempt to identify the impact of key risk factors and protective factors on QOL for the adolescent with and without a chronic condition over a six-month period. The study will also quantify variations in QOL patterns with respect to relevant risk factors and protective factors. QOL will be assessed using self-reports obtained from participating adolescents, aged 10-19.

Specific objectives of this study are:

- To describe QOL based on self-reports by adolescents with and without a chronic condition;

- To investigate determinants and protective factors of QOL for adolescents with and without a chronic condition;

- To relate variations in QOL patterns to relevant risk factors and protective factors over a six month period;

- To assess the interrelationships between the identified domains (*physical health, psychological, social, environment,* and *opportunities for growth and development*) hypothesized to constitute QOL and determine if differences exist between adolescents with and without a chronic condition;

- To document and model the dynamic changes inherent in the QOL for adolescents with and without a chronic condition;

- To explore the perception of the importance of different aspects related to the QOL of the chronically ill adolescent by teachers, parents and health care professionals.

1.7 Significance of the Study

This study will make contributions in four aspects related to QOL for both adolescents with and without a chronic condition.

1. The combination of a prospective longitudinal methodology and the use of self-reports to identify factors influencing adolescent QOL for adolescents with and without a chronic condition are a unique feature of this study.

2. The study will identify risk factors and protective factors that influence adolescent QOL over a six-month period.

3. The study will examine the interrelationship among the various domains underpinning QOL for adolescents with and without a chronic condition.

4. The study will provide information about the stability of adolescent QOL over time.

To implement effective public health interventions, an understanding of the needs for the adolescent is required. By quantifying the effects of determinants of health through a QOL perspective, it is anticipated that priorities for public health promotion and interventions can be established.

1.8 Scope of the Investigation

Psychosocial aspects for chronic conditions such as coping techniques, depression and mental status were not included in this study.

Participation in the study was on a voluntary basis. It can be assumed that adolescents who chose to participate may be more motivated than the adolescents who did not. This may have introduced a possible selection bias, which limits the generalisability of the study's results.

1.9 Overview of the Thesis

The organization of the dissertation is as follows:

Chapter 2 reviews the literature pertaining to QOL issues, QOL for the adolescent with and without a chronic condition, conceptual framework and methodological issues in QOL research. The chapter also reviews the literature on known risk factors and protective factors for adolescent QOL.

Chapter 3 provides the overall methodology of the study. This chapter outlines the methods of sampling, data collection procedures and data analyses.

Chapter 4 describes the measurement properties of the Quality of Life Profile Adolescent Version (QOLPAV) questionnaire, based on the results of an exploratory factor analysis and a second-order confirmatory factor analysis. It also examines the interdependent effects among the five factors measuring QOL based on structural equation modeling.

Chapter 5 presents the results of descriptive analyses from the results of the first questionnaire.

Chapter 6 provides data from a second identical questionnaire administered six months later. These data are then utilised to test the hypothesis relating to QOL and its determinants, using multilevel modelling.

Chapter 7 describes the perceptions that teachers, parents and health professionals have of the importance of different aspects to the chronically ill adolescent's QOL using a three-round Delphi Study. The study also assesses the similarities and differences between the three panels in their perceptions.

In **Chapter 8**, conclusion and recommendations are presented along with research implications of the study findings. In addition, limitations of the study are addressed.

CHAPTER 2

LITERATURE REVIEW: QUALITY OF LIFE RESEARCH

CHAPTER 2

Literature Review: Quality of Life Research

2.1 Overview

Interdisciplinary conceptions of quality of life are reviewed. Research and theory supporting the need for routine quality of life assessment and intervention is also discussed. The literature is reviewed relating to the problems encountered by adolescents with and without a chronic condition. Finally, determinants of adolescent QOL are discussed.

2.2 Historical Evolution of Quality of Life

2.2.1 Historical Development

Over the last twenty years the quality of life paradigm has received widespread attention in the field of medicine. However to understand how this concept gained prominence a brief history of Quality of Life is warranted.

2.2.1.1 The Social Indicators Approach

Quality of Life has meant different things at different periods during this century. It entered the vocabulary of the United States towards the end of the Second World War. At that time government policies were initially directed towards restoring national welfare after the war. Quality of Life implied the "good life" or "material affluence" as evidenced by the possession of cars, houses, and other consumer goods (DeHaes & Van Knippenberg, 1984). Spare time and spare money for leisure activities were very much part of the "good" life scene.

The term "quality of life" became popular among politicians such as President Johnson who were interested in providing a platform to trumpet the success of their administration to the electorate. Politicians were familiar with the concept of quality of life through groundbreaking research undertaken by institutions such as The Russell Sage Foundation and the National Opinion Research Center at the University of Chicago (Fallowfield, 1990). At these institutions researchers used a social indicators approach to define quality of life. This approach replaced the economic one that had in the past been the way to conceptualize the success of a nation's health. Ebbs et al. (1989) claim that this shift in attitude was due to the major political and social upheavals of the "late sixties" which revealed a switch in emphasis from a materialistic view of quality of life towards personal freedom, leisure, emotion, enjoyment, simplicity, and personal caring. While researchers centered primarily on finding effective ways to measure quality of life often the selection of domains considered to be important were researcher-driven and reflected the priorities and interests of the individual researcher (Day and Jankey, 1993). Even though early work found statistically significant relationships between sociodemographic variables and people's QOL, these relationships were weak. It therefore became clear that there was more to QOL than simply the objective circumstances in which people live.

2.2.1.2 The Psychological Indicators Approach

The seminal work of Campbell and Rogers (1972) redirected the course of QOL research. They advocated that social or objective indicators were limited in their function and only served as an indirect indicator for measuring QOL. Moreover they showed that social indicators rarely accounted for more than 15% of the variance in an individual's QOL. Psychological indicators, which refer to the individual's subjective reaction to life experiences, were seen as accounting for additional variances not predicted by objective measures. Happiness, satisfaction and related attitudes became worthy of measurement in the psychological approach.

The 1970's also saw a heightening of interest in quality of life especially relating to issues of aging, health and illness. The view that "healthcare is a right" occurred during this period and was linked to the belief that the universal availability of health care would contribute to the equality of health. Major surveys were undertaken in the United States to investigate the interrelationship of objective and subjective conditions and the level of well-being of the population (DeHaes and Van Knippenberg, 1984). Findings from these studies helped researchers to promote a better quality of life. Similarly, work with the elderly population began to question the meaning and measurement of QOL with Maddox (1976) discussing aging outcomes in terms of life satisfaction. However, according to Strain (1990) the early impetus for QOL evaluations were just political attempts to evaluate social programs rather than evaluate medical therapies.

2.2.1.3 Medical Related Quality of Life

Concurrent with technological advances in medicine, patients started to demand that Doctors take a more humane and caring approach to their medical treatments. Historically, the overriding emphasis in the medical profession for the successful outcome of treatment for disease was measured in terms of the length rather than the quality of survival (DeHaes and Van Knippenberg, 1984). Quality of Life as an endpoint for the assessment of medical care was almost non-existent. However, by the early 1980's the concept was beginning to gain prominence in the medical field. Initially nurses and physicians used it to clarify the distinction between the medical and technical aspects of care (DeHaes and Van Knippenberg, 1984). The instruments used to measure outcomes were based on the physical functioning of the patient, the most common being the Karnofsky Performance Rating Scale and the Zubrod Index. However direct confrontation with the sufferings of patients led to health professionals paying more attention to the supportive care of patients - that is, aspects of care dealing with the "whole" person and not just the physical aspect of a disease.

This emphasis on the state of health as being important to an individual's quality of life is reflected in the constitution of the World Health Organization (WHO, 1947), which states that health, is " ...physical, mental and social well-being and not merely the absence of disease or infirmity". According to Fallowfield (1990) this definition suggests that illness compromise not only the biological integrity of man, but also his psychological, social, and economic well-being. Thus QOL is seen as a multidimensional phenomenon and any measure taken during treatment purporting to improve the QOL must address the impact that disease and its treatment is having on a variety of dimensions, not simply physical functioning.

Much of the pioneering work in QOL research has focused on cancer patients, with cancer QOL research associated with the highest number of instruments and publications (Fayers & Machin, 2000). Currently, measurement of QOL has grown to become a standard endpoint in many clinical and health related studies. In part, this is a result of the realization that many treatments for chronic conditions frequently fail to cure. It is also recognition that patients place greater emphasis upon non-clinical aspects of treatment than health professionals do. Today many patients request full information about the consequences of their disease and therapy, including impacts on QOL.

2.2.2 Adolescent Quality of Life

QOL assessment has received much less attention in pediatric and adolescent populations and it has only been recently that attention has turned to these groups. The 1989 Convention on the Rights of the Child stressed the right to "adequate circumstances for physical, mental, spiritual, moral and social development" for every child (Pal, 1996, p.391). It also determined that a child has a right to express his/her opinion freely, and have that opinion taken into account, and have a special place in a loving protective family. This view of health and well being is especially appropriate to QOL research where the focus on morbidity and mortality as outcomes is being steadily superseded by broader considerations of quality of life.

2.3. Philosophical Issues Relating to Quality of Life

2.3.1. What is Quality of Life?

Quality of Life is an ill-defined term. The World Health Organization (WHO, 1947) has declared health to be a state "...of complete physical, mental and social well-being, and not merely the absence of disease or infirmity." Many other definitions of both "*health*" and "*quality of life*" have been attempted, often linking the two and, for QOL, frequently emphasizing components of happiness and satisfaction with life (Fayers & Machin, 2000).

Conceptually the term "quality of life" is ambiguous. On the one hand there is the quality of an individual's life, a reflection of how well his/her life is going. But there is also a broader concept capturing the quality of the living conditions around an individual which are independent of the individual's own life. These living conditions can encompass the environment and culture of a given society. The politician, priest, nurse, doctor and the adolescent would all offer different definitions of what constitutes quality of life. While most people have an intuitive understanding of it, QOL is a very difficult concept to define due to its dynamic nature (Fallowfield, 1990).

When measuring quality of life relating to medical matters the literature suggests that a more precise and specific definition is needed. However trying to define the term explicitly in a manner, which would permit objective measurement, is another matter.

It is generally agreed that relevant domians of QOL may vary from study to study but can include general health, physical functioning, physical symptoms, emotional functioning, cognitive functioning, role functioning, social well-being and existential issues (Fayers & Machin, 2000; Patrick & Erickson, 1993; Ware, 1987). Broader definitions of QOL include aspects such as standard of living, quality of housing and job satisfaction (Ware 1995).

In a review of the literature DeHaes & Van Knippenberg (1984) note that definitions of QOL differ in two ways. First, some researchers define QOL as a global measure, or an overall evaluation of life. "A global measure can serve as a criterion when assessing the interrelations of different components of life and the overall sense of well-being for the patient" (DeHaes & Van Knippenberg, 1984, p.811). Other researchers (Hornquist 1982, Spitzer et al., 1981) define components or domains of life such as physical, social, psychological as contributing to QOL. Some domains are considered more important than others, and the choice of importance is often based on intuition since a "standard" definition is lacking (Aaronson, 1988). Other researchers have combined both. Limitations to these varied approaches can be due to the researcher not adequately describing the process that is used to select the outcomes or domains to be evaluated. Therefore it is recommended that a conceptual model which defines the attributes that subjects have in common and ways in which these attributes may be assessed, should be clearly identified in any QOL research (Schipper, 1990;Fayers & Machin. 2000; Raphael, 1996). Table 1 illustrates some of the definitions that researchers have used when conceptualizing QOL.

Table 1: Conceptualizations of Quality of Life **

Approach	Focus	Definition
Health-related	Persons with diseases	Quality of Life represents the functional effect of an illness and its consequent therapy upon a patient as perceived by the patient (Schipper et al., 1990)
	Persons with illness or disabilities	Quality of Life is recognized as a concept representing individual responses to the physical, mental, and social effects of illness on daily living which influence the extent to which personal satisfaction with life circumstances can be achieved (Bowling, 1991)
Social Diagnosis	Persons in communities	... the adjustment and life satisfaction of community members (Grenn and Kreuter, 1991)
Developmental Disabilities	Persons with developmental disabilities	Quality of Life is the outcome of individuals meeting basic needs and fulfilling basic responsibilities in community settings such as family, recreational, school and work (Schalock, 1990)
Social Indicators	Societies or communities	Statistics of direct normative interest that facilitate concise, comprehensive, and balanced judgments about the conditions of major aspects of society (Andrews and Whithey, 1976)
Center for Health Promotion	Adolescents	The degree to which a person enjoys the important possibilities of his/her life (Raphael et al., 1966)
Lindstrom Model	Children/adolescents	Quality of Life is the total existence of an individual, a group or society (Lindstrom, 1992)

*** Taken from Raphael, 1996*

2.3.2 Differences between Quality of Life and Health-Related Quality of Life

The concept of *"health related quality of life" (HRQOL)* was initially developed and operationalized with an ill adult population and refers to the specific impact of an illness or injury, medical treatment, or health care policy on an individual's QOL (Spieth & Harris, 1996). However the boundary between *"QOL"* and *"HRQOL"* is blurred with subtle differences distinguishing the two. The former term is more consistent with the WHO definition of health, which encompasses all the domains in human existence (Pal, 1996). It is an all-inclusive concept incorporating all factors that impact upon an individual's life. *"Health related quality of life"* refers to only those dimensions, which can be affected by health service intervention. Specifically, it refers to "the subjective and objective impact of dysfunction associated with illness or injury, medical treatment, and health care policy" (Spieth & Harris, 1996, p.176). While it has become fashionable to equate *"health"* with *"QOL"*, it is important to keep in mind that *"QOL"* is a much broader concept than health.

Other differences that have been identified in the literature are:

- The majority of HRQOL definitions contain the degree of function, the level of functioning, or the amount of satisfaction derived from functioning as the focal content whereas for QOL there is also a focus on needs as an alternate focal content to function;
- Definitions measuring HRQOL do not consider affect to be a component of the psychological content of HRQOL. All definitions rely on satisfaction as the major subjective component of HRQOL (Guyatt, 1999; Patrick & Erikson, 1993; Fayers & Machin, 2000).

2.3.3 Conceptualizing Adolescent Quality of Life

It is apparent that adolescents differ from adults in their views about quality of life. While the elderly rate their ability to live independently as paramount, adolescents are less concerned with the achievements of basic functional tasks (Eiser, 1997). They are more concerned with having lots of friends, dating, parties and the accomplishments of other developmental tasks that are important to their emotional and physical growth (Whalley & Wong, 1991).

One problem encountered in conceptualizing a definition for adolescent QOL is that their perspective varies substantially across different stages of development (Spieth & Harris, 1996; Eiser, 1997, Jenney & Campbell, 1997). For example, hair loss associated with chemotherapy treatments for cancer may be especially disturbing during late adolescence when appearance, relationship with peers and social functioning are critical (Eiser, 1997).

The perception of health by the adolescent has also been found to differ to that of adults, with health and illness defined as separate concepts by the younger age group rather than a continuum (Jenney & Campbell, 1997). In a cross-sectional study of 218 adolescents aged 11- 18, 38% of 11-12 years old, 30% of 13-14 year olds and 18% of 15 and older, defined health as the "absence of illness" (Millstein et al., 1993).

Cognitive development is another important issue that needs to be considered when conceptualizing and measuring adolescent QOL issues (Jenney & Campbell, 1997). It has been argued that cognitive maturity is as important as an increase in chronological age as an indicator for a more sophisticated understanding of the concepts of health and illness (Jenney & Campbell, 1997). Parkin et al. (1997) developed a QOL questionnaire for children and adolescents with spina bifida. They found that the most frequently occurring items in the 5-12 year age group were identified as belonging to the social and emotional domains. However, in the 13-20 year age group, items identified with the social, emotional and physical domains were more common.

2.3.4 Theoretical Frameworks Guiding Definitions for Adolescent QOL

The concept of adolescent QOL was developed from frameworks that were initially developed with adult populations. They emphasized domains of adult functioning such as economic status, job performance, psychological functioning, social interactions, relationships, physical symptoms and functioning (Schipper, 1990). However not all these domains are appropriate for an adolescent population.

Although a universal theoretical perspective is lacking for adolescent QOL, several implicit theoretical perspectives have guided research. The biomedical model of health is a very useful but limited biological model of sick care that has provided a framework for the management of illness. An alternative, more comprehensive model is the biopsychosocial model. The multidimensional definition of health proposed by WHO (1947) is consistent with a biopsychosocial model of functioning which emphasizes the interdependent and mutually influential relationships among the biological, psychological, the individual, family and community subsystems involved in an adolescent's functioning (Engel, 1977).

Recent conceptual models include Lindstrom's (1992), which identified four spheres within which he examined quality of life issues related specifically to the adolescent. The "*Personal*" sphere focuses on physical, mental and spiritual resources while the "*Interpersonal*" sphere consider family structure and function, intimate friends and social networks. The "*External*" sphere includes aspects of work, income and housing while the "*Global*" sphere examines the societal environment, specific cultural aspects, human rights, and social welfare policies. While his work has been praised for its potential range of adolescent health determinants it has relied primarily on the views of parents.

Raphael et al's, (1995) conceptual framework also specifically relates to an adolescent population. It examines the personal characteristics of the adolescent (*Being*), aspects of their immediate environment (*Belonging*) and daily activities/ opportunities for growth (*Becoming*) and how they are related to health outcomes.

However controversy exists as to the importance of theory/conceptual models in the choice and measurement of adolescent QOL measures. Some researchers (Drotar, 1998) feel that the specific scientific question and goals of the research should guide in the development of measures as well as the choice of assessments for particular studies. Others (Spieth & Harris, 1996; Eiser, 1997) feel that scientific knowledge would be best served by developing a more unified and integrated theoretical approach to the assessment for pediatrics and adolescent QOL.

2.3.5 Health System Based Reasons for Assessing Adolescent QOL and HRQOL

There are four reasons why broader outcome measures are of interest to the health care system. First, advances in medical research have shifted health care resources from the diagnosis and treatment of infectious diseases to the prevention and control of chronic diseases. (Revicki, 1989). Consequently as the goals of treatment are changing, different measures of outcome are required. QOL measures can provide useful descriptive information regarding the health status of adolescents with a chronic health condition or injury (Levi and Drotar, 1998). This can include information regarding the current patient's status, comparison of patients at different disease states, and an assessment of the progress in response to medical treatment.

Second, evaluation of children's QOL can facilitate the identification of adolescents with different levels of morbidity (Eiser, 1995; Revicki, 1989). Bergner (1989) argues that treatment and its related side effects may affect all aspects of a patient's life. Therefore the evaluation of a clinical intervention requires a complete understanding of the impact of different treatments on the adolescent's physical, social and psychological status (Revicki, 1989). Use of a QOL outcome measure may facilitate the identification of acute and/or chronic dysfunction following an illness or treatment, or identify individuals who are at risk for the development of psychological difficulties (Eiser, 1995; Spieth & Harris, 1996).

Third, adolescent QOL assessments have the potential to improve the clinical decision-making process of health professionals by increasing their understanding of the experiences of the patient. The inclusion of QOL outcomes expands the evaluations of the quality of medical care by allowing assessment of the impact of the condition and related treatments on the child/adolescent's functioning and lifestyle (Spieth & Harris, 1996).

The fourth reason is to provide information for the planning of services and ongoing interventions to assist adolescents. Furthermore, where alternative treatments are available for an illness or disease, measures that are sensitive to morbidity associated with different treatments are necessary to document the costs versus benefits of available treatment (Eiser, 1995; Jenney & Campbell, 1997). By providing information about the patient's subjective experience and morbidity associated with different treatments QOL can facilitate the clinical decision making process.

2.4. Methodological Issues

There are many different approaches to the measurement of QOL all reflecting different theoretical perspectives. To date, the techniques and concepts used to evaluate QOL have been largely borrowed from psychology, sociology, and educational psychology (Fallowfield, 1990). The term "measurement" in the physical sciences conveys the impression of a precise operation carried out in a controlled laboratory and producing results, which are expressed in terms of standardized units of measure. However this scene is in direct contrast to social scientists as they attempt to develop measures to evaluate quality of life. Not only is quality of life defined in many different ways but there is also conflicting opinion as to how it is to be represented and whether it should or could be quantified (Fallowfield, 1990). As a result there have been a number of distinct and largely uncoordinated efforts to develop measures for QOL. While most measures have focused on adults of which the most widely used are the Nottingham Health Profile, the Sickness Impact Profile and the SF-36 there is an increasing interest in the development of adolescent QOL instruments.

2.4.1 Adolescent Quality of Life Measures

Child and adolescent QOL measures can be classified across three dimensions:

- The way that the measurement is conceptualized;
- The type of scores they produce;
- The range of concepts and populations assessed.

(Spieth & Harris, 1996 Guyatt et al., 1999; Levi & Drotar, 1998, Jenney & Campbell, 1997).

2.4.1.1 Conceptualizations of the Measurement – " What to Measure"

Some QOL measures consist of a single question that essentially asks, "How is your Quality of Life" which yields very limited information (Guyatt et al., 1997). More commonly QOL questionnaires are made up of a number of items or questions. These items can be grouped to form a number of domains – for example social domain (also called dimensions). A domain refers to the area of behavior or experience that the researcher is trying to measure (Guyatt et al, 1997; Fayers & Machin, 2000). Generally the four major domains of quality of life accepted by most researchers include the following categories:

- Physical/ functional status;
- Psychological status and well-being;
- Social interactions;
- Economic and/or vocational status (Fayers & Machin, 2000).

Other domains can also include areas such as mobility, self-care, life satisfaction (Guyatt et al., 1999). Some dimensions are conceptually simple, and well defined, for example: symptoms. Other domains (for example: psychological) are less well-defined in many people's perceptions and are not directly and reliably measurable (Fayers & Machin, 2000). They are commonly described as latent construct or factors.

Most researchers agree that it is a futile exercise to try and measure everything about an adolescent's QOL. Instead it is recommended to focus on a range of domains even when the study may only be interested in one or two areas (Guyatt et al., 1999). For some instruments researchers evaluate the relative importance of each domain with some being weighted more heavily than others. However, often the items are equally weighted which assumes that each domain is valued as equal (Fayers & Machin, 2000).

Basically, two primary conceptual models for pediatric/adolescent QOL assessment exist: the utility model and the health status measurement model. The original objective of the utility approach was to direct the allocation of medical funds whereas health status measurements assess the impact of health care policies on the health of the general population (Spieth & Harris, 1996).

2.4.1.2 The Utility Model

The utility model is derived from economics decision theory. It incorporates single score scales which are used to compare alternative treatments based on the subjective preferences of medical treatment effects (Spieth & Harris, 1996; Eiser, 1997; Jenney & Campbell, 1997). Respondents are asked to image a particular health condition and to express their relative preference for that condition as a choice between quantity and quality of life (Schipper, 1990, Spieth & Harris, 1996). Basically, respondents are asked to decide between a shorter life with less dysfunction or a longer life with more dysfunction. Responses can then be quantified in terms of Quality Adjusted Life Years (QALYs). The utility approach reduces questions of health funding allocation to a statement of cost-benefit ratios expressed by a single numeric index (Spieth & Harris, 1996). However critics of the utility model state that the use of a single score does not allow examination of the effects of treatment or health status on the different QOL domains (Guyatt et al., 1999). Other criticisms of the utility approach is that it may not be applicable to pediatric and a younger adolescent population due to the difficulty of this group in formulating a preference between quality and quantity of life (Spieth & Harris, 1996).

2.4.1.3 Health Status Model

Health status instruments measure many different aspects of QOL and are designed for use with a variety of conditions (Spieth & Harris, 1996). The health status approach gives a comprehensive assessment of important aspects of QOL and has been used to identify dysfunction and to evaluate the efficacy of interventions (Jenney & Campbell, 1997; Eiser, 1997). Each domain is assigned a score that can be compared with other domains and the overall index score. Health status measures have been used with children, adolescents and parents as the informant for a minor (Eiser, 1997). However critics state that the assessment may overlook changes in the child's health. They also tend to be quite long and time consuming. Additionally, they yield multiple scores that are not useful in cost-benefit analysis of alternative medical treatments (Jenney & Campbell, 1997; Eiser, 1997).

The issue of whether to use a single index or profile score has not been adequately addressed in pediatric/adolescent QOL matters and varies according to the research question (Spieth & Harris, 1996). It has been suggested that health status and utility scores may measure different aspects of health and QOL. Therefore a combination of these approaches has been recommended (Revicki, 1989).

2.4.2 Classification of QOL Scores

Patrick & Erikson (1993) suggest three general classifications for QOL measures:

- Single indicators/indexes;
- Profiles;
- Battery approach.

2.4.2.1 Single Indicator Approach

The single indicator approach focuses on one domain such as pain and can be used to summarize QOL for that particular domain. An example is the Play Performance Scale for Children (PPSC), which is used to evaluate the functional status of children with cancer (Levi & Drotar, 1998).

2.4.2.2 The Profile Approach

The profile approach gives an overall index score that summarizes a child/adolescent's QOL but also gives a score for each QOL domain. Profiles allow comparison of overall QOL as well as comparisons of different QOL domains. An example of a profile instrument is the Child Health and Illness Profile-Adolescent Version (Starfield et al., 1996), which provides a broad coverage of multiple domains such as satisfaction, comfort, activity, resiliency, achievements and disorders. The profile approach can also be used across different illness population with different chronic conditions.

2.4.2.3 The Battery Approach

A limitation of the profile approach is that few validated measures are available for the pediatric/adolescent population. For this reason combining several different validated measures to assess domains of QOL, which would result in an overall estimate of the child/adolescent's QOL, has been suggested as an alternative (Gortmaker et al., 1998; Spieth & Harris, 1996). Gortmaker et al., (1998) suggested a battery approach for the evaluation of pediatric QOL in an AIDS clinical trial. This approach included an assessment of their resilience, physical functioning, psychological function, social and role functioning and HIV related symptoms. Evaluating relevant domains of QOL with separate measures gives information that may not be obtained with a single measure. Unfortunately there are several significant drawbacks to this approach. Different conceptual frameworks, psychometrics properties, and scaling make it difficult to determine interrelationships between various aspects of health and the importance of each area of dysfunction across instruments (Starfield et al., 1996). Furthermore the battery approach does not give an overall score nor does it weigh the relative importance of each domain thus limiting comparisons of change over time (Levi & Drotar 1998). Finally the use of separate instruments is often impractical in terms of patient and staff time.

2.4.3 Generic versus Disease Specific Measures?

A number of instruments have been developed for adolescent QOL assessment. They are two primary types of QOL instruments:

- Generic;
- Disease-specific.

2.4.3.1 Generic Instruments

Generic measures are designed for broad use with many types of diseases, treatments and groups of individuals (Eiser, 1997; Spieth & Harris, 1996; Jenney & Campbell, 1997). These measures provide comprehensive ratings that allow comparisons across patient groups and across therapies (Guyatt et al., 1999). These comparisons can be used in making decisions about the allocation of resources related to health, education or social policy (Eiser, 1997). However generic measures have been criticized for their lack of sensitivity in detecting differences among diverse groups. (Levi & Drotar, 1998; Eiser, 1997). They also tend to be long which can be difficult to administer to a sick population (Eiser, 1997).

Table 2 illustrates some of the more commonly used generic measures for adolescent QOL.

Table 2: Examples of Generic Child/Adolescent Health Related Quality of Life Measures

Measure	Age	Domains Assessed	Respondent
Child Health & Illness Profile (Starfield et al., 1993)	11-17	Activity Achievement Comfort Disorders Resilience/Risk Satisfaction	Adolescent
Health Status Measure for Children (Eisen et al., 1979)	0-4 5-13	Behavioural Problems General Health Mental Health Physical Health Social Health Somatic Symptoms	Parents
Quality of Well-Being Scale (Kaplan et al., 1978)	All	Functional Status Mobility Physical Activity Physical Symptoms	Parent Adolescent

2.4.3.2 Disease-Specific Instruments

In contrast, disease specific measures focus on symptoms and problem domains most closely related to a particular disease. As such they are seen to be more responsive. However disease specific measures are not comprehensive and do not allow comparisons of QOL among children and adolescents with different illnesses (Eiser, 1997).

Table 3 illustrates some commonly used disease-specific adolescent QOL measures.

Table 3: Examples of Disease-Specific Child/Adolescent Health Related Quality of Life Measures

Measure	Age	Domains	Respondent	Specific Condition Addressed
Childhood Asthma Questionnaire-B (Christie, French, Sowden, & West, 1990)	8-11	Active Quality of Living Distress about Asthma General Health Perceptions Positive Quality of Living	Child	Asthma
Diabetes Quality of Life for Youths (Ingersoll & Marrero, 1990)	11-18	Disease Impact Disease Worries Life Satisfaction	Adolescent	Diabetes
Pediatric Oncology Quality of Life Scale (Goodwin et al., 1994)	4-18	Adjustment to Treatment Emotional Function Physical Status	Parent	Cancer

Both generic and disease-specific measures have their strengths and weaknesses. Bowling (1997) suggests the research question should direct the choice of measures. She has also recommended the use of combined measures (generic and disease-specific measures) that focus on the child/adolescent's overall QOL by assessing multiple domains and evaluating changes associated with specific diseases. However conflicting evidence exists. Osman et al., (2000) administered both a generic and a disease-specific questionnaire to a group of 396 patients aged 16-52 with asthma. They found both questionnaires were able to capture the impact of asthma on their QOL however the disease-specific respiratory scale was able to better discriminate among patients who would seek care for their asthma symptoms. Ritva et al., (2000) also found that a disease-specific questionnaire was slightly better than a generic questionnaire in predicting changes in clinical parameters for a group of 134 asthma patients. However in a study assessing QOL for 170 diabetic patients Parkerson et al., (1993) found that generic measures provided as much information as the disease-specific questionnaires.

2.4.4 The Informant Issue

A very important issue in the field of pediatric/adolescent QOL assessment is "who to ask" (Jenney & Campbell, 1997, Eiser, 1997, Levi & Drotar, 1998). Although assessments of QOL can be obtained from the child, the parent or the doctor, parents are commonly used as the major informant in QOL studies especially in the pediatric population (Levi & Drotar, 1998). The questionable reliability and validity of children's self-reports is the major reason that such assessments typically rely on parental informants.

Many studies have shown that independent assessments, by either healthcare professionals or patient's relatives, from the responses obtained when patients complete self-reports, yield inconsistent results (Fayers & Machin, 2000). It has been suggested that observers tend to underestimate the impact of psychological aspects and tend to overestimate the importance of the more obvious symptoms (Fayers & Machin, 2000). In cancer clinical trials there is also evidence that "expected" symptoms such as nausea and vomiting tend to be accepted and ignored by clinical staff (Fayers & Hand, 1997). Health professionals may also tend to base their opinions upon physical signs such as symptoms and toxicity. In many clinical studies, conventional outcomes have been shown to be poorly correlated with patient's assessments of QOL. Juniper et al., (1993) observed that correlations between clinical assessments and how patients felt and functioned in day-to-day activities were only modest. Eiser (1997) also found that while parents may reasonably assess the impact of a chronic illness on the family and sibling relations they are less able to make judgments regarding symptom experience, peer relationships or future worries for the chronically ill adolescent.

Pal (1996) has suggested that rather than a professional imposing a meaning on the concept of QOL, researchers can attempt to discover the subjective meanings attached to the concept by the population under study. He goes on to suggest that these subjective interpretations could be used to construct a variety of objective indicators using existing data or describe a number of domains, which could be investigated further in terms of levels of satisfaction on the part of the population. Day et al, (1993) took a grounded-theory approach in which they asked a group of adults to describe what quality of life meant to them. Cadman (1984) has also argued that quality of life can only be described and measured in individual terms since what constitutes quality of life for one individual may be different to another. Consequently, it is recommended that measurement of adolescent QOL should be from the individual's own perspective (Pal, 1996; Eiser, 1997).

2.4.5 Modes of Administration

Adolescent QOL questionnaires can be administered by an interviewer, by telephone, by proxy responders (discussed above), or self-administered. Each mode of administration has advantages and disadvantages. For example, self-administered questionnaires require minimal resources however there is the greater likelihood of a lower response rate, of misunderstanding the questions, and/or incomplete responses (Jenney & Campbell, 1997). While it is the most cost-effective method of administration it is only suitable for older children and adolescents (Jenney & Campbell, 1997). A questionnaire administered by an interviewer can maximize the response rate but there may be a hesitancy of the respondent to acknowledge problems that they may find particularly embarrassing. This method is also resource intensive in terms of training required of interviewers and the time an interview takes. The telephone is less costly than an interview and achieves a higher compliance rate than the self-completed questionnaire however validity issues may be raised particularly when used with younger children (Eiser, 1993).

2.4.6 Frequency of Assessments

Much of the previous research investigating adolescent QOL issues employed cross-sectional designs, which have yielded inconsistent findings on the effects of age and gender (Frey, 1996; Apajasalo et al., 1996). However cross-sectional designs cannot detect the changes that can occur in adolescent QOL. Therefore a longitudinal reference is the most appropriate method to understand the evolving effects of adolescents QOL. However there is a striking paucity of longitudinal studies reported in the literature especially in relation to the adolescent (Brown et al., 2000; Raphael et al., 1996).

Another problem is the appropriate time frame of recall used in questions asking about health, symptoms, and global QOL In adult QOL studies questions are frequently asked in relation to the previous two weeks. In child and adolescent studies, time frames of 1-4 weeks have been used. The lack of maturity in cognitive capabilities raise the question of whether a 10 year old can reliability answer QOL related questions relating to the past month. It is well known that even adults have difficulty remembering episodes of illness (Rutishauser et al., 1998). Further investigation is required to clarify the most appropriate time frame of recall to be used in child and younger adolescent's questionnaires.

2.4.7 Issues of Reliability and Validity in QOL Research

The selection of appropriate instruments to measure adolescent QOL generally depends on the objectives of the research and the targeted population concerned. It is notable that many QOL instruments have been developed for highly selected groups, which make them unsuitable for the general adolescent population. Again, due to the complex nature of QOL there is no standard form of measurement. Therefore the use of a single instrument or a combination of instruments that capture the multidimensional nature of QOL is essential. Any measure proposed to assess QOL in adults, children, and adolescents must also meet the standards for reliability and validity. For a recent discussion of validity and reliability issues related to Quality of Life measurement see Fayers & Machin, (2000). For the adolescent population, sensitivity to developmental milestones, and an awareness of the impact of cognitive development can increase both the accuracy and validity of QOL evaluations (Eiser, 1997; Spieth & Harris, 1996).

2.4.8 Data Analysis

Adequate analysis of quality of life data is extremely important but often neglected (Fallowfield, 1990). In any QOL research there are many analytical issues that need addressing. Fundamental to these is the choice of variables for analysis, the form the analysis will take, and whether the underlying statistical assumptions are satisfied by the data. In cross-sectional studies the type of analysis used will often depend on how the information will be used. If the main purpose for asking an adolescent to complete a questionnaire is to use the information to tailor theory, then a single item score or looking at variables in key domains, which appear to be causing difficulty, may be appropriate (Fallowfield, 1990). Comparisons of "means" between different groups are more difficult especially if the number of patients in each group is small. One individual with an extreme score could produce a distorted view of overall quality of life for the majority of the other participants (Krauth, 1982).

A large majority of adult studies involving QOL assessment include repeated assessments over time. Thus, in a randomized clinical trial and other health-related studies there may be a baseline assessment, followed by a series of further assessments during the active treatment period. The analysis and presentation for this type of data is relatively straightforward if the number of observations per participant is equal, but this will seldom be the case (Fayers & Machin, 2000). However recent developments in statistical techniques such as longitudinal multilevel models expand the opportunity to examine trends and individual differences in the perceptions of QOL for adolescents (Brown et al., 2000).

The relationship between statistical significance and clinical significance is also poorly understood in QOL research. That is, "at what point do significant findings reflect "important" clinical changes in QOL"? The metric associated with QOL is not well understood and does impede the translation of findings into clinical application. However Cohen (1992) has advocated the use of "effect size" which has been used by many QOL researchers to indicate clinical significance. "Effect size" is particularly useful in longitudinal designs where a change is expected to occur (Fayers & Machin, 2000).

The advances in modeling techniques such as structural equation modeling for measuring latent constructs such as anxiety /depression has great potential. SEM was pioneered in QOL research two decades ago by Andrews & Withey (1976) however since then its use in QOL research has been limited (Fayers & Machin, 2000). SEM is a sophisticated statistical technique for testing how well a theoretical model conforms to the data. These models illustrate how key factors can influence one another unidirectionally (recursive models) or reciprocally (nonrecursive models). The use of confirmatory factor analysis, which is a form of SEM, is another very powerful and important method for establishing construct validity for QOL psychometric testing (Fayers & Machin, 2000).

2.4.9 Conclusion

Definitions for QOL are controversial. Different instruments use different definitions, and frequently no specific model is formally stated. There are a range of QOL instruments available, although this range is likely to be reduced once the purpose of the study is considered. Methods for data analysis are also varied and can be quite complicated.

There is clearly much to consider in choosing QOL measures for adolescents but common features include that the adolescents themselves are asked, there are several subscales, the scales are based on multiple items, and the scales represent constructs that cannot be measured directly (Fayers & Machin, 2000).

2.5. The Adolescent with a Chronic Condition

The medical advances of the past few decades have meant that many children who would previously have died of their chronic illness now survive into adolescence and adulthood (Perrin et al., 1993). Chronic conditions include diagnoses such as diabetes, asthma, and less common conditions that are caused by genetics and birth defects. While these conditions vary widely in terms of specific limitations they all share one common feature. They require long-term management. Modern medicine can often very effectively control pain and reduce the intensity of the symptoms however the adolescent with a chronic condition can face a lifetime of hospital appointments, diagnostic procedures and painful treatments.

2.5.1. Why a Quality of Life Perspective?

In contrast to other age groups, mortality and morbidity rates for adolescents in western countries has been increasing over the past few decades. Evidence suggests that the health status of adolescents is lower than it was for their parents. (Raphael et al., 1996). There are very few studies that provide a profile of the adolescent with a chronic condition and the impact it has on their physical, social, psychological well-being and daily activities of living. Eiser (1997) stresses the need for an approach the need for community based professional services, heightened challenge to self-concept and optimal emotional development, extra financial hardships and the disruption to family and social activities. It was felt that a broader conceptual framework would facilitate the understanding of the impact of chronic illness on the total life experience of the chronically ill child and adolescent thus improving their quality of care. Stein & Jessop (1982) also suggested that a non-categorical approach signified a return to the concept of treating the "whole child" as opposed to the diseased organ or system. As a result they have recommended a two level definition and classification for chronic conditions. The first level should reflect the child's functional status or ongoing use of medical services over an extended period of time – they suggest three months (Stein & Jessop, 1982; Perrin et al., 1993). The second level should be based on the experiences of the individual child/adolescent thus emphasizing the tremendous variability of similar conditions. This can be manifested by any limitation in age appropriate activities (Stein & Jessop, 1982; Perrin et al., 1993).

2.7 Impact of Chronic Conditions during Adolescence

Adolescence begins at puberty and accompanying the pubertal changes there are corresponding changes in the personality (Whalley & Wong, 1991). The precise boundaries of adolescence are difficult to define but the period is customarily viewed as beginning with the gradual appearance of the secondary sex characteristics at about 11 or 12 years of age and ending with cessation of somatic growth at 18 to 20 years (Whalley & Wong, 1991).

The period of adolescence is a time when young people are immersed in defining a coherent sense of self. They have a normal preoccupation with bodily functions and changes, a preoccupation that can be intensified by the presence of a chronic condition. The challenges of the future while stressful to all adolescents can be especially stressful for the chronically ill adolescent who may have strong doubts on their ability to obtain a job, their sexuality and their relationships with peers. The important task of developing independence from the family can also become significantly inhibited by the presence of a chronic condition.

Adolescents live in the present and are very attuned to peer pressure, therefore the most disconcerting dimensions of an illness may be those that arouse a feeling of being different from their peers (Perrin et al., 1993). Friendships provide role models, contribute to self-identity and bring considerable emotional satisfaction from the development of interpersonal relationships (Whalley & Wong, 1992). The physical manifestations of a chronic condition may be especially distressing to the adolescent during this period.

2.7.1 Impact on the Psychosocial Domain

Results of research studies regarding the impact chronic conditions have on psychosocial functioning are confusing and full of contradictions. The literature of the past two decades has suggested that adolescents with a chronic condition sustain more psychological and behavioral problems than their healthy counterpart (Pless & Roughman, 1971; Garrison & McQuiston, 1989; Cadman et al., 1984). Earlier work often focused on the psychopathology of the chronically ill adolescent. This guided the researcher to look for abnormalities in this group by evaluating the degree of deviance from the normal population (Blum, 1992). However recent advances in conceptual and methodological approaches have led researchers to adjust their outlook on the prognosis of the chronically ill adolescent to a more favorable one. These advances include the use of appropriate control groups and the collection of data through methods of direct observation as opposed to the use of questionnaires (Garrison & McQuiston, 1989; Patterson & Blum, 1996; Blum, 1992).

Recent studies (Garrison et al., 1989; Cappelli et al., 1989, Spirito et al., 1995, Suris et al., 1996; Zani et al., 1995; Admi, 1996; Patterson and Blum, 1996; Carlson et al., 1990) have shown that most of these children and adolescents are psychologically normal but can have an increased risk for mental health and adjustment problems. However the reason(s) for this increased risk(s) vary from study to study depending on the methodological perspective and the operational definition of a chronic condition used by the researcher.

Diagnosis has been extensively reviewed in terms of impact on psychological functioning. The literature (Pless et al., 1989; Cadman et al., 1984) has shown evidence that certain characteristics of chronic conditions such as brain involvement (epilepsy)/mental retardation does seem to be associated with higher rates of emotional and behavioral problems. However Stein & Jessop (1989) found that precise clinical diagnosis was not particularly helpful in predicting social and psychological outcomes. They found greater diversity existed within specific conditions rather than across them.

Lavigne & Ryan, (1979) found the degree of visibility of the chronic condition to be associated with more psychological problems. However, Wolman et al., (1994) found that no differences existed between visible and invisible conditions when comparing psychological outcomes of adolescents with and without chronic conditions in a survey of public school students from grades 7-12. The chronic conditions included diagnoses of cerebral palsy, diabetes, seizure disorders, muscular dystrophy, scoliosis, and asthma. However it is difficult to generalize these results since the adolescents rated their condition as either visible or non-visible, and there can be varying degrees of visibility across conditions.

According to Blum (1992) there can be many factors that determine the impact a chronic condition has on psychosocial development. These include an unstable course (remission-recurrence in the case of cancer), uncertain prognosis, conditions which are painful, the course of the illness, and cost.

A study by Leung et al., (1997) describing the inter-relationship of the severity of a chronic illness and psychosocial well-being perceived among chronically ill adolescents, found that they were generally well-adjusted. The sample included 48 adolescents with either cystic fibrosis or diabetes. No healthy control group was used. Interestingly, the study also found that this sample of adolescents rated their illness less severe than their physician did.

A study by Zani et al., (1995) evaluating the impact of thalassaemia major on the psychosocial functioning of 90 adolescents and 100 healthy adolescents of comparable age, sex, and geographical background, found that the thalessemic group scored as well as the healthy group. Both groups completed questionnaires designed to analyze their network of social relationships, the degree of social integration, different aspects of self-concept and coping strategies used by the adolescents when facing stressful situations. While the results of this study are consistent with the growing literature that adolescents cope well with their chronic condition the study included only one specific chronic condition.

Cappelli et al., (1989) administered questionnaires to a group of 31 adolescents with cystic fibrosis and diabetes to assess the adolescent's perceptions of the impact of their illness on their daily life. The same number of healthy controls were also administered the same questionnaire. No differences were found between the controls and the adolescents with a chronic condition to the standardized measures used in the study. However, the questionnaires were followed up with a semi-structured interview, which revealed that the adolescent's perception of his/her physical health and the reaction of other family members were important sources of stress.

2.7.2 Impact on the Physical Domain and Daily Activities of Living

There is little information available that describes the limitations on physical and daily activities due to a diagnosis of a chronic condition. Chronic illness can interfere with school attendance, limit the level of contact with peers and reduce participation in activities such as sports.

Newacheck et al., (1991) found that chronic conditions had varying levels of impact on adolescent activity levels in a study of 7465 adolescents (10-17 years of age) participating in the 1988 National Health Interview Survey. The most commonly reported chronic condition included asthma, headaches and respiratory allergies. On average, adolescents with one chronic condition spent 3.4 days ill in bed and missed 4.4 days of school related to their condition in the year before the interview. Adolescents with multiple chronic conditions had substantially more sick days in bed and days absent from school than adolescents with a single chronic condition. Overall, 16% of adolescents with chronic conditions were reported to be limited in their activities, which included school activities, sports, or after schoolwork. Since the authors chose a very broad definition for a chronic condition, this allowed the inclusions of conditions such as allergies and headaches, which may be considered quite mild. In contrast, Cappelli et al., (1989) found that school days absent per year for adolescents with cystic fibrosis and diabetes to be substantially higher than their healthy counterpart. Adolescents with CF lost 22.6 days per year, diabetes 19.9 days compared to 9.7 days per year the healthy adolescents.

A study by Starfield et al., (1996) evaluated whether the Child Health and Illness Profile-Adolescent Edition questionnaire could discriminate between teenagers in school and teenagers attending clinics for acute and chronic conditions. One thousand and twenty-one teenagers (age 11-17 years) participated in the study. It covered aspects of health which included discomfort, satisfaction with health, disorders, achievement of social expectations, and risk and resilience. They found that chronically ill adolescents reported more limitations of activity, dissatisfaction with their health and less physical fitness than their healthy counterparts.

2.7.3 Conclusions

In summary, this review has highlighted the need to obtain a more comprehensive assessment of the physical, social, psychological and functional aspects of the chronic condition from the perspective of the adolescent. It has also shown that parents' and health care professionals' perceptions of the chronic condition are different to the perceptions of the adolescent himself/herself also highlighting the need for further study in this area.

2.8 Determinants of Adolescent Quality of Life

A variety of outcome indicators have been used in different studies to investigate adolescent QOL. The following review broadly covers the relationship between QOL and some of its contributing factors. First, background information will be provided about the descriptive characteristics for adolescents living in Western Australia.

2.8.1 Descriptive Profile of Adolescents Living in Western Australia

The following statistics reported are based on the results of Western Child Health Survey, 1995 which was a large scale epidemiological survey of the health and well-being of West Australian children and adolescents. This section explains some of the main characteristics of the surveyed population, which provided comparative data for the sample in this study.

The estimated resident population of 4-16 year olds in Western Australia (WA) numbered 331,400 as of June 1993. This was an 8% increase since 1983. Nearly 17% of these children/adolescents were living in a one-parent family at the time of the Survey (1995). The majority of the sample (88%) of the sample was born in Australia with the United Kingdom, Ireland, and New Zealand being the next most common countries of origin. Of the parents surveyed, 47% had completed a post-school qualification (vocational, degree, diploma).

Compared with many parts of the world, adolescents in WA enjoy relatively high levels of health. 81% of the 4-16 year old age group described their health as "*excellent*" or "*very good*" with only 4% reporting "*fair*" or "*poor*" health. There was also little difference in the perception of health between boys and girls. However children/adolescents who reported their health as "*fair*" or "*poor*" experienced significantly higher rates of asthma, migraine headaches and developmental delays. The general health perception for this group was also reflected in aspects of their usage of the health care system. Children with "*fair*" to "*poor*" health used health services much more than children with "*excellent*" or "*good*" health. Over 83% of children with "*fair*" to "*poor*" health had visited a general practitioner compared with 49% of children described as having "*excellent*" health.

Of the health problems reported, asthma was the leading health problem with one in five children suffering from the condition. The overall incidence of reported asthma cases declined as children grew older, that is 21% of 4-11 year old compared with 17% of adolescents' aged 12-16. Migraine and severe headaches also afflicted 8% of the surveyed population with the prevalence rate being higher among 12-16 (13%) than younger children aged 4-11 (4%). Deformity (stiffness of the foot, leg, fingers, arms or backs) was another condition reported which more prevalent with increasing age. Less than 2% of 4-11 year olds had a deformity, which increased to 5% for adolescents (12-16). Three percent of children aged 4-16 years reported developmental delays, which did not vary much with age. Epilepsy was another health problem affecting 1% of all children surveyed. Table 4 illustrates the leading health problems reported by Western Australian children/adolescents.

Table 4: Leading Health Problems

	Asthma		Migraine		Clumsiness		Deformity		Develop Delays		Heart Problem	
	No.	%	No	%	No.	%	No.	%	No.	%	No.	%
4-11	40.4	21.0	8.1	4.2	10.2	5.3	3.5	1.8	5.2	2.7	3.2	1.6
12-16	19.1	17.3	14.8	13.5	4.7	4.3	5.2	4.7	3.0	2.8	1.9	1.8
Perth	43.4	19.7	16.2	7.3	9.9	4.5	6.8	3.1	5.7	2.6	3.7	1.7
Country	16.1	19.4	6.8	8.2	5.0	6.1	2.0	2.4	2.6	3.1	1.4	1.7
Western Australia	59.5	19.6	22.9	7.6	14.9	4.9	8.7	2.9	8.2	2.7	5.1	1.7

*** Reprinted from the Western Australian Child Health Survey-1995*
Clumsiness: any difficulty with co-ordination or clumsiness
Deformity: Any stiffness or deformity of the foot, leg, fingers, arms or back

2.8.2 Quality of Life and its Determinants

Personal characteristics such as age, gender, and SES status, have all been identified as being associated with adolescent QOL. While these variables do not directly measure QOL they may indicate a higher likelihood of a current or future effect on some aspect of their QOL. However these determinants are not very well understood and have yielded inconclusive results. The following review will broadly cover the relationship between QOL and these influencing factors.

2.8.2.1 Age

The impact of the adolescent's age and developmental stage on reports of QOL has yielded inconsistent results. A negative effect on QOL with increasing age has been identified in many adolescent QOL studies (Wang et al., 2000; Devinsky et al., 2000). In contrast, Faro (1999) found that older diabetic adolescents (12-16 years) tended to worry less and report a better QOL than their younger counterparts.

Wijnhoven et al., (2001) also found that younger adolescents with a diagnosis of asthma reported a reduced QOL. Yet in a population based study of 720 school children with and without a chronic condition (aged 6-14 years old) age was not found to be associated with QOL at all (Collier et al., 2000).

2.8.2.2 Gender

It is commonly accepted that girls and boys develop and mature physically and socially along different time trajectories (Whalley & Wong, 1991). Given this premise, research has conflicting evidence concerning the effects of gender on adolescent QOL. In a study assessing 52 adolescent with diabetes Grey et al. (1998) found gender differences with girls reporting more worries than boys. A study of 1,501 children and adolescents by Raven-Sieberer et al., (2000) also found girls to report a significantly lower QOL than the boys. Staab et al. (1998) reported gender differences among 23 adolescents with diabetes. They found boys to express more negative emotions about their diabetes whereas girls were more susceptible to bouts of depression. These findings are comparable to La Greca's et al.'s (1995) adolescent QOL study. However, in direct contrast Sandberg et al. (1994) found boys with growth problems reporting a lower QOL than girls with the same condition. Yet a population based on 720 school children aged 6-14 years (both with and without a chronic condition) reported no significant gender differences in QOL scores (Collier et al., 2000).

2.8.2.3 Perceptions of Physical Health

According to Fallowfield (1990) health is noticed more by its absence than its presence. Concepts and measures of health vary depending on the frame of reference. Clinical and epidemiological approaches consider mainly death, disease, life expectancy and years of healthy life. The social sciences focus more on the social, emotional and material well-being of health as well as QOL.

Many studies have reported the increased pleasure and appreciation of life after a serious illness. A study by Cristovoa (1999) found that patients with hemodialysis (75 patients, aged 18-65) reported dissatisfaction with their physical health although they felt their overall QOL was satisfactory. In a study of 1501 adolescents Ravens-Sieberer et al. (2000) found that subjective health was methodologically adequate and a valid scientific indicator to use in epidemiological studies to identify young people with QOL impairments.

2.8.2.4 Socio- Economic Status

Differences in health status of people from different socioeconomic groups have been demonstrated in many studies (Mathers, 1996; Australian Institute for Health and welfare, 2000). However inconsistent evidence has emerged for SES as a determinant for adolescent QOL. In an adolescent QOL study by Raphael et al. (1996) SES was not related to higher QOL scores. However Devinsky et al. (1999) found adolescents with epilepsy from a lower SES background reporting a lower QOL. Dobkin et al. (2000) also identified age, SES and initial clinical outcomes as critical in a better outcome for pediatric bone-marrow transplant patients.

Some of the problems from these inconclusive results are the way in which SES is conceptualized which can include income, occupational, and educational status. However, none of these methods is perfect with each posing their own particular problems when assessing the SES status of the adolescent. The ages 12-24 represent a period of transition, from dependency on parents through to some level of independence. For some adolescents, it would be appropriate to assign SES based on measures relating to parents, whereas measures more appropriate to older adolescents would be based on their circumstances.

2.8.2.5 Other Factors

Large-scale studies in the Canada have shown parent education to be a strong predictor for the health of the child/adolescent (Townson, 1999). However one of the problems when incorporating socio-demographic factors as a determinant for adolescent QOL is the way in which it is conceptualized and assessed. It is important to recognize that although the majority of adolescents function within family environments, family structure may differ. Studies in the United States (Ransom & Fisher, 1995) and Scotland (Sweeting & West, 1995) have shown that it is not only the family structure (single, divorced, remarried etc.) but also the quality of family relationships that may predict health outcomes, which ultimately influence QOL for children and adolescents.

Social participation and close relationships also have been identified as having important effects on the QOL for the adolescent (Eiser, 1997). This includes interaction with friends, family and other individuals at school/employment. Bukowski & Sandberg (1999) also found peer relationships among adolescents to be a reliable indicator of functioning during adulthood. Despite the recognition of the importance of these different aspects to the adolescent's QOL there is limited data available. This represents an important area for future research.

The amount of personal control the adolescent perceives in their life has also been identified as a potential predictor for adolescent health (Raphael et al., 1996). According to Smith et al., (1995) the perceived ability to change a situation can influence behavior, along with mental and physical well-being. Therefore individuals who maintain a higher perception of control tend to have fewer health problems, better memories, and higher intellectual functioning.

Similarly environmental factors such as exposure to stressful or traumatic events such as a chronic condition can also have important implications for QOL. The effects of exposure to adversity such as a chronic condition appear to be negatively associated with QOL ratings (Ravens-Sieberer, 2000). However other studies have found that the negative effects of chronic conditions can be mediated by characteristics of the family environment (Eiser, 1997). In fact, some studies of cancer patients even report an increase in QOL due to an increased ability to appreciate each new day, feelings of personal strength, self-assurance and compassion (Cohen & Mount, 1992; Loew & Rapin, 1994). This paradox is now understood to reflect a psychological shift (a "response shift") that occurs in cancer patients as well as in patients with other chronic conditions such as diabetes, renal disease, and dermatological conditions (Muldoon et al., 1998).

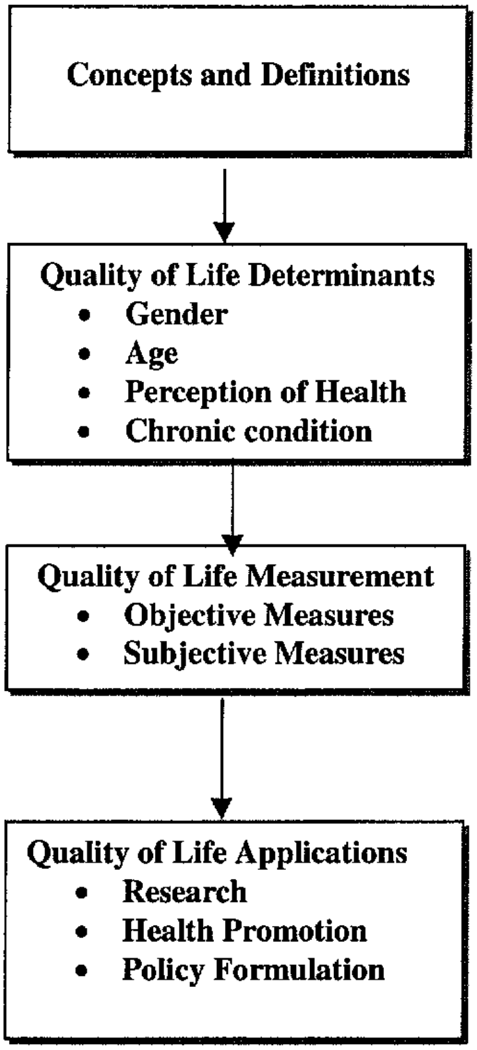
Subjective QOL evaluations can also be influenced by personality factors. For example, a single item rating such as *"Rate your overall QOL as poor, fair, good or* *excellent*" inadvertently measures personality characteristics such as the propensity to report negative affect, as well as hypochondrias and somatisation (Muldoon, 1998). Some researchers are advocating the incorporation of questions measuring personality traits into QOL questionnaires.

In conclusion, these results have highlighted the inconsistencies in determinants for adolescent QOL. Different conceptualization for adolescent QOL, methodologies employed and the presence/absence of chronic conditions can account for many of these differences. While these determinants do not explain "how" or "why" a problem can develop they can help researchers to identify adolescents with the potential for subsequent problems. As a result QOL research has stressed the importance of research into understanding the mechanisms that can account for negative outcomes during adolescence.

2.9 Summary and Conclusion

Figure 1 provides an overview of the issues relating to QOL that have been discussed in the literature review.

Figure 1: An Overview of Adolescent Quality of Life



Several themes have emerged relating to adolescent QOL:

- QOL has consistently been shown to be a subjective phenomenon that incorporates the adolescent's personal characteristics and objective life condition;
- A clear definition for adolescent QOL must be given;
- Adult measures are inappropriate for children and adolescents;
- Different measures have different functions and the researcher should clearly state the aim of the study and chose the instrument accordingly;
- The use of psychometrically sound QOL instruments is an important prerequisite for obtaining valid outcome measures;
- Self-assessment is a basic requirement for adolescent QOL research;

- Outcomes for adolescent QOL research must be relevant and practical.

In conclusion, QOL seem implicated in a wide range of adolescent health outcomes and health-related behaviors. A QOL approach provides a unifying framework for bringing together a variety of factors that either promote or inhibit health among adolescents. The challenge is then for the policy makers to translate these findings into social policies that will enhance the health for adolescents

CHAPTER 3

GENERAL METHODOLOGY

CHAPTER 3

GENERAL METHODOLOGY

3.1 Overview

This thesis consists of two parts. The first part examines quality of life (QOL) from the perspective of chronic and non-chronic adolescents. The second part examines the perceptions of QOL for the chronically ill adolescent by teachers, parents and health professionals using a three round Delphi Study.

The general overall methodology described in this chapter lays the foundation for specific issues related to Chapters' 4, 5 and 6. The Delphi Study including methodological aspects will be discussed in Chapter 7 in its entirety.

3.2 Introduction

This chapter details some common methods in the research work described in this thesis. Section 3.3 describes the conceptual basis for the study. Section 3.4 includes a description of the measurement tool, its application, limitations and issues related to its reliability and validity. Section 3.5 to 3.9 discusses the data collection procedure, sampling strategies, data analysis and ethical considerations.

3.3 Conceptual Basis for Adolescent Quality of Life

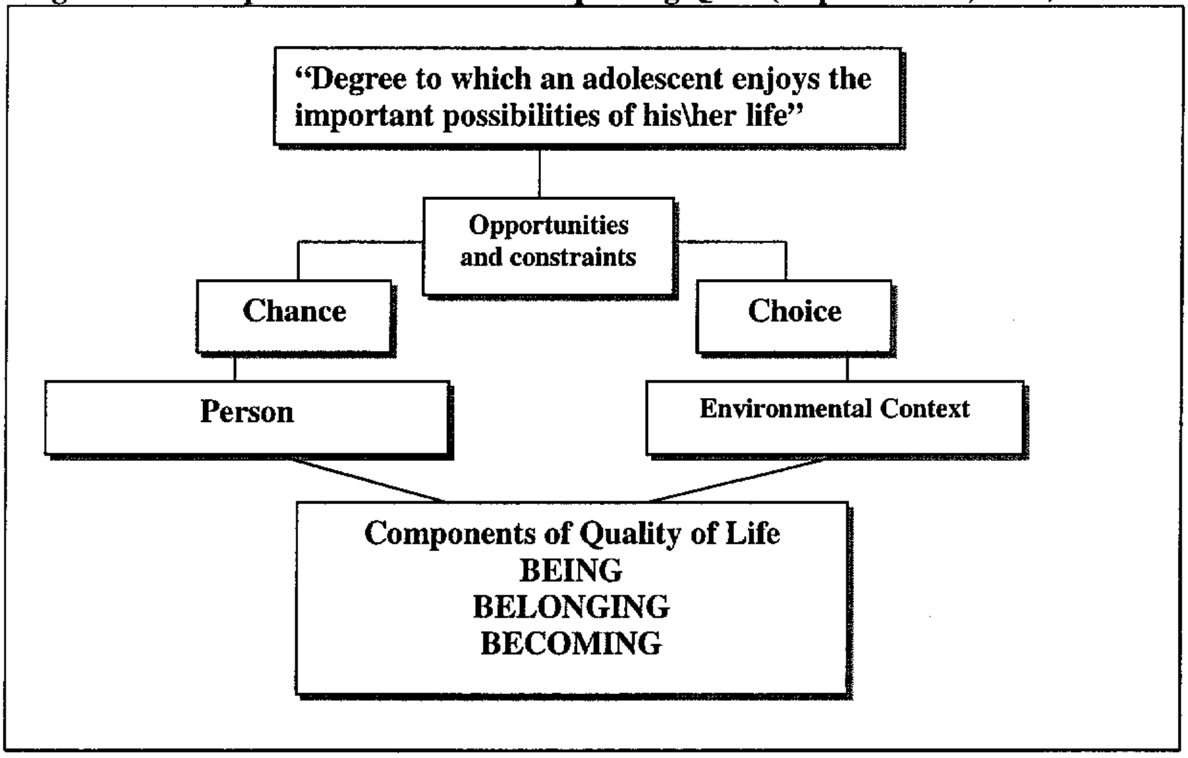
Several assumptions underpin the approach taken to conceptualise adolescent QOL in this study:

- The fundamental constituents and determinants of QOL are viewed as the same for all adolescents whether they have a chronic condition or not;

- Any meaningful view of QOL must take into account the holistic nature of the adolescent;
- QOL is seen as a multidimensional construct;
- QOL can change for adolescents in terms of some or all dimensions constituting QOL;
- QOL experienced by adolescents arises out of their ongoing interactions with their environment;
- Although the dimensions constituting QOL are the same for all adolescents, the QOL will vary from one person to another;
- Adolescents evaluate their QOL within the framework of their own personal system of cognitions, beliefs and interests;
- QOL takes into account the health of the individual as broadly defined by the World Health Organization (1948), as well as social determinants of health;
- The perspective of the adolescent is the most important in understanding his/her QOL.

Quality of Life may be defined as "*the degree to which the person enjoys the important possibilities of his/her life*" (Raphael et al., 1996). "*Possibilities*" refer to the opportunities and constraints in the adolescent's life. They result from the ongoing interaction between the adolescent and his/her environment, and as a result depend on the characteristics of both. There are two types of opportunities – those that occur by "*choice*" and those that occur by "*chance*". Choice is determined by the adolescent's decisions in a whole range of life events, whereas chance includes a person's gender or socio-economic status (SES) status (see Figure 2).

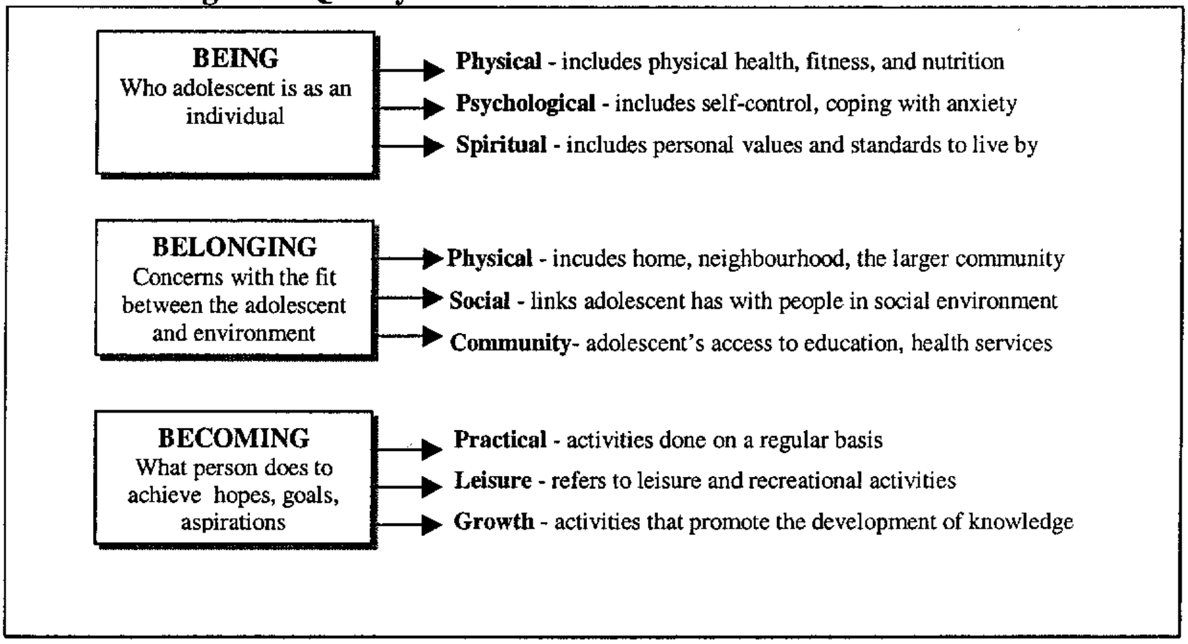
Figure 2: Conceptual Framework underpinning QOL (Raphael et al., 1996)



3.3.1. Components of Quality of Life

The conceptual framework focuses on the possibilities in three areas of life that are common to all adolescents. They are referred to as *"being"*, *"belonging"* and *"becoming"* (Raphael et al., 1996*)*. Each domain can be further divided into three subdomains. These nine subdomains and what they represent are described in Figure 3.

Figure 3: Quality of Life: Essential Domains and Subdomains



QOL in each of the nine subdomains is determined by both the relative importance attached to each domain by the adolescent and his/her satisfaction in each area. However QOL is moderated by two other factors, *control* and *opportunities. Control* refers to the adolescent's perceptions concerning how much control he/she exerts in each of the nine subdomains, while *opportunities* refers to the perceptions perceived by the adolescent for future opportunities in the nine subdomains (Rapheal et al., 1996).

This framework makes a contribution to the existing body of knowledge about QOL and also provides the theoretical background for the Quality of Life Profile Adolescent Version (QOLPAV) questionnaire, which was used in this study. The conceptual model has the advantage of incorporating elements that are consistent with the concerns of both health and social determinants among adolescents. Other approaches tend to focus on either health (Bowling, 1991) or social issues alone (Dennis et al., 1993).

3.4 Description of the Quality of Life Profile Adolescent Version Questionnaire

Data were collected using the Quality of Life Profile Adolescent Version (QOLPAV) questionnaire developed by the Center for Health Promotion at the University of Toronto (Raphael et al., 1996). The QOLPAV is a generic self-administered questionnaire, which consists of 54 items examining QOL in three broad domains of adolescent functioning – *"being"*, *"belonging"* and *"becoming"* as described in section 3.3.1. It emphasizes adolescent wellness as opposed to illness, which is consistent with the conceptual framework utilised in the study. A copy of the QOLPAV questionnaire is attached as Appendix A.

The QOLPAV questionnaire is a relatively new instrument that has been tested on a healthy Canadian adolescent population. The process of developing the questionnaire involved a review of the literature and extensive group consultations with high school students (grades 9-13 in Canada). Responses were collated, reviewed by the authors and developed into instrument items (Raphael et al., 1996). The draft instrument was pilot tested with a class of 20 Canadian adolescents. Adolescents verified the relevance of content, identified missing issues and commented on language. As a result, the questionnaire reflects the perspective of the adolescent and has a strong emphasis on content validity. It has also been shown to be reliable and correlated with measures of adolescent personality, self-reported health status, tobacco and alcohol use. The initial questionnaire also provided some evidence of discriminative validity among the subdomain's scores (Raphael et al., 1996). Discriminative validity refers to the ability of the instrument to discriminate between different constructs (Portney & Watkins, 1993).

The use of a self-completed questionnaire was adopted in this study because it was considered the best way to gather the information efficiently. While the use of face to face schedules can increase the response rate and obtain more in-depth qualitative information (Portney & Watkins, 1993) given the large sample size required and the need to collect data at two time points, this approach was considered inappropriate for the study.

3.4.1 Scoring the QOLPAV Questionnaire

In the QOLPAV questionnaire, adolescents were asked to rate each of the 54 items for importance and satisfaction using a five-point Likert scale. Importance and satisfaction scores range from 1 (not at all important / no satisfaction at all), to 5 (extremely important / extremely satisfied). These scores were then combined into an overall QOL score based on the formula **QOL = (Importance Score / 3) × (Satisfaction Score – 3).** Therefore, items that rate high in both importance and satisfaction yield a high QOL score, whereas items rated high in importance but low in satisfaction produce a relatively low QOL score. To illustrate (see Table 4), an adolescent who describes an item as "*very important*" (4) and reports being "*very satisfied*" (4) receives a score of 1.33. An adolescent who rates an item as "*not very important*" (2) and reports being "*not very satisfied*" (2) receives a score of –0.66.

Table 4: Possible Scores for the QOLPAV Questionnaire

If Importance =	And Satisfaction =	Quality of Life Score =
5	5	3.33
	4	1.66
	3	0
	2	-1.66
	1	-3.33
4	5	2.66
	4	1.33
	3	0
	2	-2.66
	1	-1.33
3	5	2
	4	1
	3	0
	2	-1
	1	-2
2	5	1.32
	4	0.66
	3	0
	2	-0.66
	1	-1.32
1	5	0.66
	4	0.33
	3	0
	2	-0.33
	1	-0.66

According to Raphael et al. (1996), a satisfaction score of 3 leads to a zero QOL score regardless of the importance score. The authors state "this is consistent with our conceptual thinking that moderate enjoyment of an aspect of life should result in a neutral score whether it is important or not" (Raphael et al., 1996, p.369).

Scores can be computed for each of the nine subdomains, the three broad domains (called "Being", "Belonging, and "Becoming") and the overall QOL (add "Being", "Belonging", and "Becoming" scores and divide by 3). Overall QOL scores produce a continuous scale that ranges from 1.50 to –1.50. A score greater than 1.50 is considered as a "very good" QOL, a score of 0.51 to 1.50 indicates an "acceptable situation" and scores between –0.50 and 0.50 indicate an "adequate situation". Scores from –0.51 to –1.50 are seen as "problematic" with scores below –1.50 being interpreted as "very problematic" (Raphael et al., 1996).

Apart from importance and satisfaction, there are questions concerning control over the nine subdomains, and nine more questions referring to the opportunities for improvement and change. A five-point Likert scale is again used with 1 = no control / no opportunities to 5 = total control / large number of opportunities. The overall control and opportunity scores were then calculated for each adolescent by summing the nine scores and dividing by the valid number of responses, thereby accounting for any missing data (Raphael et al., 1996). The overall scores still ranged from 1 to 5.

3.4.2 Demographic Information

To explore variables known, or suspected, to be associated with QOL, additional information was collected relating to gender, age, school, grade, family living situation, socio-economic status (SES), the presence of a chronic condition, its type and duration. A question asking chronically ill adolescents the age they were diagnosed with their illness was included as a means of validating the question regarding the duration of the chronic illness.

3.4.3 Sick Time

Moreover, information was also sought on whether the adolescent had experienced an injury or illness in the last 14 days and how much sick time was spent off school, in bed, and/or if hospitalization was required. Since chronically ill adolescents were recruited from mainstream schools instead of the hospital and were thus considered to be fairly healthy, this process was adopted to determine if indeed differences did exist between the two groups of adolescents. If a difference was detected, the number of sick days reported by the chronically ill group could provide information as to how much a chronic illness impacted on this aspect of their life. An open-ended question was included which asked the adolescent to describe their illness.

3.4.4 Socio - Economic Status

Details were obtained of the adolescent's residential postcode and the highest level of parental education. Although the use of postcodes as a measure of social status is known to have large errors at the individual level, it was easy to obtain, analyse and could provide additional information about the area of residence (Power and Robertson, 1986). Postcodes were based on the Index of Relative Socio-Economic Disadvantage. This SEIFA Index is derived from attributes such as low income, low educational attainment, high unemployment and jobs in relatively unskilled occupations (Australian Bureau of Statistics, 1998). Therefore, relatively disadvantaged areas have lower than average SEIFA index numbers.

The highest level of educational achievement obtained by parents was recorded using a nine-point scale. The scale ranged from completion of primary school to a university degree.

3.4.5 Perceptions of Health and QOL

Two additional summary questions regarding the adolescent's perception of his/her overall physical health (*"How would you describe your health?"*) and QOL (*"How would you describe your quality of life?"*) were included. Again a five-point Likert scale was used for each question, with 1 = Excellent to 5 = Poor. The summary QOL measure was intended as a means of validating the overall QOL score obtained from the QOLPAV questionnaire.

3.4.6 Pilot Testing of QOLPAV Questionnaire with Australian Adolescents

The questionnaire required a certain degree of literacy, motivation and cooperation for the adolescent to complete. Since it was self-administered, every effort was taken to ensure that it was easy to read, comprehend, complete and relevant to an adolescent population. The questionnaire had also been reviewed by two adolescent health experts, who provided advice on layout and language relevant to an Australian population.

The QOLPAV questionnaire including the additional demographic information, was then pilot tested on a sample of 20 Australian adolescents. This was undertaken to identify questions that were difficult to understand, ambiguous or perceived as inappropriate for Australian adolescents. Modifications were then made to the questionnaire based on their comments. The completion time for the entire questionnaire was approximately 25-30 minutes.

3.5 Reliability and Validity of the QOLPAV Questionnaire

Since the questionnaire has never been used with an Australian adolescent population, its validity and reliability were addressed.

3.5.1 Reliability of the QOLPAV Questionnaire

Reliability was assessed using Cronbach's Alpha. Table 6 provides an overview of the internal consistency alpha coefficients for the overall questionnaire, each of its nine subdomains and three broad domains. Cronbach's Alpha is dependent upon the consistency of the individual's responses from question to question. According to Nunally (1967), a reliability coefficient of $\alpha= 0.80$ is an appropriate standard for internal consistency of the original scales. The coefficients obtained for the overall measure and the three broad domains were very good, exceeding $\alpha = 0.80$ in every case. Within the nine subdomains, which consist of only six items, the coefficients were acceptable except for "*community belonging*" where $\alpha = 0.56$.

Table 6: Internal Reliability of the QOLPAV and its Subdomains Based on the Aggregated QOL Scores

QOL Domain	Alpha	No. of items	Sample Size (n)
Being items	0.85	18	289
• **Physical**	0.65	6	315
• **Psychological**	0.69	6	351
• **Spiritual**	0.67	6	335
Belonging items	0.80	18	287
• **Physical**	0.75	6	357
• **Social**	0.67	6	311
• **Community**	0.56	6	304
Becoming items	0.90	18	218
• **Practical**	0.73	6	223
• **Leisure**	0.77	6	352
• **Growth**	0.81	6	341
All Items	0.90	54	187

3.5.2 Validity of the QOLPAV Questionnaire

3.5.2.1 Content Validity

The content validity of the questionnaire was ensured through the rigorous initial development process, with the instrument having been tested and refined several times as discussed in Section 3.4. Content validity was also assessed related to an Australian adolescent population and the necessary modifications were made accordingly (see Section 3.4.6).

The generally high "*importance*" ratings provided for the items found in the QOLPAV questionnaire, also confirmed that the contents of the questionnaire assessed relevant aspects of adolescents' lives (see table 7). The very high ratings for *"growth becoming"* (subdomain called "improvement and change" in the questionnaire - see Appendix A) and *"psychological being"* (subdomain called "thoughts and feelings" in the questionnaire – see Appendix A) were consistent with views of adolescence as a period of transition, sometimes involving psychological distress (Jessor, 1991).

Table 7: Importance Scores for the Domains, and Subdomains of the QOLPAV Questionnaire

QOL Domain	Importance Score	
	Mean	**S.D.**
Being Items	4.11	0.51
• **Physical**	4.05	0.64
• **Psychological**	4.20	0.61
• **Spiritual**	4.10	0.66
Belonging Items	4.00	0.49
• **Physical**	4.03	0.68
• **Social**	4.03	0.56
• **Community**	3.93	0.62
Becoming Items	3.99	0.55
• **Practical**	3.88	0.70
• **Leisure**	3.90	0.64
• **Growth**	4.21	0.62

3.5.2.2 Construct Validity

Construct validity measures how well an instrument's results accord with hypothesized theories when measures of a construct, such as quality of life, cannot be readily observed.

It was hypothesized that an association would exist between overall QOL score (scores ranged from –1.50 to 1.50) and the global question of QOL (*How would you rate your overall QOL?*), whose response format was 1=Excellent to 5=Poor. Spearman's rank correlation between the overall QOL score (obtained from the importance and satisfaction scores) and the global QOL question was found to be –0.4670, providing a preliminary estimate on the validity of the QOLPAV questionnaire.

The results of an exploratory factor analysis and a confirmatory factor analysis, which provides further validation of construct validity for the QOLPAV questionnaire, will be discussed in Chapter 4.

3.6 Research Design

A longitudinal survey was used to collect the required information. Two identical questionnaires were distributed six months apart. Conrad (1990) recommended that to adequately capture and highlight the change inherent in chronic conditions, the use of interviews and/or questionnaires should be used at least six months apart.

3.7 Data Collection Procedure

3.7.1 Sampling Frame

The sampling frame for the study included all private and public secondary schools in the Perth metropolitan area. Stratified sampling with replacement was employed by first categorizing the metropolitan area into three zones – northern, central and southern suburbs. This was intended to reflect a diversity of SES among the schools (see Table 8).

A total of 30 schools were approached with 20 schools agreeing to participate in the study. This represented a 66.7% response rate among the schools.

Table 8: Sampling Frame

Suburb	**Number of Schools Recruited**		
	A	**B**	**C**
North	168	11	8
Central (metropolitan Perth)	113	10	7
South	65	9	5
Total	346	30	20

A=total number of schools in the area, B=total number of schools approached
C= total number of participating schools

3.7.1.1 Sample Size Requirements

The final sample size needed for appropriate statistical modeling (exploratory factor analysis, confirmatory factor analysis and structural equation modelling) was at least 300 adolescents (for both time points). This was based on the requirements needed for EFA, which is a minimum of five subjects per variable (Comrey & Lee, 1992). Since there were 54 variables in the QOLPAV questionnaire, 300 adolescents were sufficient for EFA. For the CFA and the SEM analysis, it is preferable to have the ratio of the number of subjects to the number of model parameters as 20:1, however a 10:1 ratio is acceptable (Kline, 1998). Since the purpose of CFA is a reduction in the number of variables, the sample size of 300 was still considered acceptable.

This sample size also met the study objectives with a power of 0.90 at a 5% significance level for hypothesis testing (Shott, 1990). Using a conservative estimate for the intraclass correlation (0.02) and an expected attrition rate of 10%, the sample size was inflated to ensure adequate power to avoid Type 1 error. Consequently it was decided to recruit at least 500 adolescents. Once this sample size was met, recruitment was terminated.

3.7.2 Recruitment of Schools

In July 1999 all government and private schools were stratified by first categorizing the metropolitan area into three zones as mentioned in Section 3.7.1. A random number was assigned to each school and subsequently one school was randomly drawn per strata. A letter was then sent to the school's principal (attached as Appendix D). When a refusal occurred, a replacement school was randomly selected from within the same stratum. Within each school, a limit of 30 was placed on the number of students recruited to minimize the effects of over-representation from individual schools. This limit was chosen after consulting with several school principals. Only one from the 20 schools recruited, received consents from more than 40 adolescents.

Initial contact was made through the school principal with a letter inviting participation in the study. This was followed up with a phone call to the principal to arrange an interview if they were happy to participate. The reasons given by the 10 schools that declined to participate in the study included commitments with other projects and a lack of time.

The researcher met the principal at each participating school and answered any questions they had concerning the study. The letters of invite (attached as Appendix B) were given to the principal who passed them out to each homeroom teacher. The letters of invite were usually distributed according to classroom size (usually 20 to 30 students per class). A letter addressed to each teacher providing a brief overview of the study, its importance and information where to return the completed consent forms was included. A return box was placed at the reception office of the school, where the completed consent forms were picked up a week later.

To encourage teachers to be positive about the study and to also thank them for their effort, the researcher provided muffins for the entire teaching staff when the completed consents were collected.

3.7.3 Recruitment of the Adolescents

Adolescents were recruited through the secondary school system, over the period September 1999 to October 2000. Invitation letters were distributed to all students between the ages of 10 and 19 in each school by their teacher. This age interval was based on the World Health Organization classification of adolescence (Stein et al., 1997). The letter invited adolescents both with and without a chronic condition to participate. A definition of a chronic condition along with specific examples such as asthma, diabetes, migraines, cancer and cystic fibrosis was included (see Appendix B). A week later, the completed consent forms (with both adolescents' and parents' signatures), were collected by the researcher at the front office. The consent form also obtained information from the parent regarding the presence and type of a chronic condition. This was intended to provide parental verification of the presence of a chronic illness. The questionnaire was then sent to the home address of each adolescent, along with a reply paid envelope.

The definition which guided the recruitment of adolescents with a chronic condition was "... a medical condition that has lasted or is expected to last more than three months" (Perrin et al. 1993, pg. 790). More generally, it can be defined as a condition that has resulted in a level of functional impairment or medical attention greater than expected of an adolescent of the same age (Stein et al., 1997). A non-categorical approach to chronic conditions was adopted by this study. The broader non-categorical approach recognizes the commonalities of the illness experience, despite the differences among the many specific types of chronic conditions (Stein et al., 1997). More information is provided in Chapter 2, Section 2.6.

In order to encourage continued participation and to minimize attrition, adolescents were awarded a voucher for a McDonald's egg and bacon burger upon receipt of the completed questionnaire.

To summarize, inclusion criteria for the adolescents with and without a chronic condition to be recruited included the following:

- between the ages of 10-19 based on the World Health Organization definition of adolescence (Stein et al., 1997);
- meet the requirements laid out in the operational definition for a chronic medical condition (see definition provided above);
- informed written consent obtained from both the adolescent and their parent;
- a sound understanding of the English language.

3.8 Data Analysis

All data were coded, computer entered and analyzed using the Statistical Package for Social Sciences (SPSS) Version-10 (SPSS Inc., 2000). Raw frequencies were examined to identify any coding and data entry errors. Plausibility checks were conducted and the data were cleaned appropriately prior to statistical analysis. Between-coder variation was avoided by having the same individual entering the data.

The main outcome of interest was the overall QOL (based on the aggregate scores from the nine subdomains), which was generated from the satisfaction and importance scores. To account for the clustering effect of adolescents nested within schools, multilevel statistical methods were employed (Goldstein, 1995). Multilevel modeling is appropriate for analyzing hierarchically structured or nested data. Single level models (such as multiple regression) fail when data are hierarchically structured violating the assumption of independence. The nested structure causes "intraclass dependency" among the units at the higher level of the hierarchy. Failure to account for the inherent hierarchical or clustering structure of the data may give rise to misleading results including aggregation bias, spurious associations, and problems of model mis-specification, due to lack of independence between measurements at different levels (Heck &Thomas, 2000).

For longitudinal multilevel data, the hierarchy can be defined as level 1 units (the repeated measurement occasions), nested within the level 2 unit (the individual subject). Unlike traditional fixed-effects analytical methods (e.g. ANOVA), longitudinal multilevel models can handle unbalanced data due to missing observations, since it is not necessary for each individual to have the same number of measurement occasions (Bryk & Raudenbush, 1992; Goldstein, 1995). More details related to these two statistical methodologies will be provided in Chapters 5 and 6.

To determine the factor structure for the QOLPAV questionnaire, a CFA was performed based on the satisfaction scores. This method provides a comprehensive means for assessing and modifying hypothetical models, thereby offering great potential for enhancing theoretical development of the initial structure based on EFA (Byrne, 1998; Bollen & Scott, 1993). CFA pre-specifies a factor-analytic structure and tests or confirms how well the data fit the hypothesized model (Bollen & Scott, 1993). Once the underlying measurement part of the model is considered adequate, it is then possible to assess the magnitude and direction of the interdependent effects among the identified factors using a SEM approach as recommended by Fayers & Machin (2000). In view of our study design and the hypothesis that adolescent QOL is dynamic and multi-dimensional, the use of SEM is ideally suited for testing hypothesis 2, 3, and 4 stated in Chapter 1. More details on SEM modelling will be provided in Chapter 4.

3.8.1 Treatment of Missing Data

For the questionnaire, cases with more than 50% of missing values were discarded from the data set. There was only one case removed, based on this criterion. The first question (imp/sat *-being smart about sex*), and question 28 (imp/sat- *having a boyfriend/girlfriend*), had the largest proportion of missing values among adolescents aged 12-13. In total, 1.9% (importance) and 6.1% (satisfaction) of the sample failed to answer the question about *"having a boyfriend/girlfriend"*, whereas 5.8% (importance) and 12.4% (satisfaction), failed to answer the question about *"being smart about sex"*. The high non-response in this specific age group was possibly related to their young age and lack of relevance to them at this period in their life.

Listwise deletion was the method employed in the linear regression and multilevel analysis. However, for the SEM analysis, missing data can severely reduce the power (Hill, 1997) therefore, missing values were imputed using the expectation-maximization method in SPSS 10.0 (SPSS Inc., 2000) for the CFA and SEM.

3.9 Ethical Considerations

The study design and questionnaire met the standards set by the Human Ethics Committee of Curtin University of Technology and the school boards of Western Australia. All adolescents (and their parents) were informed that participation in the study was on a voluntary basis and that the adolescent could withdraw without penalty from the study at any time.

Anonymity and confidentiality of the results was assured and maintained throughout the course of the study. Participants were assigned an ID number, which was subsequently used instead of their names in the analysis. All information and questionnaires were stored in locked filing cabinets with names and addresses of participants being stored separately from the questionnaires. The results are presented in grouped data format only.

In keeping with the University requirements, all data will be securely stored in a locked filing cabinet in a secure place located in the School of Public Health for seven years.

CHAPTER 4

ASSESSING MEASUREMENT PROPERTIES

CHAPTER 4

Assessing Measurement Properties

4.1 Overview

As discussed in the literature review (Chapter 2) Quality of Life has become firmly established as an important concept in health care. However, despite its growing popularity, research continues to be hampered by a lack of conceptual clarity regarding precisely what QOL means (Aaronson, 1988; Eiser, 1997; Fayers & Machin, 2000). The disagreement results from the fact that QOL is a complex concept and can be interpreted in a number of ways. Often QOL has been used as a label for an assortment of physical functioning and psychosocial variables (Spieth & Harris, 1996), while other definitions have emphasized components of happiness and satisfaction with life (Raphael et al., 1996,). However, it has now been generally accepted that QOL is a multidimensional construct (Aaronson, 1988; Eiser, 1997; Spieth & Harris, 1996).

QOL assessment for the adolescent has received much less attention in the literature (Raphael et al., 1996). Again, the problem of conceptualisation and determining what aspects of QOL to assess are difficult since the life experiences and daily activities of adolescents differ substantially from those of adults. Translating the various domains and components of adolescent QOL into a quantitative scale that adequately measures it is a complex task.

Most QOL instruments consist of many questions representing numerous constructs. Some of these items measure a simple aspect of QOL, while other concepts such as psychological dimensions are more complex and require multiple items (Fayers & Machin, 2000). Using confirmatory factor analysis and structural equation models to measure QOL is a relatively recent development (Fayers & Machin, 2000; Smith et al., 1999).

These methods provide researchers with a comprehensive means for assessing and modifying hypothetical models, thereby offering great potential for enhancing theoretical development of the initial structure based on exploratory factor analysis (Anderson & Gerbing, 1988; Byrne, 1998). CFA, the measurement part of SEM, pre-specifies a factor-analytic structure and tests or confirms how well the data fit the hypothesized model (Byrne, 1998). Once the underlying measurement part of the model is considered adequate, it is then possible to assess the magnitude and direction of the interdependent effects among the identified factors using the SEM approach.

4.2. Objectives of this Study

This chapter assesses the measurement properties for the Quality of Life Profile Adolescent Version questionnaire (QOLPAV). The objectives are:

- to determine the measurement properties of the latent factors underlying the QOL construct;
- to establish whether these factors can be adequately accounted for by a single second-order factor called Quality of Life;
- to estimate the direction and magnitude of the interdependent effects among the identified factors.

4.3 Methodology

4.3.1 Research Design

A cross-sectional study was conducted on Australian adolescents with and without a chronic condition, aged 10-19, to assess their perceptions of QOL.

The sampling frame has been discussed in Chapter 3, Section 3.7.1. In addition, the definition, which guided the recruitment of adolescents with a chronic condition, was described in Chapter 3, Section 3.7.3. A non-categorical approach was taken to the recruitment of adolescents with a chronic condition. Further details have been provided in Chapter 2, Section 2.6. The data collection procedure has been discussed in Chapter 3, Section 3.7.

4.3.2 Conceptual Model

According to Raphael et al. (1996) QOL may be conceptualized as "the degree to which a person enjoys the important *possibilities* of his/her life". It encompasses a multidimensional approach that emphasizes the holistic nature of the adolescent and the uniqueness of QOL as experienced by each individual.

4.3.3 Instrument

Data was collected using the generic 54 item Quality of Life Profile Adolescent Version questionnaire which examines QOL related to adolescent functioning (Raphael et al., 1996). Further details are given in Chapter 3, Section 3.4. Additional demographic information was collected related to gender, age, school, grade, family situation, socio-economic status (SES) and presence of a chronic condition, its type and duration.

Based on the results of an exploratory factor analysis, the QOLPAV questionnaire was reduced to 18 items. These 18 items were hypothesized to represent five domains (latent factors/constructs) for adolescent QOL - that is *social*, *environment*, *psychological*, *physical health* and *opportunities for growth and development*. The sub-scales (observed variables) for each of these latent constructs were also defined *a priori*. The choice of the five domainns was based on a substantive review of the literature in Chapter 2 in conjunction with the results of the exploratory factor analysis.

Satisfaction scores were used for the EFA and the CFA, since they permitted an examination of life functioning and the evaluation of the relative satisfaction by the adolescent in a variety of areas (Raphael et al, 1996). This is consistent with the conceptual framework outlined by the researcher in Chapter 3, Section 3.3.

4.3.4 Statistical Analyses

4.3.4.1 Exploratory Factor Analysis

EFA was conducted as a preliminary to confirmatory factor analysis. This enabled a large number of observed variables to be reduced to a smaller set of factors, which summarizes the structure of the domains hypothesized to measure adolescent QOL. The EFA analysis was performed using the principal axis factoring method with varimax rotation on the correlation of the observed variables, with missing values treated with listwise deletion.

4.3.4.2 Confirmatory Factor Analysis and Structural Equation Modeling

Most structural equation modelling applications, including measurement models, are characterized by five steps (Bollen & Scott-Long, 1993). These steps are:

- *model specification* - specifying the initial hypothesized model based on theory, past research or the literature;

- *identification* – identifying and testing specific parameters of the specified model;

- *estimation* – fitting the model using the appropriate estimation process, such as weighted least squares or maximum likelihood, depending on the variable scale;

- *evaluation* – evaluating the model fit using a variety of goodness-of-fit indices;
- *re-specification (post hoc analysis)* – improving the model fit as necessary, especially if the model fit indices suggest a poor fit.

These steps were used in this study for fitting both the measurement and structural models.

4.3.4.3 Two-Step Approach to Modelling: The Measurement Model prior to the Structural Model

A two-step model building approach recommended by Anderson & Gerbing (1988) and Joreskog & Sorbom (1996) was utilized. The first step involves an analysis of the measurement model that specifies the relationship between the observed variables and the latent variables or hypothetical constructs (factors). These results identify the measurement properties, including reliability and validity of the observed and latent constructs (Joreskog & Sorbom, 1996). The second step specifies the relationship among the hypothetical constructs (latent variables) as posited by theory or previous research. This is called the structural part of the model.

This two-step approach allows the researcher to determine whether the source of a poor fit to a full SEM is due to the measurement or to the structural part of the model. By testing the measurement model first this ensures that the chosen observed variables do actually measure the construct that they are intended to measure. Joreskog & Sorbom (1996) commented that testing the structural model is meaningless unless it is first established that the measurement model holds.

4.3.4.4 Confirmatory Factor Analysis (Measurement Model)

In the social sciences often the relationship amongst numerous theoretical or hypothetical constructs (or latent variables) are not directly measurable or observable.

Analysis of measurement models allows for complex modelling whereby both error associated with the measurement of the indicator variables and their unequal contributions towards the measurement of latent variables can be accounted for. The fit of these indicators as measures of the latent variables can also be tested (Holmes-Smith, 2001). Measurement models fit best when the indicator variables associated with any one latent variable are valid indicators of the trait.

CFA, the measurement part of SEM, pre-specifies a factor-analytic structure and tests or confirms how well the data fit the hypothesized model which has been based on theory or previous research (Byrne, 1998). To assess the relations between the five latent constructs (first-order factors) obtained from the preliminary EFA, and to determine whether there was a construct (QOL) common to these factors, a second-order confirmatory factor analytic measurement model was fitted to the data.

4.3.4.5 Reliability of the Composite Scales

The factor score regression coefficients obtained from the second-order CFA were used to compute composite variable regression coefficients and measurement error variances for the SEM (error variances not accounted for by the latent factors). This process ensures that the estimation of the scale/composite variable is proportionally weighted by the actual contribution made by each observed variable, thereby minimizing the measurement error in the items contributing to each scale. This also has the advantage of increasing the reliability (and validity) of the computed scale scores (Rowe, 2000).

The composite scores were computed by multiplying the observed item scores by their proportionally weighted factor score regression coefficients, such that each factor score became a continuous variable ranging from a minimum of 1 to a maximum of 5. This also means that the composite factor scores have the advantage of being measured in the same metric (Holmes-Smith & Rowe, 1994). These composite variables were then used to examine the relationships among the latent variables underlying these composite scales.

4.3.4.6 Structural Equation Models

To assess the magnitude and direction of the interdependent effects among the identified factors, a SEM approach was utilized. The structural model allows the researcher to specify and simultaneously estimate the relationships among the latent dependent factors (endogenous factors such as *physical health*, *social*, *environment*, *opportunities for growth and development* and *psychological*) and/or the independent variables (exogenous variables such as *age*, *gender*, *SES*) (Joreskog & Sorbom, 1996). The structural regression coefficients indicate the strength (i.e weak or strong) and direction (i.e positive or negative) of the relationship among the latent factors. Structural equation models differ from path analysis, which uses only observed variables in establishing the relationships among variables (Schumaker & Lomax, 1996).

For this chapter the researcher will only examine the interdependent effects among the five dependent factors hypothesized to measure QOL. Examination of the relationships between the endogenous and exogenous factors will be examined in more detail in Chapter 5.

4.3.4.7 Assessments of Model Fit for SEM and CFA

For both CFA and SEM, assessing the model adequacy may be based on various measures (MacCallum, 2000; Bolen & Scott-Long, 1993; Kelloway, 1998; Kline, 1998; Byrne 1998). A good fit to a model is the best set of parameters that minimizes the discrepancy between the implied variance /covariance matrix to the matrix of empirical variance and covariance. If the specified model is a reasonable representation of the data it purports to portray, then the parameters that are estimated will yield a small value of the discrepancy function (Homes-Smith, 2001). In other words, if the probability is greater than 0.05 the specified model is a feasible representation of the data it purports to portray. In SEM this is tested using the chi-square (χ^2) statistic.

Fit indices can be sub-divided into two types that either assess the absolute fit, or the comparative fit of the model (Kline, 1998). The assessment of absolute fit is concerned with the ability of the model to reproduce the actual covariance matrix. The assessment of comparative fit is concerned with comparing two or more competing models to assess which provides the better fit to the data (Kelloway, 1998).

In the present study we consider the following criteria to evaluate the fit of the model: *Root-mean-square error of approximation; Satorra-Bentler chi-square*; *Root-mean-square residual; Goodness-of-fit index*; *Adjusted goodness-of-fit index; Comparative fit index; Non-normed fit index* (also called the Tucker-Lewis Index) and the *Incremental fit index.* Table 9 provides a summary of these fit indices and their criteria.

Table 9: Summary of Fit Indices used in SEM

Name	**Abbrev**	**Type**	**Criteria**	**Comments**
Satorra Bentler Chi-square	χ^2	Model fit	$p>0.05$ (at the $\alpha=0.05$)	Greatly effected by sample size
Normed Chi-square	χ^2/df	Absolute Fit and Model parsimony	$1<\chi^2/df<2$	Values between 2-3 may also indicate satisfactory fit. Values close to 1 indicate good fit
Goodness of Fit and Adjusted Goodness of Fit	GFI AGFI	Absolute Fit	GFI and AGFI>0.90	AGFI takes into account the df
Root Mean Square Residual	RMR	Absolute Fit	RMR<0.05	Large values for RMR when all other fit indices suggest good fit may indicate outliers in the raw data
Root Mean-Square Error of Approximation	RMSEA	Absolute Fit	RMSEA <0.05	Values between 0.05-0.08 may also indicate satisfactory fit
Tucker-Lewis Index	TLI	Comp Fit *	TLI>0.90	Values >1 may indicate overfit
Comparative Fit Indices	CFI	Comp Fit*	CFI>0.09	CFI = 1 indicate a perfect fit
Incremental Fit Indices	ICI	Comp Fit*	ICI>0.90	Higher values indicate a better fitting model

** Comp Fit refers to Comparative Fit*

It is important to note that structural equation techniques including CFA assume that the observed data measured on an interval scale are normally distributed. When the data are ordinal in nature or has a skewed distribution, as in this study, the use of ordinary product moment correlations is not appropriate (Byrne, 1998; Hu & Bentler, 1998; Bollen & Scott-Long, 1993; Kline 1998). Instead the polychoric correlations of the data should be computed and the corresponding asymptotic covariance matrix used. Failure to do this can incur errors in the correlation estimates, distorted parameter estimates, biased goodness-of-fit statistics and standard errors (Byrne, 1998; Hu & Bentler, 1998; Bollen & Scott-Long, 1993; Kline 1998).

In the event of ordinal scaling and non-normality, the maximum likelihood method with the Satorra-Bentler's 'robust' correction for model estimation in conjunction with the polychoric correlations is recommended (Chou et al., 1991; Tepper et al., 1996; Curran et al., 1996). This method produces a scaled chi-square statistic and robust standard errors for testing the statistical significance of model parameters. The other fit indices are also adjusted using the Satorra-Bentler scaled chi-square statistic. It also appear to perform well under moderate sample size settings within 200-500 cases (Curran et al., 1996).

The second-order CFA and the SEM were undertaken using LISREL 8.3 (Joreskog & Sorbom, 1996). PRELIS 2.3, the preprocessor for LISREL, was used to generate the matrices for subsequent analysis by LISREL 8.3. Multivariate analysis of variance (MANOVA) and the EFA of the data were performed using SPSS version 10 (SPSS Inc., 2000).

4.4 Results

4.4.1 Demographic Information

In total 500 adolescents from 20 different schools agreed to participate in the study. Of these 251 adolescents without a chronic condition and 112 adolescents with a chronic condition returned their completed questionnaire (n = 363) (see Table 10). This represented a response rate of 72.6%. Participants ranged between 10 and 18 years of age, with the average age for both groups being similar (13-14). The majority of the participants (63%) were females enrolled in years 8, 9 and 10, and lived at home with both parents. No significant difference was evident between the adolescent with and without a chronic condition in their living arrangements (p=0.643), gender (p=0.288), grade distribution (p=0.050), and parental socio-economic status (SES) (p=0.06). Of the adolescents reporting a chronic condition 45% had a diagnosis of asthma, 14% allergies, 13% asthma and allergies, 5% juvenile arthritis, 5% a history of migraines/chronic headaches and 2% diabetes. The prevalence of asthma was relatively high in this sample, however it is comparable to that of the general adolescent population in Western Australia (Western Australia Child Health Survey, 2000).

Table 10. Descriptive Characteristics of the Sample

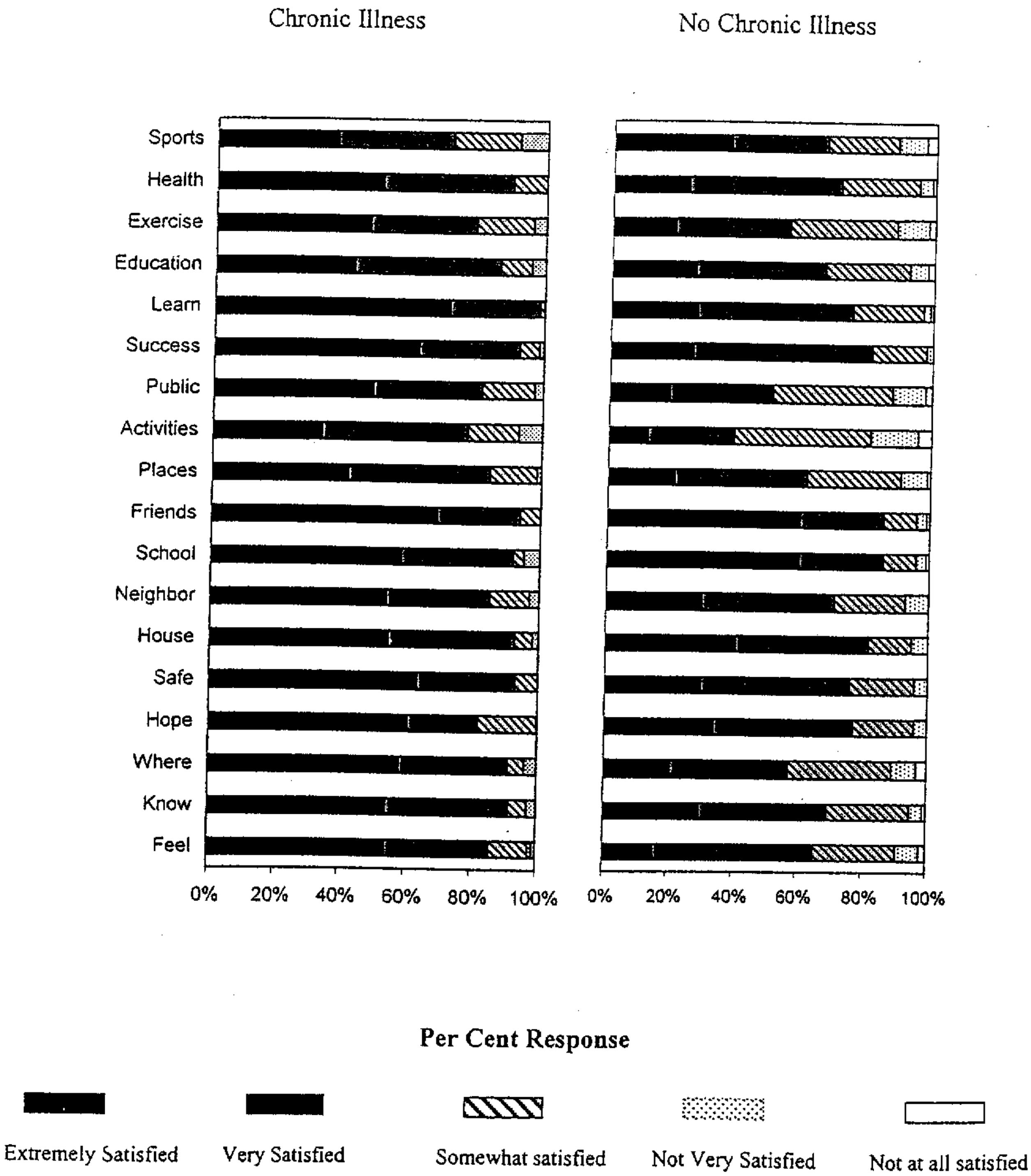
	Adolescents with a chronic condition		**Adolescents without a Chronic condition**	
	n	**%**	**n**	**%**
Sample size (N=363 total)	112	31%	251	69%
Gender (female proportion)	71	63%	172	69%
Average age (years)	13.63 (S.D. =1.33)		13.90 (S.D. = 1.56)	
SES (average)	1036.03 (S.D.=54.69)		1044.08(S.D=53.19)	
Country of birth (Australia)	94	84%	191	76%
Living Arrangement				
• Both parents	86	76%	201	80%
• Mother only	21	19%	30	12%
• Father only	4	4%	6	2%
• Other	1	1%	14	6%
Grade distribution				
• Year 6-7	17	16%	17	7%
• Year 8	31	28%	72	29%
• Year 9	29	26%	58	23%
• Year 10	27	24%	61	25%
• Year 11-12	7	6%	38	16%
Chronic Condition:				
• Asthma	49	45%	--	--
• Allergies	16	14%	--	--
• Asthma and allergies	14	13%	--	--
• Juvenile arthritis	5	5%	--	--
• Chronic headaches	5	5%	--	--
• Diabetes	2	2%	--	--
• Other	20	16%	--	--

Notes: Numbers may not add up to total "n" owing to missing cases

4.4.2. Frequency Distributions

The frequency distributions of the adolescents' (with and without a chronic condition) responses to the 18 items used for the second-order CFA and the SEM analysis are presented in Figure 4.

Figure4: Stacked Histogram for the Eighteen Items for Adolescents with a Chronic Illness (n=112) and Adolescents without a Chronic Illness (n=251).



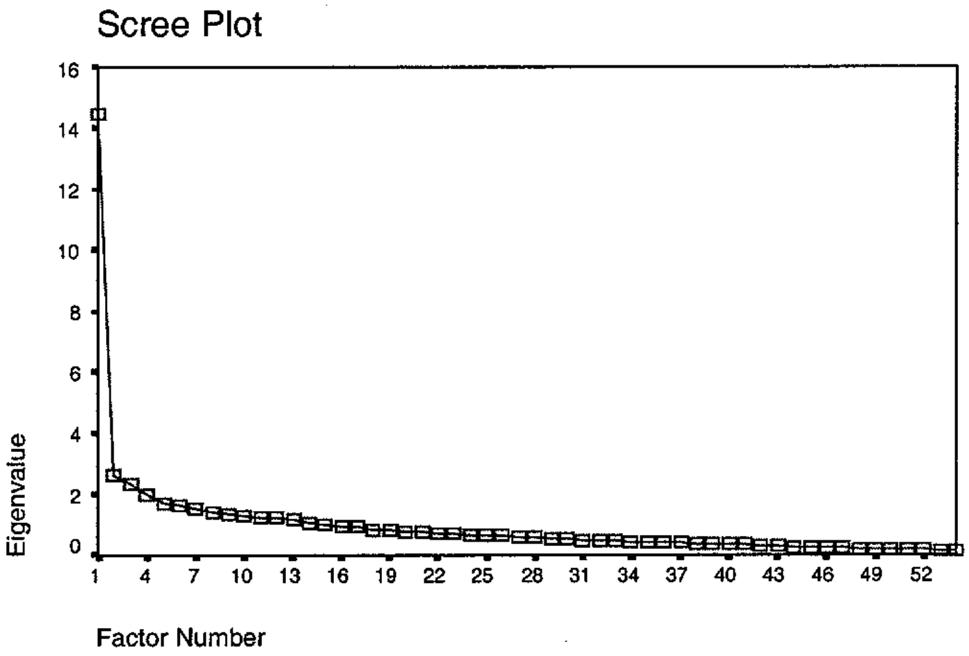
4.4.3 Exploratory Factor Analysis

In order to examine the dimensionality of the QOLPAV questionnaire, factor analysis was performed. The sample size of 363 subjects was sufficient for the analysis which required a minimum of five subjects per variables (5 x 54 items=270) (Comrey & Lee, 1992). An examination of the sample kurtosis and skewness indicate that most of the items were only minimally skewed (-1.58 to - 0.06) and/or kurtotic (-1.12 to - 2.19).

Prior to the EFA, the factorability of the correlation matrix was assessed (Compey & Lee, 1992). A considerable number of correlations among the items exceeded 0.30. The adequacy of the magnitude of the correlations was assessed using the Bartlett test of Sphericity, which tests whether the correlation matrix differs significantly from an identity matrix (i.e 1's on the diagonal and 0's on the off-diagonals). The Bartlett's test was significant (χ^2=4635.325, df=1431, p=0), suggesting there were large correlations among the items. The adequacy of the relationship between items was tested using the Kaiser-Meyer-Olkin (KMO) statistic that measures whether the correlations between pairs of variables can be explained by other factors. Coates & Steed (1997) recommend that the KMO should be greater than 0.6. The high KMO of 0.870 suggests there was probably a factor structure underlying the data.

Fifteen factors were extracted with eigenvalues greater than one and accounted for 66.9% of the total item variance. The scree plot for this data, which is simply a plot of the eigenvalues against factor numbers, is shown in Figure 5.

Figure 5: Scree Plot of the Eigenvalues Plotted against Factor Numbers



The eigenvalue for factor 14-15 to factor 54 form a straight line whereas factor 1 to 13 fall above this line. The literature has shown that the most appropriate number of factors that adequately represent the constructs underlying the variables is equal to the number of factors that come before the scree (Compey & Lee, 1992; Holmes-Smith, 2001; Coates & Steed, 1997).

An orthogonal (varimax) rotation was utilized. Loadings of variables on factors, are shown in Table 11. Variables are ordered and grouped by size of loading to facilitate interpretation. Loadings under 0.3 are not shown in the table.

Table 11: Factor Structure of Quality of Life Profile Adolescent Version Questionnaire *

Factors

Items	1	2	3	4	5	6	7	8	9	10	11
Q20. School I attend	0.73										
Q22. House/apartment I live in	0.68										
Q23. Neighbourhood I live in	0.62										
Q19. Feeling safe when I go out	0.41										
Q4. Exercising		0.71									
Q47.Participating in sports/recreation activities		0.71									
Q5. Physical health		0.66									
Q8. How I feel about myself			0.69								
Q15. Having hope for the future			0.47								
Q10. Know where I'm going			0.38								
Q9. Know who I am			0.30								
Q6. Nutrition		0.41				0.30		0.30			
Q7. Free of worry and stress	0.31		0.53								
Q3. Appearances			0.45								
Q51. Learning about new things				0.49							
Q49. Being successful at the things I do				0.44							
Q53.Planning for more education/training				0.37							
Q43. Attending public entertainment					0.68						
Q30. The friends I have					0.58						
Q36.Having things to do in my community					0.52						
Q35. Having places to go with my friends					0.32						
Q11. Acting independently						0.32		0.52			
Q12. Trusting others											
Q13. Feeling part of things											
Q14. Feeling life has meaning							0.36	0.51			
Q16. Having religious beliefs							0.57				
Q17. Helping others				0.46	0.31	0.31					
Q18. My ideas of right and wrong				0.56							
Q2. Healthy choices											
Q20. Area of the country I live in											
Q21. Earth and its environment								0.31			
Q.2 Healthy choices				0.45							
Q25. Acting responsibly				0.58			0.33				
Q26. Being appreciated by others				0.33						0.31	
Q27. Getting along with my family	0.33										
Q28. Having a boy/girl friend											0.60
Q29. Having parties and things to go to											0.54
Q31. Being able to get medical services on my own						0.30					
Q32. Getting a good education											
Q33. Having enough money										0.50	
Q34. Having jobs available while still in school									0.72		
Q37. Doing volunteer work for others						0.52					
Q38. Looking after my appearance /hygiene									0.35		
Q39. Studying and doing homework				0.30					0.50		
Q40. The chores I do at home											
Q41. The things I do in school				0.30							
Q42. The work I do at a job while still in school							0.60				
Q44. Having hobbies and personal interests		0.44									
Q45. Indoor activities											0.47
Q46. Outdoor activities		0.66									
Q48. Visiting and spending time with others								0.39			
Q50. Getting along better with others											
Q52. Planning for a job or career											
Q54. Solving my problems											

** Numbers in Table indicate factor loadings*

Only the first eleven factors are shown as factor 12, 13, 14, and 15 only had one to two items loading on each factor. Since a minimum of three items is required to measure each latent construct these factors were therefore dropped from further analysis.

4.4.3.1 Factor 1 - Environment

The first factor explained 5.1% of the variance. The factor loadings are high (ranging from 0.41-0.73) suggesting that they are relatively "pure" measures of the environment factor. Q27 (getting along with my family) does not make substantive sense with the remaining items. Q7 (free from worry and stress) also cross-loads on factor 3 quite heavily, so was not included in the CFA.

4.4.3.2 Factor 2 - Physical Health

The second factor accounted for 6.8% of the variance, with the items comprising physical health all being high (0.66-0.71), suggesting they were a good measure of this factor. Q6 (nutrition) did cross-load on other factors and was not included in the CFA.

4.4.3.3 Factor 3 - Psychological

The third factor accounted for 4.7% of the variance. It can be seen that with the exception of Q7 (free of worry and stress), Q3 (appearances) and Q14 (feeling that life has meaning), which cross-loaded on other factors, the remaining items were relatively "pure" measures of the psychological factor.

4.4.3.4 Factor 4 - Opportunities for Growth and Development

The fourth factor (opportunities for growth and development), accounted for 6.9% of the variance. The three items (Q51, Q49 and Q53) were designed to measure opportunities for growth and development and loaded heavily on this factor. However, a number of items from other dimensions also tended to cross-load on this factor.

4.4.3.5 Factor 5 - Social

The fifth factor accounted for 5.3% of the variance. The loadings were high and made substantive sense. Q17 (helping others) cross-loaded on two other domains and was dropped from the CFA analysis.

4.4.3.6 Factors' 6-15

The remaining factors contained only 1-5 items on each factor and explained only 1.6% to 3.1% of the variance. Most of the items also cross-loaded on other factors and were therefore not considered "pure" measures of the construct they were designed to measure. Factors 6-15 were also not included in the CFA due to sample size limitations.

In summary, the following rules were used to decide if an item was to be included. Items having loadings <0.3 were considered to be weak items and were deleted from further analysis. If an item cross-loaded on two different factors and had a loading of >0.3 on the second factor, then it was also deleted. The cut-off point and the meaning of items were taken into account when deciding to retain or delete them. The results of the EFA together with a review of the literature provided a guideline for selecting items to be included in the CFA. Reliability and validity for the constructs hypothesized to measure adolescent QOL were also determined. Reliability issues will be discussed in Section 4.4.6.

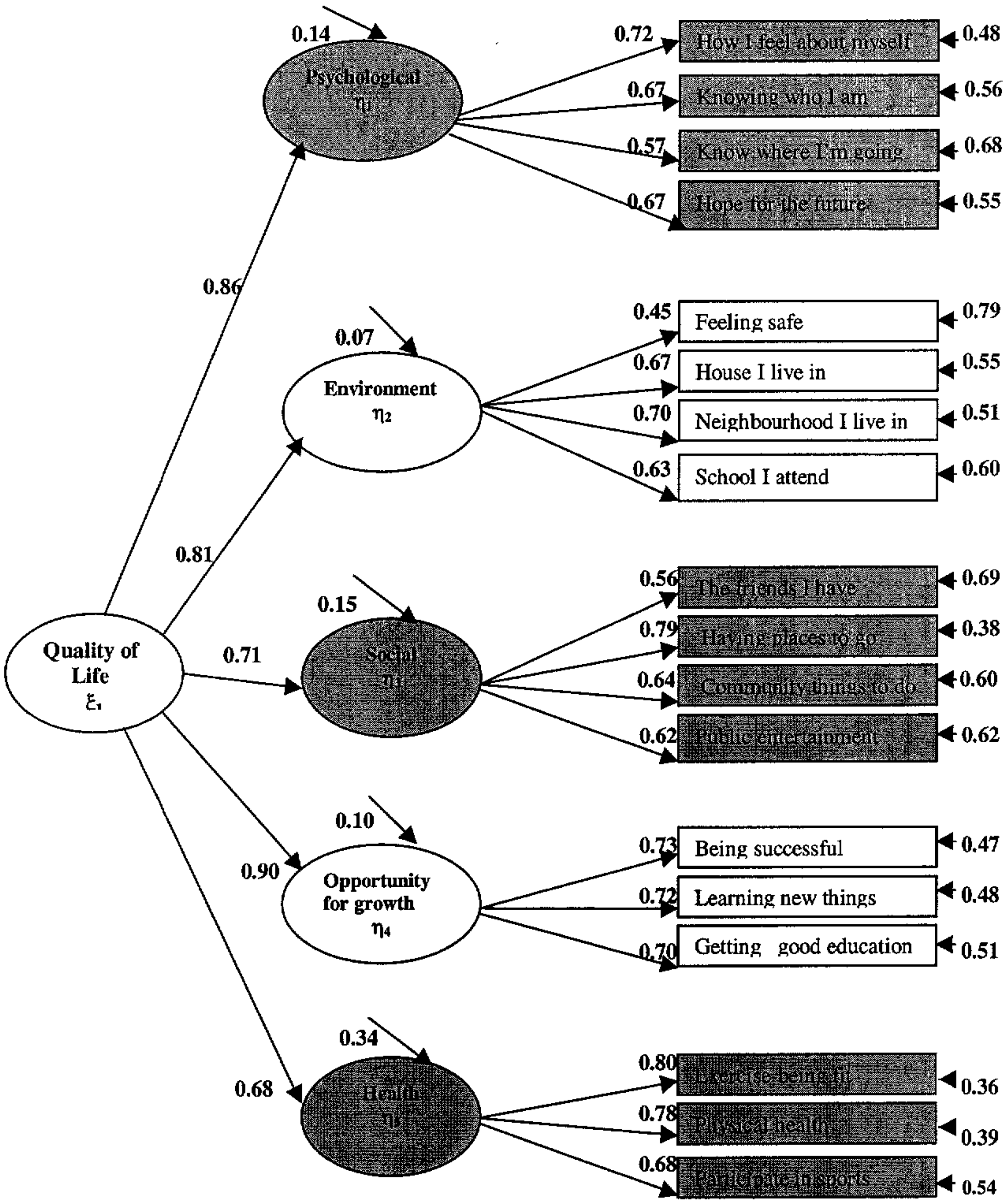
4.4.4 Adolescent QOL Constructs and Dimensions

To address the dimensions constituting adolescent QOL a second-order CFA model was fitted to the data. It was decided to combine both groups when performing the second-order CFA and SEM analysis since there was no difference in the QOL satisfaction scores between the adolescents with and without a chronic condition according to the MANOVA results reported in section 4.4.5.

4.4.4.1. Second-Order Confirmatory Factor Analysis

To identify the factor structure underlying the 18 items, a second-order confirmatory factor analytic measurement model was fitted to the combined data using the scaled covariance matrix of the polychoric correlations obtained from PRELIS 2.3. The solution, presented in Figure 6, generated one second-order factor QOL (ξ_1) and five correlated first-order factors labeled: (η_1) *psychological (thoughts and feelings);* (η_2) *environment*; (η_3) *social;* (η_4) *opportunities for growth and development* and (η_5) *physical health.*

Figure 6: Completely standardized solution to second-order confirmatory factor analysis showing loadings and error variances for the eighteen items, five underlying latent factors and a single factor.



Model Goodness of Fit Indices:

Satorra Bentler $\chi 2$ (130)=150.72; p=0.1032 RMSEA=0.021; SRMR=0.049; GFI=0.92; AGFI=0.90; NNFI=0.91; CFI=0.93; IFI=0.93

To facilitate interpretation of Figure 6 the five first-order factors are bounded by ellipses and the item descriptions within each first-order factor are bounded by rectangles. For example, loadings of the items for the *opportunities for growth and development* factor (η_4) ranged from 0.70 for 'getting a good education' to 0.73 for 'being successful'. It is evident from Figure 6 that all the factor loadings were high (ranging from 0.56 to 0.80, except for 'feeling safe' which was 0.45), indicating a moderate to strong association between each of the latent factors and their respective items. The factor loadings also made substantive sense, were meaningful and statistically significant.

As indicated by the AGFI in Figure 6, the model accounted for 90% of the variances and covariances in the observed items. The Satorra-Bentler chi-square was insignificant. The RMSEA and SRMR values were less than 0.05. All other fit indices exceeded 0.90 indicating no lack of fit. Therefore, the specified second-order model provides a satisfactory representation of the observed findings.

In the analyses reported here, no further modifications were performed on the model to achieve a better fit. This decision was taken because it was considered more important to maintain theoretical consistency than adjusting the postulated model merely to improve the fit, the latter being statistically driven rather than theoretically driven (Byrne, 1998; Bollen & Scott-Long, 1993; Kelloway, 1998).

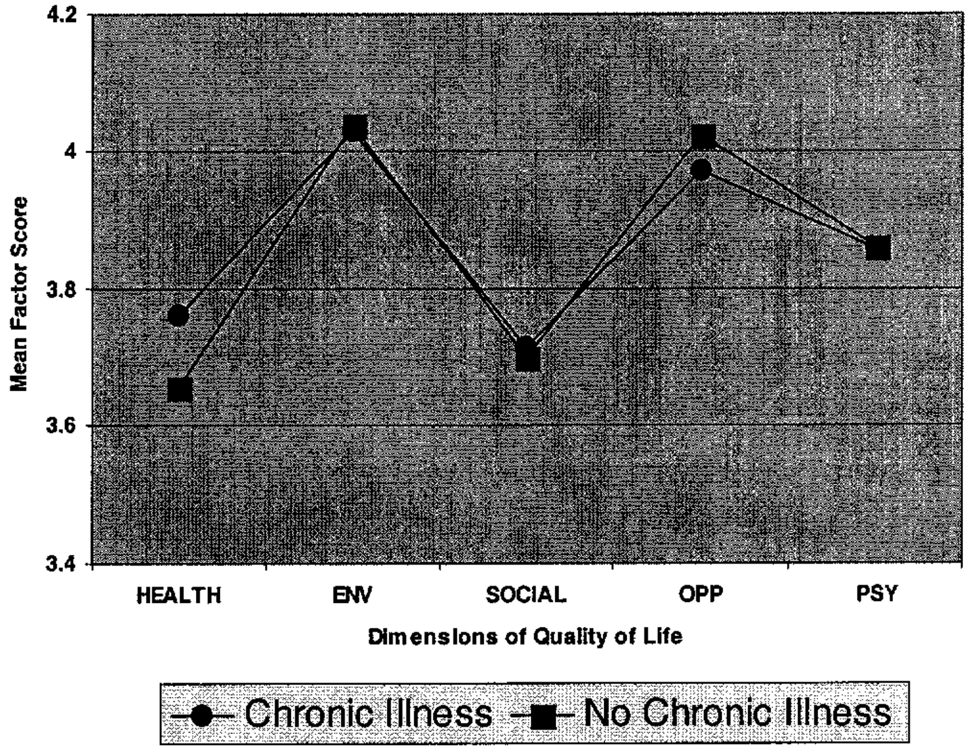
4.4.4.2 Convergent Validity

Kline (1998) suggested that evidence of convergent validity for first-order models exit if all observable variables load significantly on the respective latent factor. In second-order models, the relationship between the endogenous latent factors (*social*, *physical health*, *opportunities for growth and development*, *psychological* and *environment*) and the overall exogenous factor (QOL) must also be significant. The results showed that convergent validity was achieved. The direct effects of the second-order factor (0.68-0.90) on the five first-order factors are strong, so a relatively small proportion of the variance remains unexplained for each first-order factor (0.07 to 0.15 except for physical health, which was 0.34).

4.4.5 Comparison of Factor Scores between Chronic and Non-Chronic Adolescents

Figure 7 plots the means of the five composite factor scores for the healthy adolescents and the chronically ill adolescents. Using MANOVA, no significant difference was found between the two groups (multivariate Wilk's Lambda = 0.990, F(5, 357) = 0.721, p = 0.608). The univariate F-ratio for each of the five factors was also insignificant (p-values ranged from 0.218 to 0.976).

Figure 7: Mean Composite Factor Scores of the Five Factors for the Chronic and Non-Chronic Adolescent



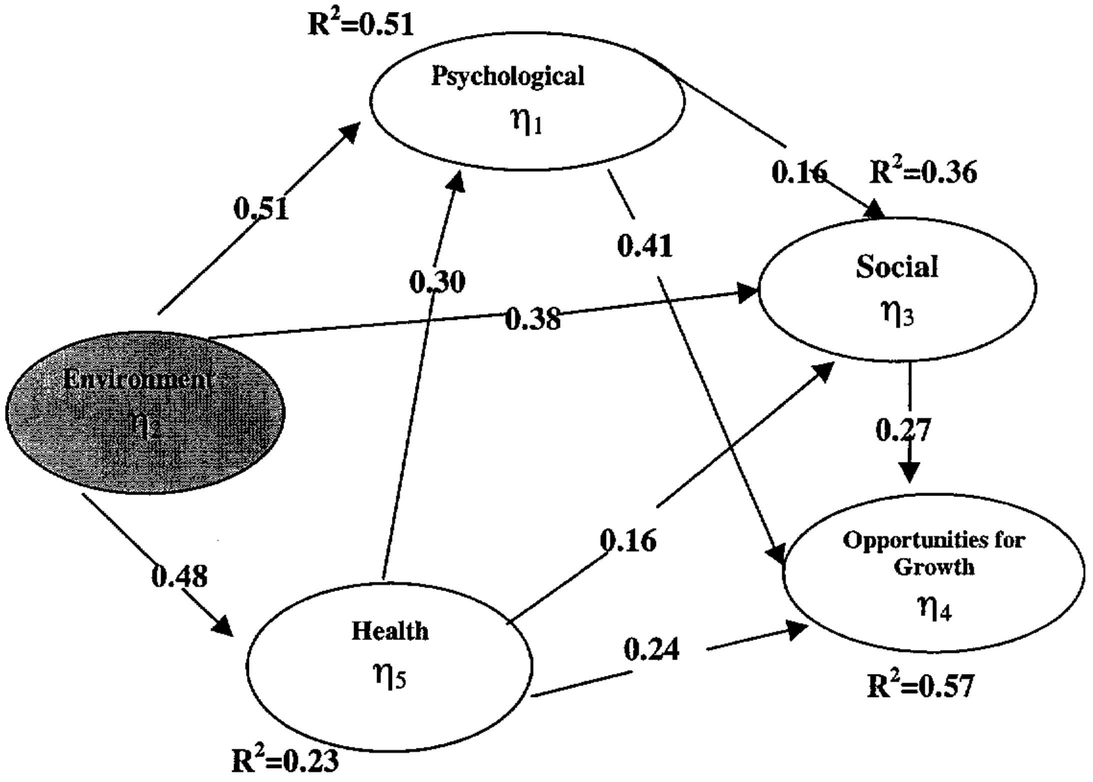
4.4.6 Reliability Assessment for the Five Latent Composite Factor Scores

In the course of computing the composite scales, the weighted factor scores were also used to determine the composite scale reliability for each of the five factors (Holmes-Smith & Rowe, 1994). The composite scale reliability scores for the five constructs were as follows: *physical health - 0.81, psychological - 0.80, opportunities for growth and development - 0.87, social - 0.86* and *environment - 0.73.* This suggests that the 18 items were reliable measures of their respective latent factors.

4.4.7 Interdependent Effects among the Five Factors using SEM

To estimate the direction and magnitude of the effects among the five QOL factors identified, a recursive SEM was fitted to the composite factor scores using the maximum likelihood estimation method. The best fitting solution is illustrated in Figure 8. The AGFI index indicated that 95% of the relative variances and covariances of the data were accounted for. All other indices and measures were satisfactory. The path coefficients proximal to the unidirectional arrows (from ellipse to ellipse), shown in Figure 8, are the standardized estimates of the direct effects of one factor score on another. These may be interpreted as standardized regression coefficients. For example, one standard deviation increase in the *environmental* factor (η_2) leads to a corresponding increase of 0.51 standard deviation units in the *psychological* factor (η_1). All estimated path coefficients were significant. The R^2 values refer to the squared multiple correlation coefficients for the structural equations. For example, 51% of the variance in the *psychological* factor (η_1) was accounted for simultaneously by the direct effects of the *environment* (η_2) factor and the *physical health* (η_5) factor scores, as well as the indirect effect of the *environment* (η_2) factor score, mediated by the *physical health* (η_5) factor score.

Figure 8: Solution to Recursive Structural Equation Regression Model, showing Standardized Direct Effects and Covariances.



Model Goodness-of-Fit Indices

Satorra Bentler χ^2 (1) = 3.16 p = 0.07; RMSEA = 0.05; SRMR = 0.013; GFI = 1.00; AGFI = 0.95; NNFI = 0.96; CFI = 1.00; IFI = 1.00

These results suggest that the "environment" factor plays an important role in determining adolescent's QOL as it influenced every other factor either directly or indirectly.

4.4.8 Direct, Indirect and Total Effects among the Five Latent Factors

A summary of the direct, indirect and total effect sizes for the final model is presented in Table 12. While direct effects are commonly used when interpreting the results of a structural equation analysis, Bollen (1989) states that total effects present a more comprehensive indication of the influence of one construct on another. Total effects augment the direct paths by reflecting additional indirect paths that run through intervening constructs to connect two constructs in question.

As depicted in Table 12 *environment* is the primary factor impacting strongly on the *psychological* factor (β= 0.51), *physical health* (β = 0.48), and moderately impacting on the *social* (β = 0.38) aspects for adolescent QOL. *Psychological* aspects for adolescent QOL (β = 0.30), *social* factors (β = 0.16) and *opportunities for growth and development* (β=0.24) were influenced by *physical health*, whereas *opportunities for growth and development* (β = 0.41) and *social* aspects (β = 0.16) of QOL were influenced by the *psychological* factor. *Opportunities* were also moderately influenced by the *social* factor (β = 0.27).

Table 12: Decomposition of Standardised Direct, Indirect and Total Effects: Relationships among Adolescent QOL Components

Scale	Environment	Psychological	Physical Health	Social	Opportunities For Growth
Environment					
Direct Effect	--	--	--	--	--
Indirect Effect	--	--	--	--	--
Total Effect	--	--	--	--	--
Psychological					
Direct Effect	0.51	--	0.30	--	--
Indirect Effect	0.15	--	--	--	--
Total Effect	0.66	--	0.30	--	--
Health					
Direct Effect	0.48	--	--	--	--
Indirect Effect	--	--	--	--	--
Total Effect	0.48	--	--	--	--
Social					
Direct Effect	0.38	0.16	0.16	--	--
Indirect Effect	0.18	--	0.05	--	--
Total Effect	0.56	0.16	0.21	--	--
Opportunities					
Direct Effect	--	0.41	0.24	0.27	--
Indirect Effect	0.54	0.04	0.18	--	--
Total Effect	0.54	0.45	0.42	0.27	--

Note: Absolute values less than 0.10 indicate a "small" effect, value about 0.3 a "medium" effect; and those greater than 0.50 indicate a large "effect" (Kline, 1998).

4.5 Discussion

Using second-order CFA and SEM, the latent factors underpinning the QOL construct and the interdependent effects among these factors, for adolescents with and without a chronic illness, were assessed. The findings have both substantive and methodological implications for further research on the conceptualisation of adolescent QOL. Despite the controversy concerning the appropriate dimensions of adolescent QOL, our measurement model lends support for the inclusion of factors assessing *physical health, environment, social, psychological* and *opportunities for growth and development.* The results also suggest that the selected 18-item scale provided satisfactory representation of these core dimensions. Such findings provide valuable insights on the choice of valid instruments and domains for measuring adolescent QOL.

The SEM results provide further information on the inter-relationships among the factors affecting the perceptions of QOL. The finding that *environment* had significant direct and indirect effects on the other four factors, enhances the understanding of QOL. The *feeling of safety, the home lived in, the school the adolescent goes to*, and the *neighborhood* were all significant variables for this construct (see Figure 6). Clearly, many of these aspects may affect an individual's QOL as well as one's health. Concerns about security may also limit an adolescent's social activities as well as his/her sense of well-being, as reflected by the positive, strong effect of the *environment* on both the *psychological* and *social* factors. Although research on the environmental aspect of adolescent health is limited, it has been implicated in mental disorders, poor social behaviour, and poor academic performance (Coleman, 1974). Hechlinger (1992) also identified a link between housing and neighbourhood quality with crime, violence and drug use among adolescents.

Somewhat surprisingly, the *social* factor (*friends the adolescent had, places to go, things to do, public entertainment*) had little effect on the other five factors except for *opportunities for growth and development* (see Figure 7). However, only 36% of the variability of this factor was explained by the direct effect of the *environment* and the indirect paths mediated by *physical health* and the *psychological* factor. There is some evidence of the role the family plays in the development of the adolescent, suggesting that other intermediate factors such as family relationship might partly explain the interdependent effects among these five factors (Raphael et al., 1996). It is also possible that the relationships between the social, physical health and psychological factors are bi-directional. However, our results were comparable to a study by Smith et al. (1999), which found that social functioning did not have a major impact on physical functioning and mental health when measuring QOL.

Opportunities for growth and development were significantly influenced by three factors-*social, physical health* and *psychological.* This demonstrates the importance attached to their future prospects by both healthy and chronically ill adolescents, which include being *successful in their endeavours, getting a good education* and *learning new things* (see figure 7). This is consistent with the literature that adolescents are interested in future vocations and doing well in school (Parkin et al., 1997; Raphael et al., 1996). Jessor (1991) has also suggested an association between adolescent health behaviour and the perception of life chances in a study of American adolescents.

The *psychological* (thoughts and feelings) factor had a strong positive effect on *opportunities for growth and development* and a lesser effect on the *social* factor. The hypothesized relationship (both direct and indirect), accounting for more than 51% of the variability highlighted the interrelationships among these factors. While adolescents as a group represent a relatively healthy segment of the population, there is increasing evidence that their health status is lower than it was for their parents (Raphael et al., 1996). Recent literature also suggested a significant incidence of physical and mental disorders in the adolescent population (Australian Institute of Health and Welfare, 2000). These findings underscore the importance of the role played by *psychological* and *social* factors on the adolescent's well-being, and emphasize the need for developing health promotion practices geared towards these issues.

This study found no significant difference between the healthy and chronically ill adolescents' perceptions of QOL. Incidentally, other studies also reported that adolescents with a chronic condition adapt to their conditions remarkably well and do not view their circumstances as negative (Stawski et al., 1995; Lindstrom & Kohler, 1991).

The use of SEM appears to be a useful approach for assessing the reliability and validity of QOL instruments, testing measurement models and examining the relationships among multiple dependent and independent latent variables. It is recommended that QOL researchers continue to employ multiple item constructs and rigorously test the measurement model. Through this rigorous process, measurement error can be minimized (by excluding unreliable items, using weighted composite scores rather than unit weights) and can be taken into account when modelling the various relationships.

A limitation of the SEM approach is the requirement of large sample sizes for parameter estimation in the presence of many latent variables and/or a large number of items (Rowe, 2000). In the present study due to the sample size, we assumed that the relationships between the five factors were recursive (one-way). It is probable that some of the relationships may be bi-directional, especially between the *physical health* and *psychological* domains. It was also also not possible to assess other domains such as daily activities, which may be relevant to an adolescent's QOL.

4.6. Summary

This chapter represents an initial effort to assess QOL for the adolescents with and without a chronic illness. The results of the CFA and SEM are unique and contribute to adolescent QOL research. Further replication with large samples is needed in order to confirm the validity of the measurement model and the interrelationships among the domains, as well as assessing the effects of covariates such as age and gender on QOL.

CHAPTER 5

DETERMINANTS OF ADOLESCENT QUALITY OF LIFE

CHAPTER 5

Determinants of Adolescent QOL

5.1 Overview

An understanding of the determinants of quality of life (QOL) for adolescents with and without a chronic condition can provide important insights for public health initiatives aimed at improving the status of the adolescent. In this chapter based on a review of the literature, several predictors for adolescent QOL will be explored using a multiple linear regression approach. The significant predictors will then be examined via structural equation modelling (SEM) based on the five domains (*physical health*, *social*, *psychological*, *environment*, and *opportunities for growth and development*), obtained from the second order confirmatory factor analysis (CFA). It is anticipated that these results will provide insight into the antecedents of adolescent QOL.

5.2 Introduction

Demographic variables (gender, low socio-economic status and large family size), environmental characteristics and parenting behaviour, have all been identified as risk factors for the health of both adolescents with and without a chronic condition. (Eiser, 1997; Raphael et al., 1996). As mentioned in the literature review (Chapter 2) a considerable portion of previous research into QOL has focused on the influences of direct antecedents. Researchers have generally ignored mediating influences, instead seeking to explain QOL linking it directly with factors such as age, physical health, mental health and social support (Granzin & Haggard, 2000). These studies have generally used correlation and regression to test their proposed relationships. Recently however, researchers have proposed and tested more comprehensive models of the complex process of influences on QOL. Seeking to simultaneously explain both QOL and its determinants, they have proposed influences not only from multiple antecedents to QOL, but also links that connect the determinants themselves using a structural equation modeling (SEM) approach (Smith et al., 1999). A structural equation modeling approach employs multiple indicators, which provide more accurate measurement and consequently more precise testing of the hypothesized explanatory relationships (Bollen, 1989; Maruyama, 1998). While these techniques have been applied to an adult population they have not been used with an adolescent population.

This chapter explores the determinants of QOL for the adolescent with and without a chronic condition. The aims are:

- to determine if adolescents with a chronic condition perceive their QOL differently from healthy adolescents;

- to assess the relationship between physical health and QOL for both the adolescent with and without a chronic condition;

- to explore which variables best explain QOL based on the overall QOL scores and the five latent factors (*psychological, social, environment, physical health and opportunities for growth and development*) hypothesized to measure adolescent QOL (based on the results obtained from the second-order confirmatory factor analysis (CFA).

5.3 Methodology

The study and sampling design, the data collection procedures, the conceptual model and the Quality of Life Profile Adolescent Version (QOLPAV) questionnaire have been discussed in Chapter 3.

5.3.1 Determinants of Quality of Life for Adolescents

Independent variables included in the analysis are age, gender, socio-economic status (SEIFA Index based on the postal code and treated as a continuous variable), perceptions of physical health, and the amount of control and opportunities perceived by the adolescent in his/her life.

5.3.2 Statistical Analysis

All data were coded and entered using SPSS-Version 10 (SPSS Inc., 2000). Plausibility checks were made and inconsistent data were cleaned prior to statistical analyses. Univariate statistics were first applied to characterize the sample. Specific hypotheses on the overall QOL scores related to gender, health status, SES and age were subjected to statistical tests. Potential variables influencing the overall QOL scores were next explored using a standard (simultaneous) regression model. For a detailed discussion on how the QOL score was obtained see Chapter 3, section 3.4.1.

It should be cautioned that the regression assumption of independence may be violated when sample data are clustered (Kreft & DeLeeuw, 1998; Goldstein, 1995). In this situation, adolescents were clustered within schools, whose observations tend to be correlated (Heck & Thomas, 2000). Failure to account for this inherent hierarchical or clustering structure of the data may give rise to misleading results including aggregation bias, incorrect parameter estimates and corresponding standard errors, and problems of model mis-specification due to lack of independence between measurements at different levels (Kreft & DeLeeuw, 1998; Goldstein, 1995; Heck & Thomas, 2000). In order to accommodate the clustering effect and to assess the sensitivity of the analysis, multi-level modeling was undertaken.

5.3.2.1 Multilevel Models

Multilevel models, or variance component models, are a form of linear mixed model which allows the incorporation of both random (school) effects, as well as the conventional fixed effects in the regression equation. It provides information about the variation within and between clusters (schools). The standard linear regression model assumes a non-hierarchical structure, so that independence of observations may be justified if the intra-class (intra school) correlation is negligible. The Mlwin-Version 2.1 (Rabash et al., 2000) statistical package was used to perform the hierarchical multilevel modeling.

5.3.2.2 Multiple Regression Analysis and Structural Equation Modeling

QOL is a multidimensional construct and can obviously be better understood if all dimensions are considered at the same time. However, many researchers have chosen to aggregate all the items together to obtain an overall QOL score. By doing so, they imply that QOL is a one-dimensional concept. The results of the second-order CFA model in Chapter 4 have shown that adolescent QOL can be conceptualized by five latent factors (*physical health*, *social*, *psychological*, *environment*, and *opportunities for growth and development*). Therefore, it was decided to examine the effects of the independent variables on the five QOL domains using multiple regression within a SEM framework.

The results of the multiple regression model using the overall QOL scores, provided a preliminary view of which variables and paths were likely to be significant in the full SEM. Relationships among the QOL components and their influencing factors were then modeled through SEM. The use of SEM was considered to be the most appropriate approach to examine the effects of the independent variables on the five QOL domains. It overcomes the problems associated with conventional analytical techniques. Furthermore, it also allows for the specification and simultaneous estimation of relationships among multiple endogenous (dependent) variables and permits measurement error in both the exogenous (independent) and endogenous variables (Bollen & Scott-Long, 1993). More specifically, SEM can be used to:

- Estimate the relationships among dependent variables;
- Estimate relationships among latent constructs underlying observed variables;
- Allow unequal weighting for the multiple observed variables of a latent construct;
- Estimate reliability and validity in both latent and observed variables;
- Allow for correlations among the measurement errors (Holmes-Smith, 2000; Bollen & Scott-Long, 1993).

The SEM analysis was undertaken using LISREL 8.3 (Joreskog & Sorbom, 1996). PRELIS 2.3, the preprocessor for LISREL, was used to generate the matrices for subsequent analysis by LISREL 8.3.

5.4 Results

5.4.1 Demographic Information

Adolescents ranged between 10 and 18 years of age, with the average age (13 years) for both groups being similar (see Table 13). The majority of the participants were females enrolled in years 8, 9 and 10, and lived at home with both parents. No significant difference was evident between the adolescent with and without a chronic condition in their living arrangements (p=0.643), gender (p=0.288), grade distribution (p=0.050), and parental socio-economic status (SES) (p=0.06).

Table 13: Descriptive Characteristics of Chronic and Non-Chronic Adolescents

	Adolescents with a chronic condition		Adolescents without a chronic condition	
	n	%	n	%
Sample size (N=363 total)	112	31%	251	69%
Gender (female proportion)	71	63%	172	69%
Living Arrangement				
• Both parents	86	76%	201	80%
• Mother only	21	19%	30	12%
• Father only	4	4%	6	2%
• Other	1	1%	14	6%
Grade distribution				
• Year 6-7	17	16%	17	7%
• Year 8	31	28%	72	29%
• Year 9	29	26%	58	23%
• Year 10	27	24%	61	25%
• Year 11-12	7	6%	38	16%
Average age (years)	13.63 (S.D. =1.33)		13.9 (S.D. = 1.56)	
SES (average)	1036.03 (S.D. =54.69)		1044.08 (S.D.=53.19)	

Notes: Numbers may not add up to total "n" owing to missing cases.

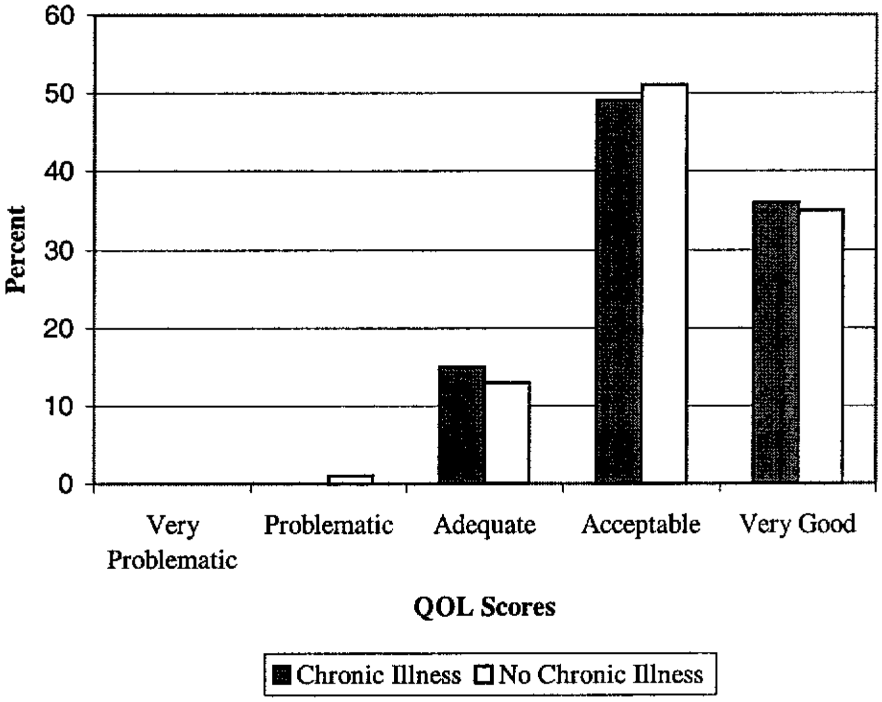
5.4.2 Overall QOL Scores

According to Raphael's (1996) scoring system, an overall QOL score greater than 1.50 is considered as "*very good*", a score of 0.51 to 1.50 indicates an "*acceptable*" situation and scores between –0.50 and 0.50 indicate an "*adequate*" situation. Scores from –0.51 to –1.50 are seen as "*problematic*", with scores below –1.50 being interpreted as "*very problematic*".

Overall QOL scores were positive with both groups reporting an "*acceptable*" to "*very good*" QOL as evident in Figure 9. The mean QOL score for those with a chronic condition was 1.28 (S.D.=0.71), and 1.22 (S.D.=0.67) for those without. Only 1% of the entire sample reported a problematic QOL and this occurred in the group without a chronic condition. However, the difference between the two groups was not significant (t = –0.721, df = 359, p = 0.47), which was further supported by the global QOL measure, which again detected no statistical difference ($\chi^2 = 3.740$, df = 4, p = 0.587).

No significant difference was reported between males and females in both groups (chronic: t = 0.900, df = 110, p = 0 .37; and non-chronic: t = -0.074, df = 247, p= 0.941). A negative association between age and QOL was evident for both groups (chronic r = -0.235; non-chronic r = -0.228).

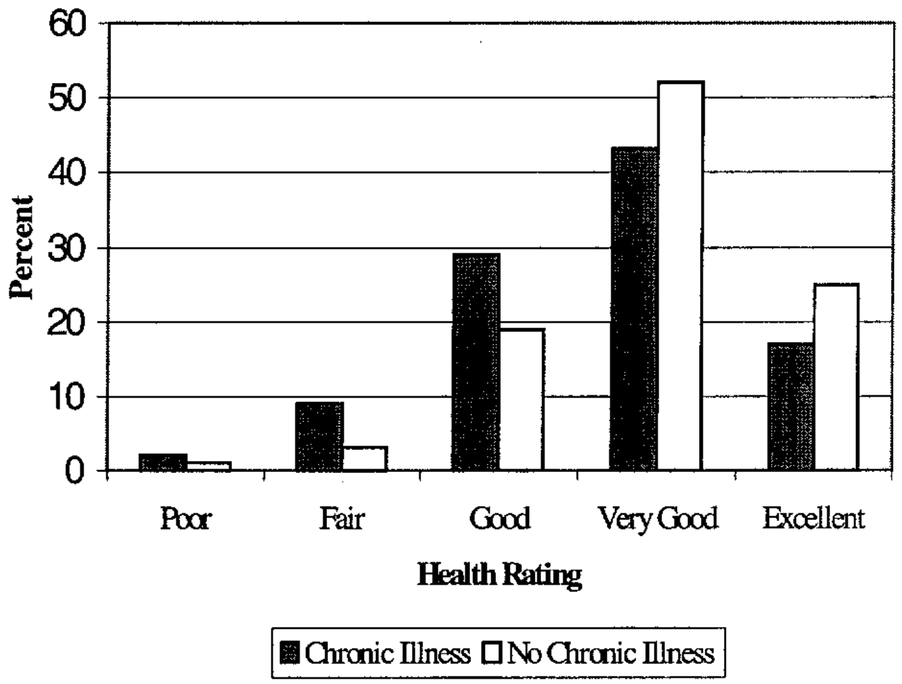
Figure 9: Distribution of QOL Scores



5.4.3 Perceptions of Physical Health

As expected, self-reported health was related to QOL scores (r = -0.451). A chi-square test to investigate the association between the perceptions of health and the two groups was significant ($\chi^2 = 14.716$, df = 4, p = 0.012). As evident from Figure 10 there is a higher proportion of adolescents with a chronic condition in the self-assessed health status “good”, “fair” and “poor” categories compared to adolescents with no reported conditions. Once again, self-assessed health was slightly related to age (r = 0.121) but not related to gender ($\chi^2 = 3.084$, df = 4, p = 0.687).

Figure 10: Distribution of Health Ratings



5.4.3.1 Health and the Number of Sick Days Reported

As expected, the overall number of sick days reported by the chronically ill adolescent was related to health (r = 0.32), however this was not the case for the adolescent without a chronic illness (r = 0.09).

It was also reported that in the 14 days immediately prior to filling out the questionnaire, 30% of the adolescents with a chronic condition and 21% of the adolescents without, had missed school due to sickness or injury. The average number of sick days experienced by healthy adolescents was 0.23 day (S.D.= 0.58), whereas those with a chronic condition was 0.50 sick days (S.D.= 2.648). Of the group reporting a chronic condition, 2% required hospitalization while 40% of this group took time off school due to specific complaints related to their chronic illness. However, the difference in sick days between the two groups was not statistically significant (t = -1.758, df = 357, p = 0.081).

5.4.4 Control and Opportunities

These scores did not contribute to the computation of the overall QOL scores, however they provided a context in which to interpret the QOL scores (Raphael et al., 1996). Both control and opportunity scores were positively correlated with overall QOL as evident in Table 14. However there was no statistical difference between the two groups in terms of the amount of control perceived in their lives (t = 0.536, df =359, p = 0.592) and the opportunities available to them (t = -0.670, df = 355, p = 0.503).

Table 14: Correlation of Control and Opportunities to QOL Scores

Variable	Chronic(n=111)	Non-chronic (n=252)
Control	r =0.575	r=0.496
Opportunities	r =0.369	r= 0.231

5.4.5 Socio-Economic Status

Socio-economic status was not associated with the overall QOL scores (r = -0.056). There was also no significant difference between the two groups of adolescents in terms of their SES (t = 0.936, df = 361, p = 0.06).

5.4.6 Determinants of QOL

Before performing the full structural equation model, a multiple regression analysis was conducted to examine the relationship between the overall QOL score and a set of independent variables (*age*, *gender*, *SES*, *the presence of a chronic condition*, *control*, and *opportunity*). Results of the multiple regression analysis can provide useful information of the factors influencing QOL.

Since there was no observed difference in the QOL scores between both groups of adolescents, a multiple regression model based on the combined sample was undertaken. Preliminary analysis of the data showed that the assumption of normality was reasonably satisfied by the response variable. A standard regression procedure found that age, perceptions of health, control and opportunities, were significant determinants of QOL. Gender, the presence of a chronic illness and SES were not significant. While the presence of a chronic condition and gender did not improve the overall goodness-of-fit, it was decided to retain these terms in the model to reflect the chronic status of the adolescent and the larger female representation. The final regression results are summarized in Table 15. For the combined sample of 356 observations (after removing missing data) age, control, opportunities and perceptions of physical health together accounted for 36% of the variability of the QOL scores, after controlling for the adolescent's chronic status and gender. Younger adolescents were more likely to report a higher QOL score, whereas the amount of control perceived by the adolescent had a positive impact on their QOL. However adolescents who perceived their health as poorer reported a lower QOL evaluation. The fit of this model was further assessed for violations of standard regression assumptions. Residuals and other diagnostics revealed no apparent problem.

Table 15: Determinants of QOL for the Chronic and Non-Chronic Adolescent from Multiple Regression Model

	ALL	
	Coefficients	**(s.e)**
Age *** (in years)	-0.073	(0.022)
Control*	0.717	(0.072)
Opportunities **	0.076	(0.040)
Perceptions of health *** (0=excellent, 1=very good, 2=good, 3=fair, 4=poor)	-0.183	(0.037)
Presence of chronic condition (0=without chronic condition 1= chronic condition)	0.119	(0.066)
Gender (0=male, 1=female)	0.010	(0.063)
Constant	-0.432	(0.417)
Adjusted R square	0.358	

*Note: ** significant at the 0.05.*
**** significant at the 0.01.*

The regression model above did not take into account the hierarchical or clustering effect of the data – that is adolescents nested within schools. To determine the proportion of QOL variance due to the correlational effect of students from the same school, a multilevel variance component model was fitted using Mlwin-Version 2.1 (Rabash et al., 2000). The proportion of variance in QOL due to the school effect was 0.002, which is also an estimate of the intra-class correlation. Therefore, observations generated from the sampled adolescents may be assumed to be independent in view of the multilevel analysis.

5.4.7 The Full Structural Equation Regression Model

Next, SEM was used to examine the relationship between the five latent variables (*physical health, social, psychological, opportunities for growth and development* and *environment* factors), measuring adolescent QOL. Data on these latent variables was obtained from the second-order CFA, with the significant independent variables from the linear regression.

Since adolescent QOL is hypothesized by all five latent factors, but to varying degrees, SEM is the most appropriate method as it allows the testing of causal pathways between the exogenous and endogenous latent variables simultaneously. The models used in this testing were all recursive (only hypothesized as going one way).

The predictor variable "*opportunity*" was deleted from the path model, as it was similar to the composite factor "*opportunities for growth and development*" obtained from the second-order CFA model. The correlations of the relevant variables are summarized in Table 16.

Perusal of Table 16 revealed no high correlations (>0.8), between the factors which could cause collinearity problems in the full SEM. Model assumptions of normality and linearity were checked for the continuous variables (age, control, physical health, social, psychological, environment, and opportunities for growth and development) which were minimally to moderately skewed with moderate kurtosis.

Table 16: Correlation Matrix of Variables used in SEM (n=363)

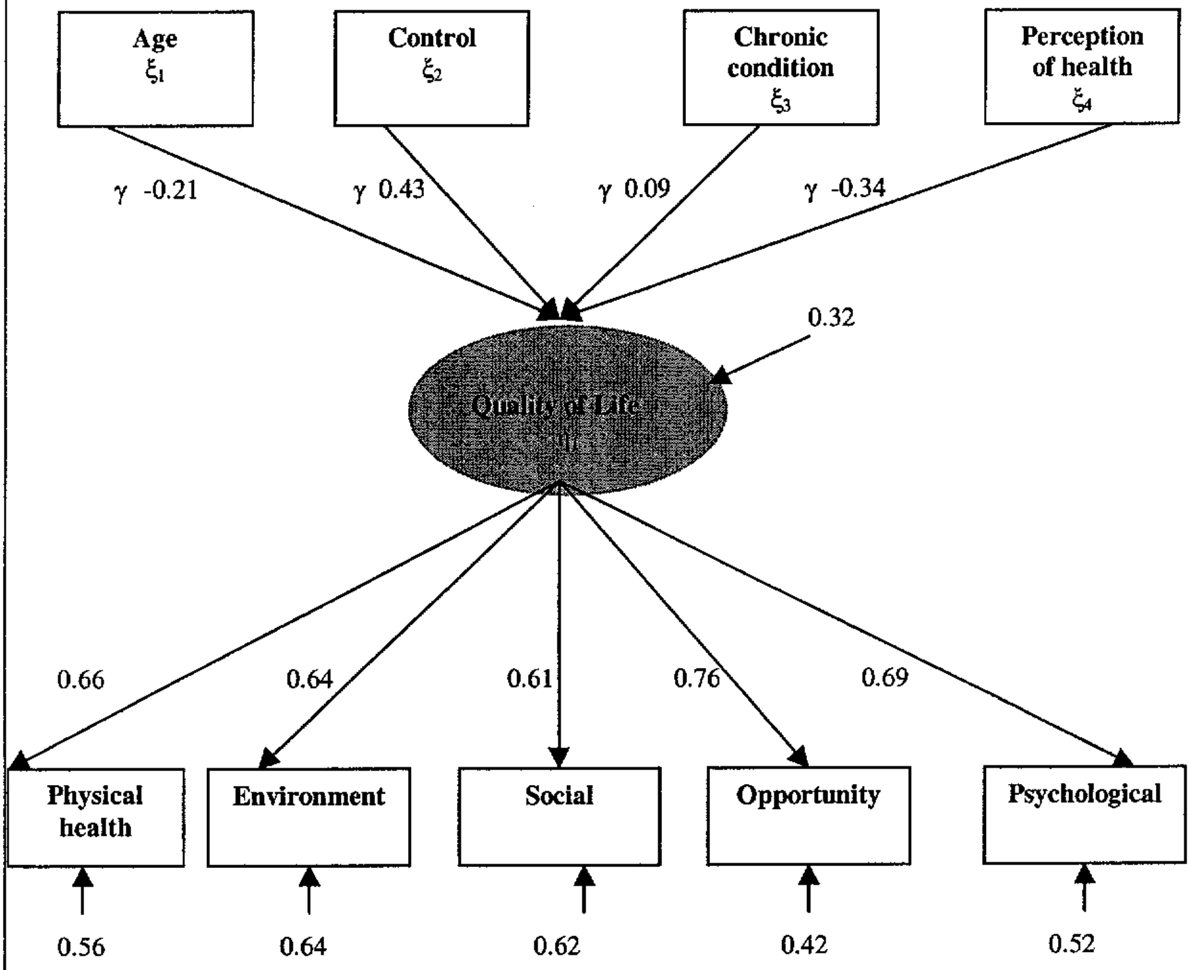
Variable	1	2	3	4	5	6	7	8	9
1. **Age**	---								
2. **Control**	-0.470	---							
3. **Health**	0.121	-0.314	---						
4. **Chronic Condition**	-0.084	-0.063	0.177	---					
5. **Psychological**	-0.222	0.382	-0.276	0.005	---				
6. **Environment**	-0.129	0.373	-0.279	0.006	0.473	---			
7. **Social**	-0.130	0.412	-0.169	-0.008	0.387	0.395	---		
8. **Physical health**	-0.207	0.336	-0.519	-0.060	0.433	0.352	0.338	---	
9. **Opportunities**	-0.248	0.362	-0.310	0.040	0.537	0.423	0.541	0.509	---

Note: Health=perceptions of overall health; Opportunities=Opportunities for growth and development; Chronic Condition=Presence of a chronic condition

All variables to be included in the full SEM model were continuous variables except for the presence of a chronic condition and perceptions of physical health. Therefore, polyserial correlation matrices and asymptotic covariance matrices were used. The estimation procedure used was weighted-least squares (WLS), followed by maximum likelihood (ML). This results in the Satorra-Bentler chi-square, which takes into account both continuous and categorical data and small sample sizes (Holmes-Smith, 2001). For further discussion see Chapter 4, Section 4.3.4.7.

In the SEM analysis, single indicators were used to measure the constructs of age, control, presence of a chronic condition and perceptions of health, since they are assumed to be measured without error (only one indicator item). When fitting the full model, the estimated composite regression scores obtained from the second-order CFA for *physical health*, *psychological*, *social*, *environment*, and *opportunities for growth and development* (for more details see Chapter 4, Section 4.3.4.5), were used in the estimation of the full model (Holmes-Smith 2001; Holmes-Smith & Rowe 1994). The adequacy of the model was evaluated using the same goodness of fit criteria employed in Chapter 4, Section 4.3.4.7. The model depicted in Figure 11 provided the best fit. All parameter estimates are standardized.

Figure 11: Influence of Predictor Variables on Adolescent QOL



Model Goodness-of-Fit Indices:

Satorra Bentler χ^2 (21)= 9.94, p=0.979; RMSEA = 0.000; RMR=0.50; GFI= 0.94 AGFI=0.90; NNFI = 0.90; CFI=0.90; IFI=0.90.

Note: η represents the latent dependent variables; ξ represents the latent independent variables; γ represents the relationship between the exogenous (independent) variables and endogenous (dependent) variables

The results indicate that the model fits the data reasonably well, therefore no model respecification was undertaken since post hoc model adjustments of this type may capitalize on chance variations (Byrne, 1998).

As shown in Figure 11 the estimated parameters indicating the strength of the relationship, given as standardized gamma weights (γ), showed a number of moderate associations between the single-indicator predictors and domain-specific QOL constructs. Age showed a non-significant modest inverse relationship ($\gamma = -0.21$, $p>0.05$) with the five constructs measuring adolescent QOL. Control had a significant positive moderate influence ($\gamma = 0.43$, $p<0.05$), while poorer reports of health had a significant negative influence ($\gamma = -0.34$, $p<0.05$) on the five constructs. The presence of a chronic condition was not significant and did not influence the QOL construct ($\gamma = 0.09$, $p>0.05$).

Quality of Life can be defined by *physical health, psychological, social, environment* and *opportunities* for *growth and development,* as evident by the high factor loadings (0.61-0.76) on the QOL construct. All loadings were statistically significant at the 1% level, with more than 90% of the QOL variance explained by the model.

5.5 Discussion

This chapter illustrated that there was no difference between healthy and chronically ill adolescents in their overall QOL scores. Both groups in this sample generally reported a positive QOL. The positive QOL scores are comparable with other studies, which found that adolescents with a chronic condition adapt to their conditions remarkably well, and do not view their circumstances as negative (Stawski et al., 1995; Lindstrom & Kohler, 1991). However, it is possible that the lack of difference in QOL between the two groups in our study, may be because the adolescents with a chronic condition were still relatively healthy at this period in their life. Further validation of these results may be confirmed in a longitudinal design that can accommodate changes in QOL (to be reported in the next chapter). However these higher ratings for QOL by the chronically ill adolescent do provide some support that a chronic illness may be mediated by intervening factors, such as social support or environmental characteristics, that enable the adolescent to maintain and even enhance their QOL (Stuibergen et al., 2000).

Not surprisingly, the study did find that chronically ill adolescents rated their overall physical health poorer than their healthy counterparts. This is comparable with results from the Australian National Health Survey (2000). The number of sick days reported by the chronically ill group was also higher than the healthy group, reflecting the impact a chronic condition can have on this aspect of their life. This is also consistent with earlier studies (Newacheck et al., 1998; Newacheck et al., 1991; Western Australia's Child Health Survey, 1995). While physical health is only moderately related to the overall QOL scores it does appear to have a bearing on the perception of QOL by both groups. The adolescent's perceptions of their physical health significantly impacted upon the QOL construct, with a poorer perception of health resulting in a lesser QOL score. Using health to make inferences about QOL is a common approach in the literature and our results do provide some support (Bowling, 1997).

The negative association between QOL and age is logical and generally supported by developmental theory (Grey et al., 1998). The older adolescent (15-19 years old) is more concerned with developing autonomy and moving away from parental influences, as well as experimenting with risky behaviors. They can be expected to report relatively lower QOL scores as a consequence of the tremendous changes in various aspects of their life. Our results are comparable with a study by Wang et al., (2000) who also found a continuing decrease in QOL scores among older Japanese adolescents. Older adolescents with epilepsy were again identified as at risk for a poorer QOL rating in a study by Devinsky et al. (1999). However, age was not found to be a significant predictor in the SEM analysis and further investigation into these inconsistencies is warranted.

It is interesting to observe that self-perceived control was positively correlated with overall QOL scores and a significant predictor for adolescent QOL. This is consistent with the literature that a stronger sense of personal control is associated with better health outcomes (Frey et al., 1998; Cappelli et al., 1989). Again, if personal control could be demonstrated in a longitudinal study to be predictive of QOL scores, it would support the increasing importance being ascribed to it as a determinant of health (Raphael et al., 1996).

Opportunities available to adolescents were also positively associated with overall QOL scores. This demonstrates the importance attached by adolescents to their future prospects. An earlier study found that adolescents with a chronic illness perceived QOL as having "normal opportunities of life" but they expressed concerns about opportunities related to independence (Parkin et al., 1997). Similar work by Raphael et al. (1996) identified leisure opportunities as an area of adolescents' concerns. In contrast, a study by Hui (2000), identified academic achievements and future prospects as the most pressing concern in a survey of Chinese adolescents.

The results found that there was no difference between males and females in both groups when evaluating their QOL. It was also not a significant predictor for adolescent QOL. It should be remarked that conflicting evidence exists in the literature. A study found gender differences for males with a chronic condition reporting a higher QOL (Apajasalo et al., 1996), while other studies identified that females with a chronic condition are more prone to depression, anxiety and unhappiness than males (Devinsky et al., 1999; Staab et al., 2000). However the lack of difference reported here could be due to the higher prevalence of females in the sample.

SES has been suggested as protective of the adolescent with a chronic condition (Devinsky et al., 1999), while Raphael et al., (1996) found only a weak relationship between QOL and SES. Higher parental education has also been suggested as protective of the adolescent with a chronic condition (Australian Institute of Health and Welfare, 2000). However, in a comparison of well and chronically ill school-age children from two large community-based samples, behavioral and adjustment problems were reported for ill children relative to the well children, independent of the educational status of their parents (Stein et al., 1998). While the literature highlights the inconsistencies regarding SES, the results of this study found that SES was not a significant predictor for adolescent QOL. Nevertheless, it is quite possible that measurement for SES based on postcodes may not be sensitive enough to detect any significant relationship.

Finally, the use of structural equation models (SEM) has been shown to be useful for studying adolescent QOL. The five composite factors identified from the results of the second-order CFA were derived from factor scores regression analysis rather than by using additive or average scores. This approach is considered to be superior to the unit weight approach, as discussed in Chapter 4, Section 4.3.4.5. The SEM also attempted to more accurately model the "true" relationship among the variables by accounting for measurement error.

5.6 Summary

This chapter has illustrated that the broader view of health determinants appear to be promising for enhancing the QOL for both the chronically ill and healthy adolescent. However, these results are cross-sectional in nature and thus limit the examination of adolescent QOL to associations, rather than across-time causal effects. As such, these results will next be tested in a longitudinal model that will examine the stability of determinants for adolescent QOL over a six-month interval.

CHAPTER 6

A LONGITUDINAL ASSESSMENT OF ADOLESCENT QUALITY OF LIFE

CHAPTER 6

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6.1 Overview

In Chapter 5, several determinants of quality of life (QOL) were identified for the adolescent with and without a chronic condition. In Chapter 4, five latent factors that measured adolescent QOL based on the results of a second-order confirmatory factor analysis (CFA) were identified. In this chapter, the stability of these determinants was examined over a six-month period. This assessment was undertaken on the overall QOL scores as well as the five factor composite scores obtained from the second-order CFA.

6.2 Introduction

The results of the cross-sectional study from Chapter 5 identified control, perceptions of global physical health, opportunities and age to be significant determinants for adolescent QOL. The results also identified a moderate amount of variability in the overall QOL scores between both groups. Understanding what underpins such differences may be useful to designing interventions that may improve the QOL for adolescents.

Little is also known about changes in QOL over time. This gap in knowledge is partly due to problems in collecting and analysing longitudinal health data, which often has missing observations attributable to dropout. Analysis of such data is difficult using standard repeated measurement techniques, which require balanced data with each individual measured at the same time point (Goldstein, 1995). One solution is to use a series of score differences between baseline and later time points (Fayers & Machin, 2000). However, this approach has a number of limitations such as the loss of valuable information on individual change since the scores for all adolescents do not necessarily change in the same direction (Priestman & Baum, 1976). Recent developments in statistical techniques expand the opportunity to examine trends and individual differences using longitudinal multi-level or hierarchical models.

The aim of this chapter is to describe the patterns of QOL in a group of adolescents with and without a chronic illness over a six-month period. Specifically the objectives are:

- to consider how the QOL for adolescents varies over time using the overall QOL scores and the five composite factor scores obtained from the CFA (*physical health*, *environment*, *social*, *psychological*, *opportunities for growth and development*);
- to explore which variables best explained changes in QOL over the six month period.

6.3 Methodology

The sampling design, the data collection procedures, the conceptual model and the QOLPAV questionnaire have been discussed in Chapter 3.

6.3.1 Study Design

A longitudinal design was employed to assess the perceptions of QOL for adolescents with and without a chronic condition aged 10-19 over a six-month period.

6.3.2 Univaiate Analysis

Descriptive statistics were performed using SPSS Version 10 (SPSS Inc., 2000). Univariate analyses such as independent and paired t-tests were used to determine if any differences existed among the groups.

To determine the magnitude and significance of the changes in QOL for both groups from baseline to six months, "effect size" was also determined (Cohen, 1992). Effect size has been used by QOL researchers as an index of sensitivity to change (Fayers & Machin, 2000). It is based solely upon the distribution of the observed data, and in particular the variability of the measurements. It is calculated as the mean difference of the change in the QOL score recorded for assessments of the same subject at two different times, divided by the standard deviation of the baseline group. An effect size of 1 corresponds to a mean change of one standard deviation in the sample studied. Cohen (1992) has suggested that effect sizes of 0.2 to 0.4 are considered "small", 0.5 to 0.8 "moderate", and those above 0.8 "large".

6.3.3 Multilevel Longitudinal Models

As mentioned in Chapter 5, Section 5.3.2.1 multilevel modeling is essentially an extension of multiple regression and is appropriate for analyzing hierarchically structured or nested data. It is more consistent with social theories than are traditional methods of analysis (ordinary regression), in that the multiple levels of data are accommodated (Rowe, 2000). The nested structure causes "intraclass dependency" among the units at the higher level of the hierarchy. When data are hierarchically structured, the assumption of independence is violated. Failure to account for the inherent hierarchical or clustering structure of the data may give rise to misleading results including aggregation bias, incorrect parameter estimates and corresponding standard errors, and problems of model mis-specification due to lack of independence between measurements at different levels (Rowe, 2000; Kreft et al., 1998; Goldstein, 1995; Heck et al., 2000).

Repeated measures or longitudinal data can be described as measurements on a variable for the same group of individuals at a number of consecutive points in time (Van der Leeden, 1998). In longitudinal multilevel data sets, the hierarchy can be defined as level 1 units (the repeated measurement occasions), nested within the level 2 unit (the individual subject). This approach allows for the partitioning of variance and covariance between each of the levels. This variation may in turn be accounted for by explanatory variables.

For this study, parameters to explain the longitudinal effects of the change in the adolescent's perception of their QOL were estimated using a two- level model. The simplest two level unconditional base, (no predictors) model for estimating change in QOL, is described below. This model is equivalent to a one-way analysis of variance with random effects as shown below:

$$Y_{ij} = \alpha + (u_j + e_{ij})$$

The subscript "i" refers to the QOL response score "Y" for adolescent "j" on occasion "i". The fixed part of the model α represents the grand mean of adolescent QOL scores (intercept). The terms " u_j" and "e_{ij}" represent the random components. Specifically, "u_j" is the variance around the grand mean due to between adolescent differences and "e_{ij}" is the variance around the grand mean due to times within adolescent differences. These two random components are assumed to be normally distributed and uncorrected, with a mean of 0 and variances σ_u^2 and σ_e^2.

The intraclass adolescent correlation (I.C.C) is given by $\rho = \sigma_u 0^2/\sigma_u 0^2 + \sigma_e^2$. This correlation provides an estimate of the proportion of the total variance in QOL scores that is due to between adolescent differences (level two). One minus the intraclass correlation gives the proportion of variance within adolescents due to time (level one).

The I.C.C. is a measure of the degree of dependence among the adolescents. The more they share in common space (going to the same schools) or time, the more they are similar (Kreft & De Leeuw, 1998). Dependent observations also arise from repeated measurements of the same person, which is the case in this study. Non-zero I.C.C implies that the assumption of independence is violated (Goldstein. 1995; Kreft & De Leeuw, 1998).

Since our analyses included predictor variable (X) the extended model becomes:

$$Y_{ij} = \alpha + \beta X_i + u_i + e_{ij}$$

(Goldstein, 1995; Bryk & Raudenbasch, 1992; Kreft & DeLeeuw, 1998; Snijders & Bosker, 1999). To test the significance of the random parameters a sequence of models is compared on the basis of explained variances compared to the "null" model. Examination of the differences in the likelihood ratio can be compared with the chi-square distribution with the appropriate degrees of freedom, indicating how much better a model can account for the variance at the specified level (Goldstein, 1995; Bryk & Raudenbasch, 1992; Kreft & DeLeeuw, 1998; Snijders & Bosker, 1999).

Each covariate in this study was added to the base model as a fixed effect to explain QOL variation between adolescents and the change in QOL within each adolescent over time. Covariates investigated at level 2 included age in years, control, opportunities perceived and overall perception of physical health. This subset of covariates were chosen based on the results of the multiple regression analyses, which identified these variables as significant predictors for adolescent QOL at the 5% significance level (for further details see Chapter 5, Section 5.4.6).

Mlwin-Version 2.1 was used for the analysis in this study (Rabash et al., 2000).

6.4 Results

6.4.1 Demographic Information

A total of 363 adolescents (251 healthy adolescents and 112 adolescents with a chronic condition) completed the first questionnaire and 300 (204 healthy adolescents and 96 adolescents with a chronic condition), completed the second questionnaire. This represented an overall response rate of 82.6% from the first questionnaire to the second.

As indicated in Table 17, participants from the second questionnaire ranged in age between 10 and 18 years of age, with the average age for both groups being similar. The majority of the participants (both questionnaires) were females and lived at home with both parents. There was no statistical difference between the chronic and non-chronic adolescent based on their age (p=0.286), gender (p=0.583) and living arrangements (p=0.595) for the second questionnaire. Further details regarding the results of the first questionnaire were given in Chapter 5, Section 5.4.1. Similar to the first questionnaire the majority of the chronic adolescents reported a diagnosis of asthma (48%), which is comparable to that of the general population in Australia (Australia's Health, 1998).

Table 17: Descriptive Characteristics of the Sample

	Six month follow-up			
	Chronic		Non-chronic	
	n	%	n	%
Sample size	96	32%	204	68%
Gender (female proportion)	66%		67%	
Average age (years)	14.35 S.D (1.47)		14.50 S.D (1.33)	
Living Arrangement				
• Both parents	81	81%	156	77%
• Mother only	15	15%	32	16%
• Father only	4	4%	9	5%
• Other	--	--	5	2%
Chronic Condition:				
• Asthma	48	48%	---	---
• Allergies	15	15%	---	---
• Asthma and allergies	5	5%	---	---
• Juvenile arthritis	2	2%	---	---
• Chronic headaches	2	2%	---	---
• Diabetes	2	2%	---	---
• Other	25	25%	---	---

Note: numbers may not add up due to missing items

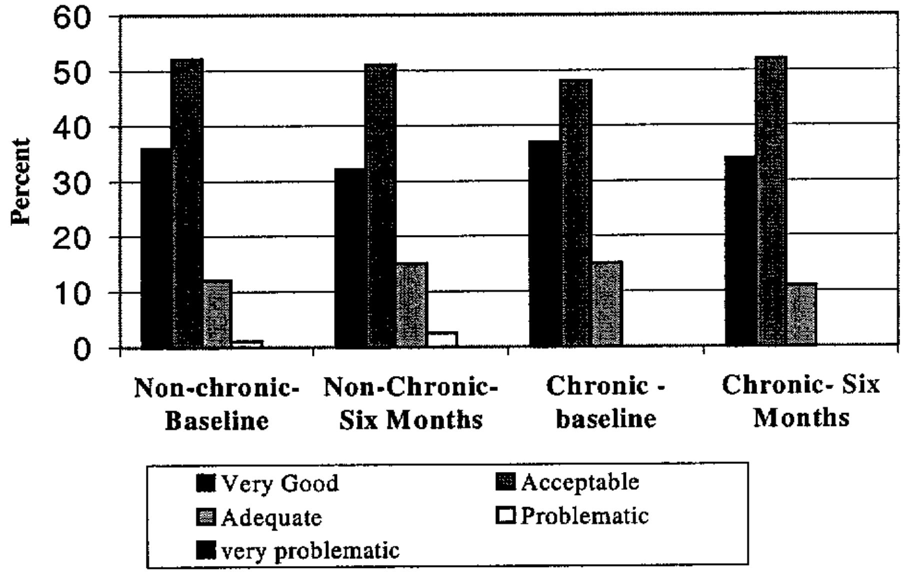
Demographic information relating to parent's education and the adolescent's ethnicity was not collected for the first questionnaire. However the results from the second questionnaire revealed that the majority of the combined sample (n=300) were born in Australia (80%), spoke English at home (95%) and their parents had a university education (32%).

Attrition across the six-month period was reported at 17.3%. The attrition rate is consistent with those noted in other longitudinal studies (Duncan et al., 1998). The characteristics of the adolescents completing the questionnaire at six months were compared to the entire group. Those who dropped out of the study tended to be younger and did not report a chronic condition. These limited differences indicate that there was little bias resulting from attrition.

6.4.2 QOL Scores and Stability

Overall QOL scores were positive, with both groups at the start of the study and at six months, reporting an acceptable to very good QOL. Only 1% (baseline) and 2.5% (six months) of the entire sample reported a problematic QOL. On both occasions, this occurred in the group without a chronic condition. See Figure 12.

Figure 12 : Distribution of QOL Scores over Six Months



As evident in Table 18 there was a decline in the overall QOL scores for both chronic and non-chronic adolescents over the six-month study period.

Table 18: Mean Scores for Overall QOL

Variable	Baseline		Six month follow-up	
	Chronic (n=112)	Non-chronic (n=251)	Chronic (n=96)	Non-chronic (n=204)
	Mean (S.D.)	Mean (S.D.)	Mean (S.D.)	Mean (S.D.)
QOL scores	1.28 (0.71)	1.26 (0.66)	1.18 (0.66)	1.19 (0.70)

Changes in QOL scores over six months were considered for each group. There was no statistical change in the mean QOL score evaluations between the administration of the first and second questionnaire for both the non-chronic adolescent (t = 1.214, df = 202, p=0.226) and the adolescent with a chronic condition (t = 1.989, df = 92, p = 0.050). However, it should be noted that the results for adolescents with a chronic condition approach statistically significant levels.

There was no difference in the perceptions for QOL between the chronic and non-chronic adolescents at baseline (t = -0.721, df = 359, p = 0.470) and at six months (t = -0.012, df = 296, p = 0.991). As a result, it was decided to combine the data when performing the multilevel longitudinal data analysis.

A negative association between age and QOL scores was reported on both occasions for both groups, ranging from –0.310 to –0.244.

6.4.3 Control and Opportunities Scores

These scores did not contribute to the computation of the overall QOL scores, however they provided a context in which to interpret the scores (Raphael et al., 1996). Mean scores for control and opportunities can be found in Table 19.

Table 19: Mean Scores for Control and Opportunities

Variable	**Baseline**		**Six month follow-up**	
	Chronic (n=112) **Mean (S.D.)**	**Non-chronic (n=251)** **Mean (S.D.)**	**Chronic (n=96)** **Mean (S.D.)**	**Non-chronic (n=204)** **Mean (S.D.)**
Control	4.04 (0.45)	4.10 (0.45)	4.06 (0.49)	4.10 (0.49)
Opportunity	3.65 (0.83)	3.59 (0.75)	3.53 (0.77)	3.50 (0.80)

The stability of the control and opportunity scores was tested using paired t-tests. There was no statistical difference in the perceptions of control for the chronic (t=-0.899, df=92, p=0.371) and the non-chronic adolescent (t=0.454, df=202, p=0.650). There was also no significant change in the opportunities perceived by the chronic adolescent (t=0.815, df=90, p=0.730) and the non-chronic adolescent (t=-0.351, df=201, p=0.726) over the six months.

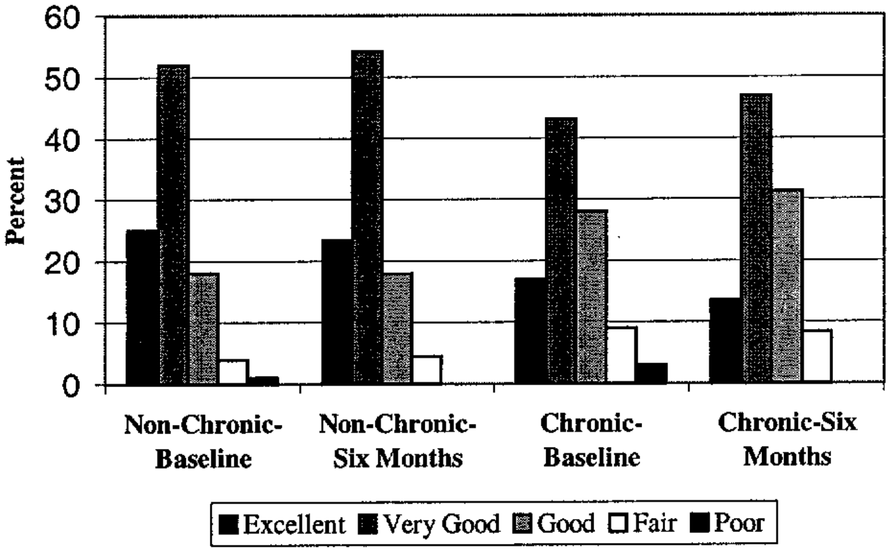
Both control and opportunity scores were positively correlated with the QOL scores on both occasions ranging from 0.231 to 0.589.

6.4.4 Perceptions of Physical Health

A Wilcoxon Signed Rank test to investigate the differences between the adolescent's perceptions of their physical health over the six-month period was performed. There was no significant difference for healthy adolescents (p= 0.145), or adolescents with a chronic condition (p=0.750).

A Mann-Whitney test to determine if a difference existed between the two groups was significant on both occasions (p=0.001; start and at six months). As evident from Figure 13 there is a higher proportion of adolescents with a chronic condition reporting a "good", "fair" and "poorer" physical health status compared to the non-chronic adolescent.

Figure 13: Distribution of Health Ratings over Six Months



In the preceding 14 days prior to filling out the second questionnaire, 31% of the adolescents with a chronic condition and 20% without, reported an illness/injury at six months. This is comparable to the results of the first questionnaire. However there was an increase in the number of sick days reported by healthy adolescents (1 to 12 days) at six months (see Table 20). Although there was a drop in the mean number of sick days reported by adolescents with a chronic condition this could be seasonally influenced (administration of the 2nd questionnaire was during summer time and better health reports would be expected). Of these sick days, 2% of the chronic group required hospitalization while 40% took time off school due to specific complaints related to their chronic illness (at the start and at six months). However, the difference in sick days between the two groups was not statistically significant at baseline (t=-1.758, df=357, p=0.081), or at six months (t=-0.416, df=299, p=0.678).

Table 20: Mean Sick Days for the Chronic and Non-Chronic Adolescent at Baseline and Six Months

Variable	Baseline		Six month follow-up	
	Chronic(n=112) Mean (S.D.)	Non-chronic (n=251) Mean (S.D.)	Chronic (n=96) Mean (S.D.)	Non-chronic (n=204) Mean (S.D.)
Sick days	0.50 (1.6)	0.23 (0.67)	0.35 (0.94)	0.29 (1.17)
Hospitalization	0.12 (1.3)	---	0.12 (0.90)	---

Sick days = the number of sick days in the preceding 14 days, hospitalization= the number of days hospitalized in the past 14 days due to illness/injury

6.4.5 Effect Sizes for QOL, Control and Opportunities Scores

As indicated by Table 21 the effect sizes (Cohen, 1992) for the change in the overall QOL, control and opportunities scores for both adolescents with and without a chronic condition were small. According to Fayers & Machin (2000) these changes can be interpreted as not meaningful.

Table 21: Change Scores and Effect Sizes Observed over Six Months for QOL, Control, and Opportunities

Variable	x_2-x_1 *		SD at baseline		Effect Size-SRM	
	Chronic	Non-chronic	Chronic	Non-chronic	Chronic	Non-chronic
QOL	0.10	0.07	0.71	0.66	0.14	0.11
Control	0.02	----	0.45	----	0.04	----
Opportunities	0.12	0.09	0.83	0.75	0.15	0.12

Chronic n=112, Non-chronic n=251 at baseline; Chronic n= 96, Non-chronic n=204 at six months

* *x_2 refers to the mean score at six months; x_1 refers to the mean score at baseline*

6.4.6 Determinants of QOL over Six Months

A longitudinal multilevel model was fitted to the data to determine the stability of the significant covariates (*age*, *control*, *opportunities*, and *perceptions of health*). These were identified as significant predictors for adolescent QOL based on the results of the multiple regression in Chapter 5, Section 5.4.6. The presence of a chronic illness was again included in the model to account for the chronic status of the adolescent. Preliminary analysis of the data showed that the assumption of normality was reasonably satisfied by the response variable (QOL), on both occasions. Since there was no observed difference in the QOL scores between both groups of adolescents, a longitudinal multilevel regression model based on the combined sample was undertaken. Iterative generalized least squares estimation (IGLS) was used.

The results of the null model in Table 22 suggest that adolescent (level two) variation dominated the random differences between occasions (level one variation). Specifically, 62.2% of the variation in the QOL scores was due to differences between adolescents, while 37.8% of the variance was due to within adolescent difference (time difference).

Covariates to explain the between adolescent differences (level 2), are presented in Table 23. Each covariate was added to the base model as a fixed effect. As evident in Table 23 all parameter estimates and are statistically significant except for time and the presence of a chronic illness. Overall QOL scores for both groups deteriorated over the six months. Age, control and perceptions of physical health constituted the major explanatory variables at the adolescent level. Increasing age and deterioration in physical health had a significant negative effect on QOL, whereas improved control and opportunities had a positive effect. The results presented in Table 23 indicate that the seven explanatory variables accounted for 38.1 % of the variance in the QOL scores.

The log-likelihood statistic for the model was 929.822, indicating a significant reduction in deviance units from the base variance component model of 1216.869 variables. The between adolescent variability fell to 0.161, a 45% reduction after adjusting for the relevant covariates. The within adolescent variability also exhibited a 26% reduction.

Table 22 and 23: Variance Component Model showing Proportions of Between Adolescent and Within Adolescent (due to time) Residual Variance: Parameter Estimates and Standard Errors in Parentheses

Table 22: Base Variance Component Model

N=653		**Estimate**	**(SE)**
Fixed Parameters			
Intercept		1.240	(0.033)
Random Parameters			
Level 2-Between adolescents variance		0.294	(0.031)
Level 1-Within adolescent variance due to time		0.178	(0.015)
Intraclass correlation	62.2%		
The log likelihood deviance estimate	1216.869		

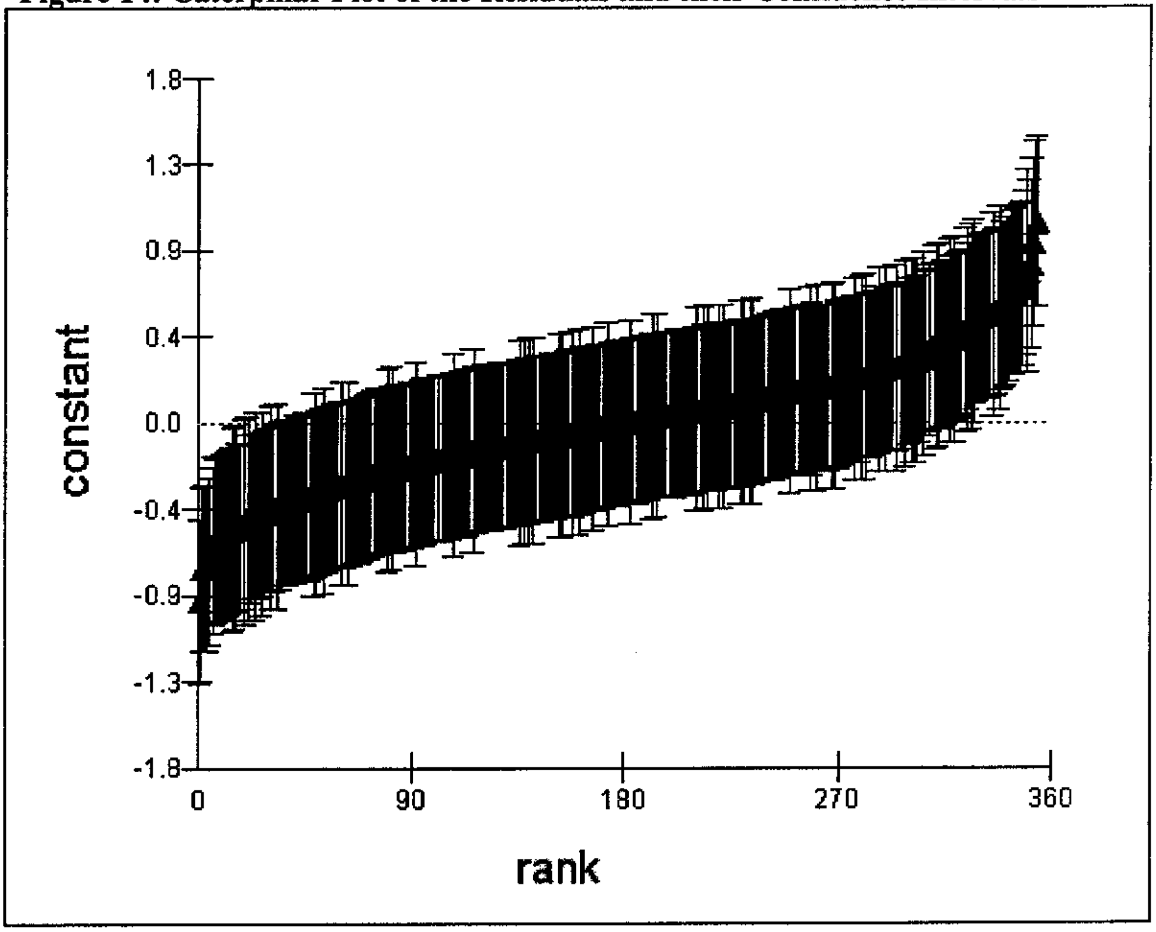
Table 23: Adjusted for time, age, presence of a chronic illness gender, control, opportunities, and perceptions of health

N=653		**Estimate**	**(SE)**
Fixed Parameters			
Intercept		0.555	(0.329)
Time		-0.014	(0.031)
Age		-0.105	(0.018)*
Control		0.528	(0.046)*
Opportunities		0.107	(0.026)*
Chronic Illness		0.078	(0.057)
Physical Health		-0.178	(0.027)*
Random Parameters			
Level 2- Between adolescents variance		0.161	(0.019)
Level 1- Within adolescent variance		0.131	(0.011)
% of variance explained:	38.1%		
The log likelihood deviance estimate	929.822		

*Note: * significant at p=0.05*

A comparison of the between adolescent variation (level 2) is shown graphically in Figure 14. The variation in each adolescent's QOL scores is modelled about the grand mean. According to the confidence intervals around the scores there are only a small number of adolescents at each end of the plot where the confidence intervals for their residuals exclude zero. These residuals represent adolescent departures from the overall line predicted by the fixed parameters, which means that the majority of the adolescents did not differ significantly from the average line at the 5% level. Since there are no explanatory variables these lines have zero slopes.

Figure 14: Caterpillar Plot of the Residuals and their Confidence Intervals



It should be noted that the clustering effect of the adolescents within schools within was negligible, as reported in Chapter 5, Section 5.4.6 (I.C.C. =0.002). As a result, it was decided to simplify the longitudinal multilevel analysis by ignoring the random school effects (that is, level 1- time, level 2- adolescent, and omitting level 3-school).

6.4.7 Change in the Latent Composite Factors Scores over Six Months

To determine if there was any change in the five composite QOL factor scores obtained from the second-order CFA, both univariate and multivariate tests were employed. The results of paired t-tests for the combined sample are presented in Table 24. Differences were found between the baseline and the composite factor scores at six months. There was a statistically significant difference in the *social* (p=0.001), *physical health* (p=0.023) and *opportunities for growth and development* (p=0.024) latent composite factor scores.

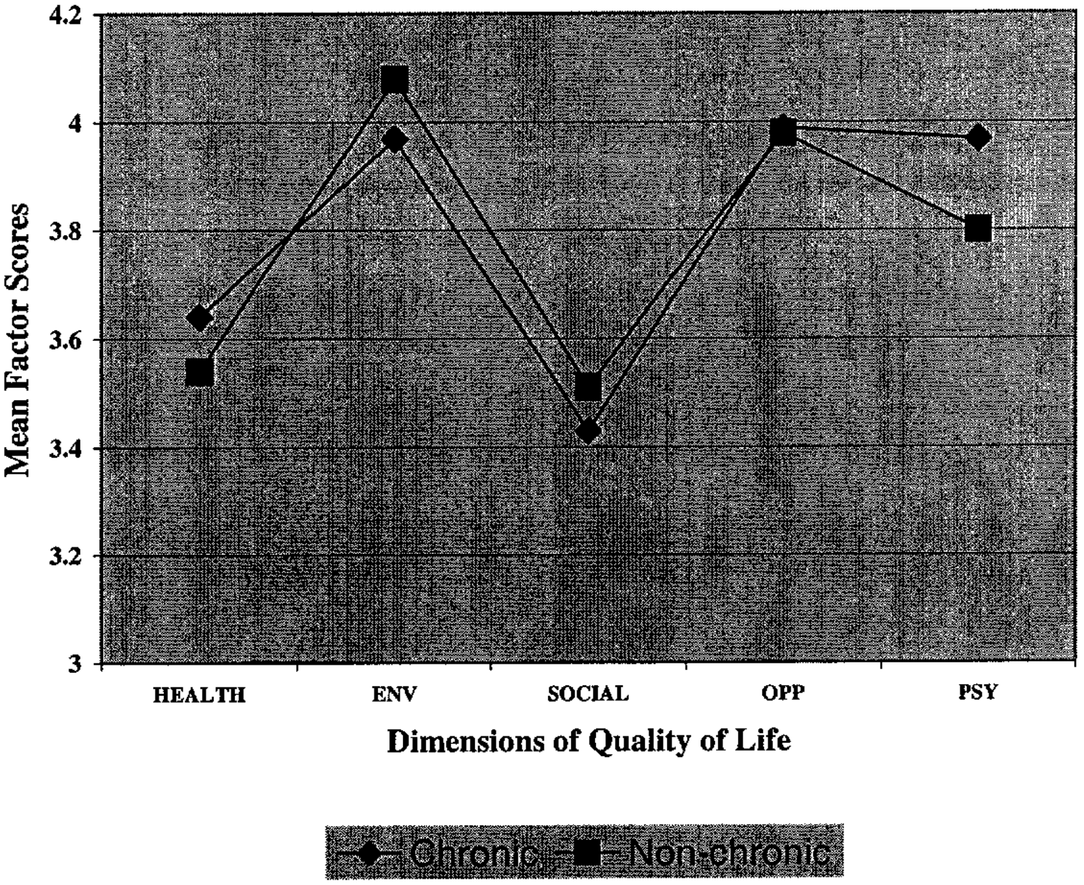
Table 24: Paired T-tests (combined group) for the Five Composite Latent Factor Scores Between Baseline and Six Months

Variable	Six month follow-up		
	t	df	p
Social	-3.261	301	0.001
Environment	0.956	301	0.340
Physical health	-2.283	301	0.023
Opportunities	-2.262	301	0.024
Psychological	0.068	301	0.946

6.4.7.1 Comparison of Latent Composite Factor Scores between Chronic and Non-Chronic Adolescents

To determine if there were any significant changes in the five composite factor scores between the two groups at six months, a MANOVA was employed. Figure 15 plots the means of composite factor scores for healthy adolescents and chronically ill adolescents. Significant differences were found between the two groups (multivariate Wilk's Lambda = 0.945, F(5, 282) = 3.312, p = 0.006), unlike the first questionnaire where there was no apparent differences between the two groups (see Chapter 4, Section 4.4.5).

Figure 15: Mean Composite Factor Scores of the Five Factors for the Chronic and Non-Chronic Adolescent



The mean composite factor scores for chronic and non-chronic adolescent at six months are tabulated in Table 25.

Table 25: Latent Composite Factor Scores for Chronic and Non-chronic Adolescents

Variable	Six month follow-up Chronic (n=96) Mean (S.D.)	Non-chronic (n=204) Mean (S.D.)
Social	3.439 (0.745)	3.512 (0.740)
Psychological	3.971 (0.674)	3.806 (0.741)
Environment	3.977 (0.703)	4.085 (0.684)
Physical health	3.644 (0.964)	3.542 (0.917)
Opportunities	3.994 (0.567)	3.982 (0.597)

6.4.7.2 Effect Size for the Five Latent Composite Factor Scores

As indicated by Table 26 the majority of the effect size scores for both groups were minimal (Cohen, 1992). However, a small negative effect of the *social* f actor (-0.34) for both the chronically ill adolescent and the non-chronic adolescent (-0.28) was evident. A small negative effect size of the *physical health* factor for the non-chronic adolescent was also reported.

Table 26: Effect Size Scores Observed for the Five Composite Factor Scores

Variable	x_2-x_1 *		S.D. at baseline		Effect Size-SRM	
	Chronic	Non-chronic	Chronic	Non-chronic	Chronic	Non-chronic
Social	-0.27	-0.20	0.78	0.71	-0.34	- 0.28
Psychological	-0.11	0.05	0.70	0.63	-0.15	0.07
Environment	0.06	-0.05	0.73	0.63	0.08	-0.08
Physical health	0.01	-0.22	0.86	0.78	0.01	-0.28
Opportunities	0.03	- 0.01	0.61	0.62	0.04	- 0.01

Chronic n=112, Non-chronic n=251 at baseline
Chronic n=96, Non-chronic n=204 at six months
* *x_2 refers to the mean score at six months; x_1 refers to the mean score at baseline*

6.5 Discussion

This study describes the patterns in longitudinal QOL in a group of chronic and non-chronic adolescents. It considers differences in QOL between adolescents, changes in QOL over time and the extent to which predictor variables accounted for the observed patterns in QOL. The final model supports the hypothesis that adolescent QOL is the outcome of a complex interplay between different factors.

The main finding was that perception of global physical health, control, opportunities and age explained a large degree of the variance in the overall QOL scores. The fact that the adolescent's perception of their global physical health was an important explanatory variable may be attributed to the heavy weighting of the term "*health*" in their personal assessment of QOL. The term health is often used interchangeably with functional performance in the QOL literature (Mozes et al., 1999). Davies and Ware (1981) found that perceptions of global health reflected physical health problems such as limitations in physical functioning in acute and chronic conditions. Similar findings were also found by Kraus et al. (1994). In our study the perception of overall physical health reported by both groups was high with no adolescents reporting any functional limitations.

The results also provided support for the inclusion of social determinants of health, such as control and opportunities, as predictors for QOL. Research (Australian Institute of Health and Welfare, 2000) has identified that parental styles characterized by low care and harsh control, consistently emerge as a risk factor against a range of health problems. Similarly, the importance of providing adolescents opportunities for improving leisure and daily activities and for engaging with growth-enhancing environments, be these schools, workplace or neighborhoods has been stressed (Raphael et al., 1996). These results suggest areas that would be fruitful targets of intervention to maintain and perhaps even enhance adolescent QOL. Successful intervention for one risk factor is likely to bring multiple benefits since strong associations exist between health compromising behaviour in adolescents. (Australian Institute for Health and Welfare, 2000).

Both groups in this sample generally reported an overall positive QOL on both occasions. While deterioration in their assessment was evident at the end of the six months it was not statistically significant. However it must be noted that 1% of the adolescents reported a problematic QOL at baseline, which increased to 2.5% at six months. This occurred in the non-chronic group. With mental health problems, depression and suicide rates on the increase for adolescents in Western Australia the utility of a QOL approach for identifying adolescents at risk for poor health outcomes even in the absence of diagnosable illness has been demonstrated.

A breakdown of QOL into its multidimensional dimensions provided more detailed information concerning adolescent QOL. The social factor, which was measured by "*friends*, *having places to go to*, *having things to do in the community*, and *public entertainment*" reported a decline over the six months by both groups of adolescents. While the effect size of this drop was small (-0.34 for chronic and –0.28 for non-chronic), it was still significant. Clearly, there is no single explanation for the change. One possibility could be the timing in the distribution of the questionnaires. The first questionnaire was distributed while adolescents were in school, whereas the second questionnaire was distributed during late spring and summer. In the summer months some adolescents may not be surrounded by their normal circle of friends and may feel "isolated". This finding reinforces the importance of the social network for both the chronic and non-chronic adolescent.

The benefits of multilevel longitudinal analysis for QOL research were also demonstrated. The longitudinal nature of the design provided strength for interpreting the results, which could not be achieved with a cross-sectional design. The repeated measure problem of carry over effect, latent effect and learning effect should not have influenced the findings as the two questionnaires were administered six months apart (Carmines & Zeller, 1979)

CHAPTER 7

PARENTS', TEACHERS' AND HEALTH PROFESSIONALS' PERCEPTIONS OF THE QUALITY OF LIFE FOR THE ADOLESCENT WITH A CHRONIC CONDITION: A DELPHI STUDY

CHAPTER 7

Teachers', Parents' and Health Professionals' Perceptions of the Quality of Life for the Adolescent with a Chronic Condition: A Delphi Study

7.1 Overview

A three-round Delphi Study was undertaken to explore the perceptions that teachers, parents and health professions have of the QOL for the adolescent with a chronic condition.

7.2 Introduction

Teachers, health professionals, and parents all share an interest in directing adolescent development. However, they may have very different perspectives on both the dimensions of importance and the values placed on different health states for the adolescent (Cadman et al., 1996). In a qualitative study by Admi (1996) adolescents with cystic fibrosis resented being defined as patients or handicapped preferring to define themselves as having a health problem. They also perceived that health professionals and lay people tended to view the shortened life span of cystic fibrosis as central to their lives. A study by Viet et al. (1995) also found that healthcare professionals can lack an understanding of adolescent issues and may describe them in negative terms. Differences in perceptions of adolescents' needs by health professionals are also supported by findings of comparative studies between the groups (Graves and Hayes, 1996; Sawyer et al., 1992). Furthermore, past research suggests that parental perceptions also correlate poorly with those of the child/adolescent they are representing (Stawski et al., 1995; Ecob et al., 1993, Eiser, 1997). Guyatt (1997) has even suggested that QOL reports from children under 10 years of age may be more reliable than reports furnished by their parents. Even Doctors and parents differ in their evaluation of the impact of treatment on QOL and low correlations between the raters are normal (Eiser, 1997). Differences in reports between children, parents and teachers describing childhood emotional and behavioral problems have also been reported (Sawyer et al., 1992).

Schools present their own unique problems to the chronically ill adolescent. Previous studies have suggested that teachers are not well informed about the chronic conditions experienced by many of the students in their class (McCarthy et al., 1996). Other studies have documented that teachers often do not have the specific knowledge required to adequately integrate a child with a specific health condition into their classroom (Jackson and Penny, 1992; McCarthy et al., 1996). A classroom environment that can include verbal abuse, less peer support for ill students and irregular attendance in class because of illness can often result in lower academic achievements (Martin & Nisa, 1996).

Therefore this exploratory study will employ the Delphi method to:

- Describe the similarities and/or differences between teachers', parents' and health professionals' perceptions of the importance of different domains related to the QOL of the adolescent with a chronic condition;

- Determine whether teachers, parents and health professionals perceive the QOL of the adolescent with a chronic illness to be the "same", "better" or "worse" than an adolescent without a chronic illness.

7.3 The Delphi Methodology

7.3.1 Background

Since its introduction as a research methodology in the late 1940's, there has been over 1000 published research papers documenting the use of the Delphi method. (McKenna, 1994). Originally it was used as a process for technological forecasting (Helmer, 1967). However its applications have broadened and the Delphi method has been widely applied in health research within the fields of technology assessment, education and training, and in the development of nursing and clinical practice.

The aim of the Delphi method is to identify opinion and to reach agreement regarding specific issues (Turoff, 1970). It can be used to set goals, priorities and to develop solutions to problems (Turoff, 1970). It can also be used to clarify positions and delineate differences among diverse reference groups (Delbecq, 1975). Lindeman (1975) maintains that the Delphi method is especially effective in difficult areas which can benefit from subjective judgments on a collective basis, but for which there may be no definitive answer.

Our review of the literature did not identify any use of the Delphi technique to explore parents', teachers', and health professionals' perceptions of the chronically ill adolescent's QOL.

7.3.2 The Delphi Study

The Delphi method is a means of determining the extent to which a consensus exists among a group of people, which takes place in a series of rounds. The method has three features: anonymity, controlled feedback and statistical group response (Jones and Hunter, 1995). Anonymity is usually secured through a questionnaire. The controlled feedback of information occurs in a series of rounds in which the questionnaire is returned to respondents showing the responses made in the previous rounds. This provides an opportunity for individuals to change their views if they wish. The process works to achieve this consensus by moving from a broad to a narrow focus with each questionnaire (Adler & Ziglio, 1996). Statistical group responses ensure that each opinion is representative of the final response. The advantages of the Delphi method are that it allows each member to hold a view while collecting data on the group as a whole. This avoids the dominance of one group member since equal weight is accorded to each response. Finally, the results give an indication of the extent of agreement among the participants.

Turoff (1975) recommends that Delphi studies be limited to three rounds since response rates can be anticipated to decline, especially from the second round onwards. In this study an appropriate balance of quantitative and qualitative methods was utilized. The qualitative method of open-ended questions was valuable for capturing and conveying why participants felt different aspects were important to the QOL for the adolescent with a chronic condition.

7.3.3 Panel Selection

In most cases, the criterion for deciding on sample size is not and cannot be a statistical one. Adler & Ziglio (1996) suggest that with an homogenous group of experts, good results can be obtained with small panels of 10-15 individuals. Turoff (1975) recommends that a Delphi sample size should be between 10-50 participants whereas Duffield (1993) states that the panel size is a matter for the researcher's discretion.

Small, selective panels (twenty-five in each panel) of parents, teachers, and health professionals were recruited to participate in this study. Multiple data sources in the selection of the participants was also utilized to increase the validity of the results (Grobich, 1999) and to reduce bias (Jones and Hunter, 1995).

"Expertise" or "informed opinion" is usually the key requirement in selecting members for a Delphi panel. Expertise implies knowledge and experience with the issues under investigation. All panelists recruited had experience with a chronic illness, such as having a child/adolescent or a close relative in the family with a chronic condition. One concern of the Delphi method is the interpretation of the term "expert" (Sackman, 1975; McKenna, 1994; Duffield, 1989). Goodman (1987, pg. 732) noted that:

> **" It would seem more appropriate to recruit individuals who have knowledge of a particular topic and who are consequently willing to engage in discussion upon it without the potentially misleading title of "expert."**

Therefore, it was anticipated that the "informed" opinion of the parents, teachers and health professionals would provide a balanced approach to the information being sought (Duffield, 1988).

Both the teachers and parents were recruited through three local schools while the health professionals were recruited through a nursing agency, schools, and Curtin University.

7.3.4 Procedure

To assess the importance of items relevant to the chronically ill adolescent's QOL, sixteen items were chosen based on a literature review (Boice 1999; Raphael et al., 1999) and consultations with two experts on adolescent health. The entire Delphi process took nine months with each round lasting approximately three months from the distribution of the questionnaire till the completion of the data analysis. The definition of a chronically ill adolescent given to the three panels was "a medical condition that has lasted or is expected to last more than three months" in any individual aged 10-19 (Perrin et al., 1993). More generally, it can be defined as a condition that has resulted in a level of impairment or medical attention greater than expected of an adolescent of the same age (Stein et al., 1997).

Participants in round one were asked to rank each of the sixteen items in order of perceived importance (See attached as Appendix F). A five point Likert scale ranging from 1 = not important at all to 5 = extremely important, was used. Questions were typically phrased: *"How important do you think physical health is to the QOL for the adolescent with a chronic condition?"* Each question was followed by an open-ended question in which the participants were asked to explain "*why*" they felt that particular aspect was important. The initial questionnaire was analyzed according to the panel the participant belonged to. Consequently, three different questionnaires were developed for round two (See attached as Appendix G).

All participants were mailed round two of the survey to review the responses from round one. The second questionnaire was divided into three sections – "*extremely important items*", "*very important items*" and "*important items*", which were based on the responses obtained from round one. The panellists were asked to prioritize the items in each section with 1 = most important item, 2 = the next important item and so on. Such ranking of items enabled the panellists to prioritize the importance of the different items to the adolescent's QOL. It was also intended to encourage reflection and critical examination of the round one results.

The third and final round consisted of the re-ordered ranks in order of importance as perceived by each panel (See attached as Appendix H). The ranks were based on the means of each of the items obtained from the round two answers. In addition, a five-point confidence rating scale was included. This allowed each panellist to indicate their level of agreement with the group consensus ranking, ranging from 1 = strongly disagree to 5 = strongly agree. The mean of this confidence rating is known as the group confidence rating (GCR). A mean above 3 indicates that the Delphi lies reasonably close to the "true" answer, while a mean below 3 implies an unsatisfactory answer (Pill, 1971).

All panelists were assured of anonymity and confidentiality.

7.3.5 Statistical Analysis

Descriptive statistics were computed for the first questionnaire. The Kruskals-Wallis non-parametric test was used to investigate possible differences between the responses of the teachers, parents, and health professionals. This test is an alternative to the F-test when variance and normality assumptions for parametric tests are not met and the sample size is small. (Portney and Watkins, 1993). It is also appropriate test to analyse ordinal level data when more than two groups are compared (Portney and Watkins, 1993).

Kendall's coefficient of concordance was then used to examine the degree of agreement among the three panels. The test is particularly useful for analyzing data that have three or more groups and the data are ordinal or interval/ratio. (Hicks, 1990). While Kendal's coefficient of concordance indicates the strength of the association between the variables, it is not useful in determining the significance of the results.

The qualitative responses obtained from round one were managed using the QSR Nudist (version 4) software package. Content analysis was then performed.

The second and third round data were analyzed via:

- Frequency distributions of all variables, including the mean and standard deviation of ranked variables;
- The Group Confidence Mean (GCM) in the third round to determine consensus among each panel;
- Weighted Cohen's Kappa to assess the degree of agreement from round 2 to round 3 among the three panels.

7.4 Results

The results of the three rounds of the Delphi Method by panel are summarized and presented. These include both statistical findings and qualitative responses to the open-ended questions from round one.

The questionnaire from round one served two purposes. It provided demographic data relating to the Delphi panel and identified the respondent's broad opinions regarding QOL for the adolescent with a chronic condition. The results of the second round questionnaire showed how the respondents ranked variables, in order of perceived importance. The final round revealed the participants' final decisions regarding the ranking of the variables under investigation.

7.4.1 Demographic Characteristics of the Three Panels

Twenty-five questionnaires were sent to each of the three panels. A total of 18 (72%) teachers, 17 (68%) parents, and 14 (56%) health professionals responded to the first round questionnaire. The majority of the participants from all three panels were female (88%) with the average age being 41 (range 26-66). Sixty-two percent of the teachers taught in secondary schools, while seventy-five percent of the health professionals were nurses. Most of the parents were full-time mothers undertaking home duties (63%).

A breakdown of the demographic characteristics for each of the three panels is presented in Table 27. There were no statistical differences between the three panels in terms of age (p=0.260), gender (p=0.711) and marital status (p=0.206). However there was a significant difference between the educational status (p=0.000) as evident in Table 27.

Table 27: Demographic Characteristics of the Three Panels

	Teachers n=18	**Parents** n=17	**Health Professionals** n=14
Age (in years)	41.28 (S.D.= 9.35)	38.67 (S.D.=5.93)	43.64 (S.D.=9.85)
Gender			
• Males	17%	11%	7%
• Females	83%	89%	93%
Marital Status			
• Married	83%	83%	57%
• Divorced	6%	11%	7%
• Single	11%	---	29%
• Widowed	---	---	7%
• De Facto	---	6%	---
Education			
• Left school before completing year 12	---	22%	---
• Completed year 12	---	28%	14%
• Tafe course	---	22%	7%
• University degree	78%	17%	50%
• Other (diploma)	22%	11%	4%

7.4.2 Delphi Round One

7.4.2.1 Items Rated as Extremely Important by Each Panel

Table 28 shows the items rated as "*extremely important*" to the chronically ill adolescent's QOL by each panel.

Table 28: Items Rated as Extremely Important by Each Panel - Round One

Items	Teachers %	Parents %	Health Professionals %
Adolescent's attitude	67	50	43
Family's attitude	72	56	--
Family relationships	72	72	57
Friendships with the same age group	72	50	50
Managing their own medical care and making decisions about their illness	--	39	--
Plans for the future	39	--	--
Physical health	--	44	43
Severity of the chronic illness	--	--	36
Treated as a "normal" person	50	61	--

The initial Delphi questionnaire generated some disagreement among the three panels in terms of items rated as "*extremely important*" to the QOL for the adolescent with a chronic illness. From the total of sixteen items, which were presented to each panel in the first round, nine of these items (53%) were rated as extremely important. Of these nine items, only three were rated as extremely important by all three panels. They were the "*adolescent's attitude*", "*friendships with the same age group*" and "*family relationships*".

A large majority of the teachers (50%) and parents (61%) rated "being treated as normal" as extremely important to the chronically ill adolescent's QOL. The overwhelming reason for the high ranking was *"the adolescent does not want to be seen as different by their peers"*. However one parent felt that "*it was okay to recognize that the adolescent is different and has specific needs.*"

Parents (39%) were the only panel that felt adolescents managing their own medical care and making decisions about their illness were extremely important. However, opinion within the panel of parents did differ in how much control the adolescent should have in making decisions about their illness. One parent felt it "*depended on the age of the person but for someone between 15-19 their opinion should be sought*". In contrast another parent felt *"that the young person regardless of age should take control over their illness.*"

Physical health was rated as being extremely important by 44% of parents and 43% of health professionals. As pointed out by a member from the panel of health professionals, poor physical health *"may exclude the adolescent from activities which are enjoyed with a friend not only affecting the ability to join in but also affect the development of friendships and their defining their self-concept through ill health."*

Severity of the illness was also rated as extremely important by 36 % of the panel of health professionals. Several respondents felt that *"... the more severe the chronic illness the greater potential for a poor quality of life"* and that *"... it would affect any goal setting, achievement, and attitude for all tasks and thought processes".* Another respondent felt that the severity of the illness would *"affect the degree to which the adolescent can " fit in" and "feel normal."*

It is interesting to note that health professionals were the only panel to include both physical health and severity of the illness as extremely important, perhaps reflecting their own experiences with chronically ill patients.

Reliability of the first questionnaire was estimated using Cronbach's Alpha. Nunally (1976) has suggested that the generally accepted standard for reliability estimates be above 0.70. The coefficient obtained for this survey was 0.79, which indicates that the questionnaire was sufficiently homogenous.

7.4.2.2 Items Rated as Very Important by Each Panel

Table 29 shows the items, which the panels rated as very important to the chronically ill adolescent's QOL.

Table 29: Items Rated as Very Important by Each Panel - Round One

Items	Teachers %	Parents %	Health Professionals %
Family's attitude	--	--	43
Friendships with the opposite sex	50	--	--
Hobbies / interests	50	72	64
Independence	50	50	71
Managing their own medical care and making decisions about their illness	56	--	43
Participation in school / sports activities	--	39	--
Physical health	44	--	--
Physical visibility of the illness	--	39	43
Plans for the future	--	50	57
School / academic achievements	--	44	--
Severity of the chronic illness	39	33	--
Spiritual beliefs	39	--	--
Treated as a "normal" person	--	--	43

The only items rated as *very important* by all three panels was independence and hobbies/interests. Half of teachers and parents along with 71% of health professionals felt independence *"helped the adolescent to cope better in life and provide confidence"*. Again, a high percentage of teachers (50%), parents (72%) and health professionals (64%) also rated hobbies/interests as very important. Reasons were based on the psychosocial benefits of hobbies/interest to QOL, such as: *"opportunity to socialize"*, *"provide a sense of achievement"*, *"can be therapeutic"*, and *"provides a distraction from the illness"*.

The panel of teachers ranked friendships with the opposite sex (50%) and spiritual beliefs (39%) as being very important to the adolescent's QOL.

As expected, parents perceived school/academic achievements (44%) and participation in school/sports activities (39%) to be *very important*. In comparison, the majority of health professionals felt the attitude of the family (43%) and being treated as a "normal" person (43%) were very important.

A high percentage of the panel of parents (50%) and health professionals (57%) agreed that making plans for the future was *very important* to QOL. Physical visibility was also highly rated with 39% of the parents and 43% of the health professionals perceiving it to have a serious effect on the adolescent's QOL.

However there was more variability within the individual members of each panel, with lower percentages denoting agreement. The variability in ratings among the three different panels may be attributed to the different priorities of each panel and to their own unique experiences with the chronically ill adolescent.

7.4.2.3 Items Rated as Important by Each Panel

There was more agreement within each of the three panels as evident by the fairly high percentage of each panel in their ranking. Table 30 shows the items rated as important to the chronically ill adolescent's QOL.

Table 30: Items Rated as Important by Each Panel - Round One

Items	Teachers %	Parents %	Health Professionals %
Friendships with the opposite sex	--	50	43
Participation in school /sports activities	32	--	64
Physical visibility of the illness	24	--	--
School / academic achievements	44	--	50
Spiritual beliefs	--	44	50

The majority of health professionals (50%) and teachers (44%) felt school/academic achievements were *important*. Friendships with the opposite sex were rated as important by 50% of parents and 43% of health professionals. Spiritual beliefs were also rated as important by both parents and health professionals. Lastly, only teachers rated the physical visibility of the illness important, as opposed to both parents and health professionals who had rated it as *very important*. However agreement among the panel of teachers was low with only 24% of them rating physical visibility of the illness as important.

Overall, there were obvious differences in scoring between the teachers, parents, and health professionals. However none of the items were statistically significant using the Kruskal Wallis Test with the exception of the attitude of the family and the importance of being treated "normal" by family and friends. Both items were ranked lower in importance by the panel of health professionals. The results of these statistical differences between the three panels at the 5% significance level using the non-parametric Kruskal-Wallis test are presented in Table 31.

Table 31: Results of the Kruskal-Wallis Test from Round One

Focus Item	Number	Mean Rank	Sig-Kruskal Wallis Test
Importance of being treated "normal" by family and friends			
Teachers	18	26.75	0.027
Parents	17	29.44	
Health Professionals	14	17.36	
Importance of the family's attitude towards the adolescent's chronic illness			
Teachers	18	29.25	0.039
Parents	17	26.38	
Health Professionals	14	17.86	

Kendall's coefficient of concordance was used to measure the magnitude of agreement within each panel. The level of agreement within the panel of parents (W=0.33) and teachers (W = 0.31) was virtually identical. However the level of agreement was much lower within the panel of health professionals (W = 0.19) indicating more variability in their rankings.

7.4.3 Delphi Round Two

Round two had fewer respondents than round one. Of the 49 round two questionnaires sent to all initial participants, 44 (89%) were returned and analyzed. Non-response mainly occurred in the teachers and parents groups.

Table 32 summarizes the prioritization of items in order of importance by each panel based on the mean ranks obtained from the second round questionnaire (the first item was rated the most important, the second item the second most important and so on).

Table32: The Prioritization of Items in Order of Importance - Round Two

Teachers	Parents	Health Professionals
Extremely Important Items		
1. Attitude of the adolescent	1. Physical health	1. Attitude of the adolescent
2. Attitude of the family	2. Attitude of the adolescent	2. Severity of the chronic illness
3. Family relationships	3. Treated as a "normal" person	3. Family relationships
4. Treated as a "normal" person	4. Family relationships	4. Physical health
5. Making plans for the future	5. Attitude of the family	5. Friendships with the same age group
6. Friendships with the same age group	6. Friendships with the same age group	
	7. Managing their own medical care and making decisions about their illness	
Very Important Items		
1. Physical health	1. Severity of the chronic illness	1. Treated as a "normal" person
2. Severity of the chronic illness	2. Independence	2. Independence
3. Independence	3. Physical visibility of the illness	3. Attitude of the family
4. Managing their own medical care and making decisions about their illness	4. School and academic achievements	4. Physical visibility of the illness
5. Hobbies/interests	5. Making plans for the future	5. Making plans for the future
6. Friendships with the opposite sex	6. Participation in school/sports activities	6. Hobbies/interests
7. Spiritual beliefs	7. Hobbies/interests	7. Managing their own medical care and making decisions about their illness
Important Items		
1. Participation in school/sports activities	1. Friendships with the opposite sex	1. Friendships with the opposite sex
2. Physical visibility of the illness	2. Spiritual beliefs	2. Participation in school/sports activities
3. School and academic achievements		3. School and academic achievements
		4. Spiritual beliefs

There were three items which all three panels ranked as "*extremely important*" to the QOL for the adolescent with a chronic illness. They were "*attitude of the adolescent*" (ranked first by teachers and health professionals and fourth by parents); "*family relationships*" (ranked third by teachers and health professionals and fourth by parents) and "*friendships with the same age group*" (ranked sixth by teachers and parents and fifth by health professionals). However various members of the three panels commented that it was very difficult to prioritize the items.

There was a great deal of variability in assigning focus items as *very important* by each of the panels. Only two items were ranked as *very important* by all three panels: "*independence*" and "*hobbies/interests*". Again they were prioritized differently with teachers ranking independence third, while parents and health professionals ranked it second whereas *hobbies/interests* was ranked fifth by teachers, seventh by parents and sixth by health professionals.

7.4.4 Delphi Round Three

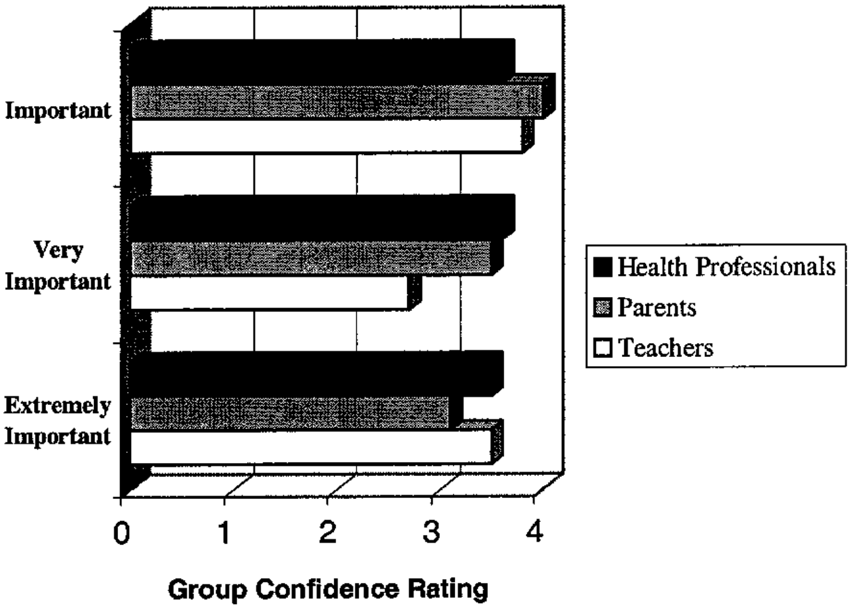
There was only one dropout between the second and third (final) round.

In the final round each panel was presented with the re-ordered list of variables. Respondents were then asked to indicate the degree to which they agreed with the ordering by the panel and to re-order the ranking if they did not agree with the panel.

A high degree of consensus (a GCR mean score of 3 or greater) was achieved by each of the panels except for the ordering of *very important* items by the panel of teachers. The GCR was 2.7 for this item. The lack of agreement was evident in the prioritizing of independence, severity of the illness, and managing their own medical care.

Figure 16 shows the GCR for each item by each of the panels.

Figure 16: The Group Confidence Rating for Each Panel



It is remarkable that so few changes occurred in the order of established ranks (from round two to round three). This implies a definite trend in the thought process about the relative importance of the items under investigation. It is also possible that the apparent consensus in the third round may simply reflect participation in the Delphi study. This process may have facilitated an understanding of the issues involved and allowed the participants to think about factors that influence the chronically ill adolescent's QOL.

Inter-rater reliabilities were also determined for all sixteen items using Weighted Cohen's Kappa. They ranged from 0.67 – 0.76 indicating fair to substantial levels of agreement in the ranking of items from round two to round three among the three panels (Portney and Watkins, 1993). The only item, which had a low Kappa statistic (0.37), was the ranking of the very *important items* by the panel of teachers.

7.4.4 Qualitative Analysis

The qualitative responses were also examined for common themes and/or differences between the panels. The common theme, which emerged from all three panels, was the perception that chronically ill adolescents do not want to be seen as *"different"* and *"want to fit in"* with their own age group. Other common themes, which reoccurred throughout the questionnaire, were the importance of the adolescent having a *"positive attitude"* and *"setting goals for the future"*. Only the importance of being treated as *"a normal person"* is presented in Table 33.

Table 33: Importance of Being Treated as a "Normal" Person

Teachers	Parents	Health Professionals
• Being seen as different can cause a poor self-image • Adolescent does not want to be seen or treated as "different" • Being seen as "different" can be a constant reminder of the chronic illness • Can cause stress for the adolescent	• Accepted for themselves and not their illness • Encourages a feeling of "belonging" with their own age group • Can have a positive effect on their self-esteem • Can have a positive effect on their illness	• Helps to lessen the feelings the adolescent may have of being "different" • Help the adolescent to "fit in" with their peers • Help the adolescent to put their illness in perspective and not become "obsessed" about it • It is damaging psychologically to self-image if family focuses on illness

7.4.5 Perception of Overall Quality of Life for the Adolescent with a Chronic Condition by the Three Panels

A final question asked each panel to rate the overall QOL of the adolescent with a chronic illness as 'better', 'worse', 'the same as' or 'not sure' to the QOL for the healthy adolescent. All three panels (50% of parents and health professionals, 68% of teachers) perceived the chronically ill adolescent's QOL to be **worse** than their healthy counterpart. Reasons cited by the panels included: " … *a poorer attitude as a result of the chronic illness*"; *"the adolescent may be limited by what they can do"; "poor physical health"; "lack of independence*"; "*… having greater obstacles to* *overcome than a healthy adolescent*", "*their illness makes them different to everyone else*" and "*their health prevents them from making long-term plans*".

These reasons are substantiated by the panels' collective responses to quantified questions. Table 34 shows the percentage of agreement from each panel on the following statements:

Table 34: Percentage of Panel Who Agreed with the Following Statements

Q: Do you think an adolescent with a chronic illness feels that:	Teachers	Parents	Health Professionals
• They are discriminated against because of their health	44.1	50.0	35.7
• Their health interferes with their satisfaction with life	72.2	72.2	72.4
• Their health has made them a burden to society	22.2	22.3	21.4
• Their health has made them a burden to their family	54.5	44.5	50.0
• Their health prevents them from making long term plans	44.5	44.4	50.0
• Their illness makes them different to everyone else	66.6	50.0	72.4

7.5. Discussion

Each panel achieved consensus in assigning varying levels of importance on a number of pre-selected items to the QOL for the adolescent with a chronic condition. Only the panel of teachers did not reach consensus on the prioritization for the ranking of the very important items. There were also some differences among the three panels particularly in the prioritizing of these items.

The importance of physical health to the chronically ill adolescent's QOL has been well documented (Spilker (eds), 1990). However only the panel of health professionals and parents rated it as extremely important. This variability in rating may be attributed to the different priorities of each panel and also to their own unique experiences with the chronically ill adolescent. Parents and health professionals deal with the physical demands of a chronic illness on a daily basis and are aware of the repercussions of poor health. Parents were also the only panel to rate "managing medical care and making decisions about the illness" as extremely important. Perhaps more than any other group they understand the importance of adolescents taking control over this aspect of their life. Parents again were the only panel to perceive "family attitudes" as extremely important. The importance of family attitudes was also identified by adolescents with cystic fibrosis with their families' reactions impacting significantly on how they felt about their illness (Admi, 1996). In comparison, teachers were the only panel to rate "making plans for the future" as extremely important reflecting their own unique perspective on the importance of education to the adolescent's future prospects. Chronically ill adolescents also expressed concerns about future employment and career opportunities in a study by Woodgate et al. (1998).

Eiser (1993) has identified the significance of social support as a mediator in coping with the effects of chronic illnesses. However, for the chronically ill adolescent, often the social network can be reduced to family members and/or a few close friends. It is encouraging that all three panels highly prioritized friendships with their peers and family relationships as extremely important to the adolescent's QOL. This finding compares well with a study by Cappelli (1989) who found that the chronically ill adolescent's major concern was the impact of their illness on other family members.

Of particular interest was the overwhelming perception among the three panels that chronically ill adolescents have a worse QOL than their healthy counterparts. However, research has shown that adolescents with a chronic condition adapt to their conditions remarkably well and do not view their circumstances as negative (Stawski et al., 1995; Lindstrom & Kohler, 1991). Furthermore, the themes identified in our study are similar to the findings of Woodgate (1998) that chronically ill adolescents do not want to be treated as "*different*" but want to be "*treated like a person*".

Limitations of the study concern the structure of the Delphi questionnaire. Round one started with a pre-selected set of items identified from the literature review. This may have considerably reduced the number of ideas obtained from the panel. For example several participants felt that other aspects such as sexuality and body image were also relevant to the adolescent's QOL. The limited sample size also did not allow any inferences to be made in terms of generalizations to a larger population. Therefore the results obtained from this study should be considered as ‘well-informed speculations’ of the perceptions of teachers, parents and health professionals.

7.6 Summary

Based on the results of this exploratory study it is encouraging that each panel recognised the importance of all sixteen items to the chronically ill adolescent’s QOL. However it is still evident that the public view the chronically ill adolescent in a poorer light compared to their healthy counterparts. It is only with education and health promotion strategies aimed at improving the image for the chronically ill adolescent among the general public will their true potential be realised.

CHAPTER 8

IMPLICATIONS, RECOMMENDATIONS AND CONCLUSIONS

CHAPTER 8

Implications, Recommendations and Conclusions

"Failure to monitor QOL is neither good medicine nor is it good science".
Fallowfield (1990, pg.71)

The central aim of this study was to provide a better understanding of adolescent quality of life (QOL), given that adolescence is a " period of stress and storm". This was achieved by assessing key determinants for adolescents with and without a chronic condition over a six-month period. In addition, the inter-relationships among five domains (*physical health*, *psychological*, *environment*, *social*, and *opportunities for growth and development*) hypothesized to constitute QOL, were explored. The results suggest that any public health initiative should consider the complex interplay of factors that affect adolescent QOL.

8.1 Implications

The conceptual framework adopted for QOL in this study was unique in that it focused on a "*wellness*" rather than an "*illness*" perspective. The multidimensional conceptualisation for adolescent QOL, helped to guide the research as it emphasized "***the degree which the adolescent enjoys the important possibilities of his/her life***". The focus on the adolescent's own unique subjective determination for his/her QOL is supported by the growing body of literature related to adolescent QOL. The questionnaire used (Quality of Life Profile Adolescent Version), was developed with direct input from adolescents on aspects relevant to their lives. The inclusion of social determinants of health such as the amount of control and opportunities perceived by each adolescent is another key feature.

A review of the literature found no definitive conceptualisation for adolescent QOL. The second-order confirmatory factor analysis (CFA) provides initial validation for adolescent QOL to comprise the following domains - *physical health, environment, social, psychological,* and *opportunities for growth and development.* To the researchers knowledge, adolescent QOL has not been previously conceptualised using these five constructs.

The results of this study are encouraging with the majority of the chronic and non-chronic adolescents reporting a "positive QOL". This study also showed that there was no difference between the two groups in their perception of overall QOL. In fact, the adolescents with a chronic condition reported a better QOL than the non-chronic adolescents. While studies have shown that adolescents with a chronic condition are at an increased risk of psychological, emotional and health related problems (Garrison et al., 1989; Zani et al., 1995; Patterson & Blum, 1996), this is not the case with this sample. Indeed, despite the fact that the study was unable to measure the severity of the adolescent's chronic condition, the results suggest that they are coping extremely well.

No difference was found in the assessment of overall QOL over the six-month period for the combined sample. However three of the five specific domains related to adolescent QOL dimensions did show a change for both groups (*social, physical health* and *opportunities for growth and development).* This highlights the fact that while summary scores may provide an overview of QOL, they may obscure important differences that may impact on specific domains of QOL.

The study adopted a longitudinal design, which provided insights into the determinants of QOL over a six-month period. Data were collected from 20 high schools in Western Australia by assessing a cohort of 363 adolescents at baseline and 300 adolescents at six months. The determinants for QOL identified from the results of the first questionnaire (age, perceptions of health, control and opportunities) remained stable over the six months. The longitudinal design was able to identify potentially modifiable psychosocial factors (for example: control and opportunities perceived by the adolescents) and provided a stronger evidence base for determining a causal relationship between these variables and QOL. Comparing the same adolescents over time has greater scientific rigour than comparing adolescents cross-sectionally.

The results from the longitudinal multilevel regression analysis confirmed that although a large proportion of the variation can be accounted through the covariates, 38% of the variability in QOL scores was due to time. This highlights the dynamic nature of QOL and the importance of a longitudinal study design to capture these changes over time. These preliminary findings have both substantive and methodological implications for further research on adolescent QOL.

The study also identified that older adolescent are at risk for a poorer QOL. Recent research continues to provide conflicting evidence regarding the effect of age on QOL. While it is expected that the adolescent's perception of QOL will change as a function of time, further work is needed to clarify the direction of change, the determinants that may contribute to differences in QOL and to identify groups that are vulnerable to a poorer QOL.

The results of the structural equation modelling were informative. The fact that the *environmental* factor was found to have significant direct and indirect effect on the other four factors has implications for improving adolescent QOL. The significant effect of the *psychological* factor on both the *social* and *opportunities for growth and development* emphasises the importance of these factors. It is now recognized that many aspects of poor health initiated in adolescence (such as depression and anxiety), are carried into adulthood and contribute to the burden of disability and mortality (Australia's Health, 2000). With the growing incidence of mental health problems among adolescents, these findings have direct implications for public health practitioners.

From the Delphi Study, it is encouraging that the majority of parents, teachers and health professionals have identified all sixteen items relating to the chronically ill adolescent's QOL as important. Since these three groups play an influential role in the life of the chronically ill adolescent, it is important that they are able to recognize the problems encountered by this group. However, the majority of the three panels perceived the chronically ill adolescent to have a worse QOL than their healthy counterpart, which is inconsistent with the research emerging relating to the perceptions of chronically ill adolescents.

8.2 Limitations

The limitations of this study are:

- The presence of a chronic condition was based on self-report (confirmed by parental consent), but the associated clinical characteristics were unknown. As a result, the severity, course or prognosis of the condition could not be assessed, which may have some influence on the study's results. The fact that asthma occurred in a large proportion of the chronic subjects, also limits the generalisability of the results.

- All adolescents that participated in this study were volunteers, which led to a convenience non-random sample of 10-19 year olds. This may have contributed to self-selection bias or "a healthy volunteer bias" even in the recruitment of the chronically ill adolescent.

- The adolescent sample was also relatively homogenous in their SES status. This may be due to using postcodes as a means to measure SES status. The use of postcodes is known to be imprecise at the individual level (Powers & Robertson, 1986).

- For the sample size available, certain bi-directional relationships between the five latent factors could not be tested, especially between the *health* and *psychological* factors. Other domains of QOL such as "*daily activities of living*", "*community activities*", or even " *spiritual well-being*" have not been investigated. A larger sample size would permit an examination of the relevance and feasibility of these domains to the adolescent's QOL.

- The adolescents who participated in this study may not be representative of all adolescents in Western Australian schools or the adolescent population in Australia.

- It is possible that the dynamic nature of QOL observed in this study may not be solely due to the time effect, but rather a blending of the time effect on the adolescent's age, as the effect is confounded with the age variable or even the age/gender interaction. Future work should consider incorporating an underlying parametric QOL function for judging the significance of time effect.

8.3 Recommendations

Considerable psychometric effort has been made in this study to assess the reliability and validity of the QOLPAV questionnaire, thus contributing to the development of a sound psychometric multidimensional adolescent QOL measure. The five-factor adolescent measurement model derived from the study permits construction of an 18 item short version of the QOLPAV questionnaire. This short version could be used as a tool for regular monitoring of adolescent health related issues. Information provided from regular usage of the QOLPAV questionnaire (both the long and short version), could also form the basis for establishing an adolescent QOL database. This database could then be used for further research and refinment of the measuring instrument.

The longitudinal study allowed an examination of the stability of QOL determinants over six months. An extension of this study would be to examine the links between the identified determinants over a longer period. Two time points may not be sufficient to capture the inherently dynamic nature of adolescent QOL. A prospective methodology to study adolescent QOL and its determinants using five time points over a two-year period could be undertaken. Latent growth models (LGM), which are variants of structural equation models, are applicable to model longitudinal data, assess individual differences and determine which variables are influential on the rate of development. In view of the assumption that QOL is a dynamic, multi-factorial construct and not all dimensions contribute equally, the use of LGM is ideally suited (Duncan et al., 1996).

It may be worthwhile to consider other variables such as smoking habits, alcohol consumption and parenting styles as potential determinants of QOL. In addition, research evaluating "how" adolescents have adapted to their circumstances could be undertaken. Coping styles have been implicated in affecting QOL outcomes and would be a relevant area to expand upon the current work.

The use of qualitative methodology can provide additional insights into standardized assessments of outcomes using QOL measures. Some researchers (Heiney, 1995; King et al., 1997) have advocated the use of in-depth interviews, focus groups and open-ended questions to facilitate standardized questionnaires. This approach is especially applicable to adolescent issues that may be particularly difficult to incorporate into a quantitative methodology (for example: evaluation of appropriate health promotion interventions, sensitive issues related to chronic conditions).

In view of the various factors that can influence QOL during adolescence, more emphasis on adolescent QOL in terms of educating health care professionals and teachers is warranted. Moreover, an increased awareness of the importance of QOL should be advocated.

8.4 Conclusions

Adolescent health information such as QOL is important to health care researchers and policy makers. It provides a reliable base for policy and program development and also enables monitoring of the impact of those policies and programs on the population. The need to improve the information available on the health and well-being of young Australians has been recognized by both the Commonwealth and State governments (Australian Institute of Health and Welfare, 1999).

The results of this study suggest that public health strategies should consider relevant factors that influence adolescent QOL. Identification of protective factors and those that place adolescents at an increased risk for problems will enable better targeting of promotion and intervention programs. The broader view of health determinants from a QOL perspective directs attention to pertinent factors for enhancing the overall physical and mental health status of the adolescent. The challenges then are for policy-makers and public health providers to translate these findings into practice that will support health-enhancing environments for adolescents with and without a chronic condition.

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APPENDICES

Appendix A

Curtin University of Technology Western Australia

Quality of Life Profile
Adolescent Version

What does Quality of Life Mean?

O.K. let me try to explain....

Contact Details:
Lynn Meuleners
School of Public Health
Curtin University of Technology
Direct Phone: 9266-2817

Case No.______
Office Use Only

What is Quality of Life?

Quality of Life, in simple terms, means: "How good is your life for you?"

To answer the question "How good is your life for you?" you are asked to focus on yourself and rate some parts of your life. These are rated on a simple scale of 1 to5.

These parts are divided into nine areas we think are part of the lives of all people. It includes your thoughts and feelings, beliefs, values, your daily activities, where you live, people around you, what you do for enjoyment, and opportunities for improvement and change.

First, you will rate how important these parts are to you and how satisfied you are with them. Then, you will indicate how much control you have over them and whether there is the chance for improvement or change.

This sounds like a lot, but you will find that you can rate them rather quickly. It should take approximately 25 minutes to complete the entire questionnaire. Your help is greatly appreciated.

A pictorial example is given on the next page to help you understand what " quality of life" means. This is followed by a set of instructions to help you answer each question.

Thank you very much for your continued participation in this study.

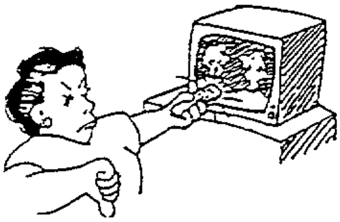
All of us sometimes ask ourselves how good things are

For example, did you ever ask yourself:

How good is this ice cream cone?

OR

How good is this TV program?



But all of us are different. So, what is good for one person is not always good for another.

This hat is good for me

This hat looks the pits on me.

It is the same with your whole life. But everyone is different . So, the question to ask yourself is:

"How good is your life for you?"

And that's what we mean by Quality of Life.

Instructions

Importance:

The first question to ask yourself when you are answering questions 1 to 54 is:

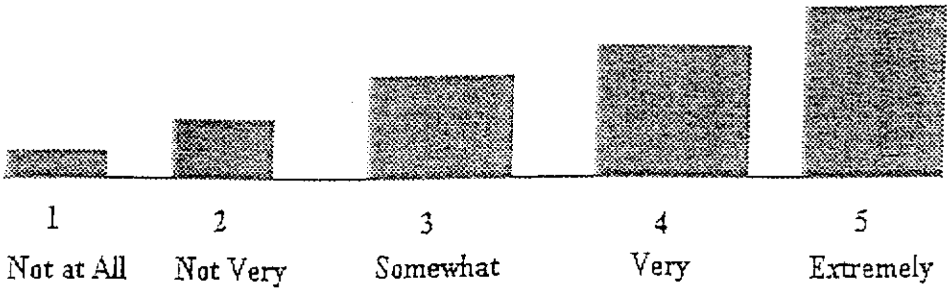
"How Important is this to me in my life?"

If you need to, think about it this way: "How much do I care about this?"

Then you need to put the number that best describes how you feel on the line using the scale below as your guide

- If you feel that the item is extremely **important** to you then write the number 5 on the line.
- If you feel that the item is very **important** to you then write the number 4 on the line
- If you feel that the item is **somewhat important** to you then write the number 3 on the line
- If you feel that the number is **not very important** to you then write the number 2 on the line
- If you feel that the item is **not at all important** to your life then write the number 1 on the line.

Rating Scale: Importance/Satisfaction



An example is shown below:	How Important To Me Is:	How Satisfied Am I With:
2. Making healthy choices	4	5
3. My appearance how I look	3	3

Satisfaction:

The second question to ask yourself is:

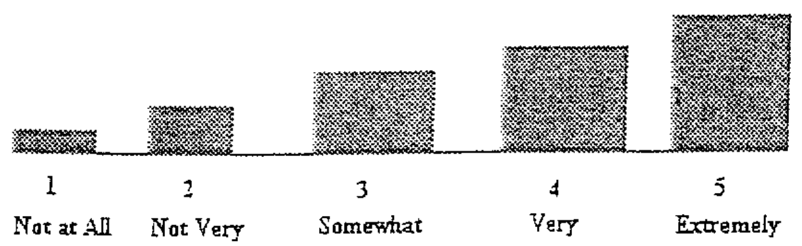
"How Satisfied am I with this part of my Life?"

If you need to, think about it this way: " How happy am I with this part of my life?"

Then like the previous question you put the number that best describes how you feel on the line using the scale shown below

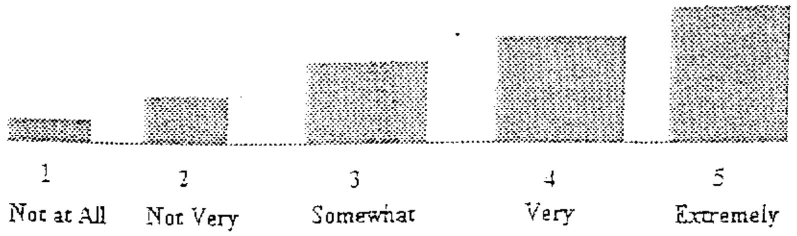
- If you feel **extremely satisfied** with this part of your life then write the number 5 on the line
- If you feel **very satisfied** with this part of your life then write the number 4 on the line
- If you feel **somewhat satisfied** with this part of your life then write the number 3 on the line
- If you feel **not very satisfied** with this part of your life then write the number 2 on the line
- If you are **not at all satisfied** with this part of your life then write the number 1 on the line.

Rating Scale: Importance/Satisfaction



- Please answer all the questions in terms of your life as it is right now!
- If you feel that the question does not apply to you, place N/A (not applicable) in the answer space.
- If you cannot answer the question because you are unsure place a DK (don't know) in the answer space.
- Please complete your ratings as honestly as you can

Rating Scale: Importance/Satisfaction



My Body and Health:	How Important To Me Is:	How Satisfied Am I With:
1. Being smart about sex	______	______
2. Making healthy choices (alcohol, smoking)	______	______
3. My appearance-how I look	______	______
4. My exercising and being fit	______	______
5. My physical health	______	______
6. My nutrition and the food I eat	______	______

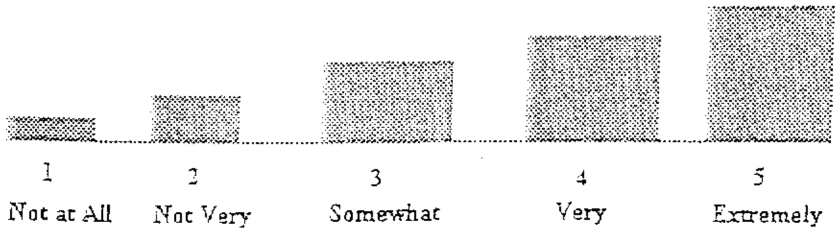
My Thoughts and Feelings:

7. Being free of worry and stress	______	______
8. How I feel about myself	______	______
9. Knowing who I am	______	______
10. Knowing where I am going	______	______
11. Thinking and acting independently	______	______
12. Trusting others	______	______

My Beliefs and Values:

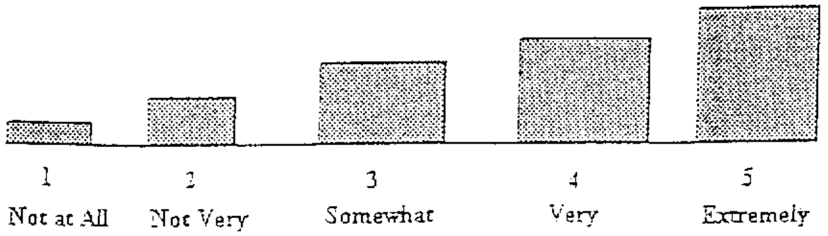
13. Feeling part of things	______	______
14. Feeling that life has meaning	______	______
15. Having hope for the future	______	______
16. Having religious or spiritual beliefs	______	______
17. Helping others	______	______
18. My own ideas of right and wrong	______	______

Rating Scale: Importance/Satisfaction



Where I Live and Spend my Time:	How Important To Me Is:	How Satisfied Am I With:
19. Feeling safe when I go out (school, neighborhood)	______	______
20. The area of the country I live in	______	______
21. The earth and its environment	______	______
22. The house or apartment I live in	______	______
23. The neighborhood I live in	______	______
24. The school I attend	______	______
The People around Me:		
25. Acting responsibly towards others	______	______
26. Being appreciated by others	______	______
27. Getting along with my family	______	______
28. Having a girlfriend/boyfriend	______	______
29. Having parties and things to go to	______	______
30. The friends I have	______	______
My Access to Things:		
31. Being able to get medical/ social services on my own	______	______
32. Getting a good education	______	______
33. Having enough money	______	______
34. Having jobs available while still in school	______	______
35. Having places to go with my friends	______	______
36. Having things to do in my community	______	______

Rating Scale: Importance/Satisfaction



The Daily Things I do:	How Important To Me Is:	How Satisfied Am I With:
37. Doing volunteer work for others	______	______
38. Looking after my appearance and hygiene	______	______
39. Studying and doing homework	______	______
40. The chores I do at home	______	______
41. The things I do in school	______	______
42. The work I do at a job while still in school	______	______

The Things I do for Enjoyment:

43. Attending public entertainment	______	______
44. Having hobbies and personal interests	______	______
45. Indoor activities (e.g. TV, reading, etc.)	______	______
46. Outdoor activities (e.g. walking, cycling, etc)	______	______
47. Participating in sports and recreation activities	______	______
48. Visiting and spending time with others	______	______

The Things I do to Improve and Change:

49. Being successful at the things I do	______	______
50. Getting along better with others	______	______
51. Learning about new things	______	______
52. Planning for a job or career	______	______
53. Planning for more education or training	______	______
54. Solving my problems	______	______

Control

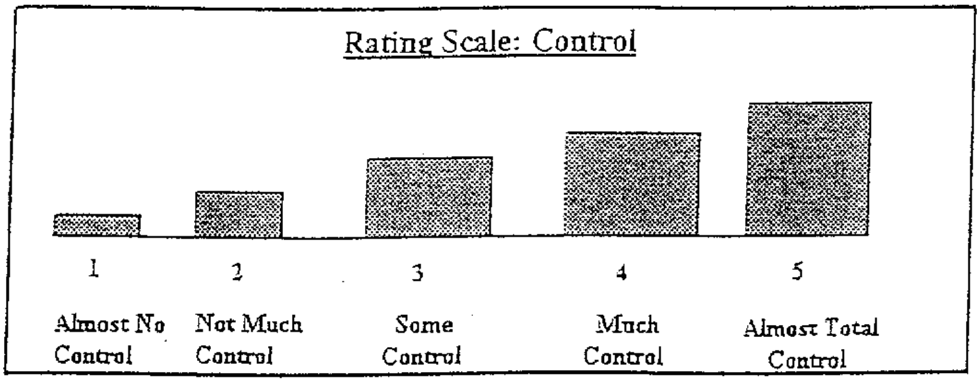
The third question to ask yourself is:

"How much control do I have over this part of my life?"

If you need to think about the question another way, try: " How much am I in charge of this aspect of my life?"

Place the number on the line that describes how you feel using the scale below.

- Write the number 5 if you have **almost total control** in that part of your life
- Write the number 4 if you have **much control** in that part of your life
- Write the number 3 if you think you have **some control** in this part of your life
- Write the number 2 if you have **not much control** in this part of your life
- Write the number 1 if you have **almost no control** in this part of your life.


Rating Scale: Control

How much control do I have over ....?

55. My physical health ______
56. My thoughts and feelings ______
57. My beliefs and values ______
58. The place where I spend my time ______
59. Who I spend my time with ______
60. Being able to use what my community has to offer ______
61. The everyday things I can do in my life ______
62. The things I can do for fun and enjoyment ______
63. The things I can do to improve myself ______

Opportunities

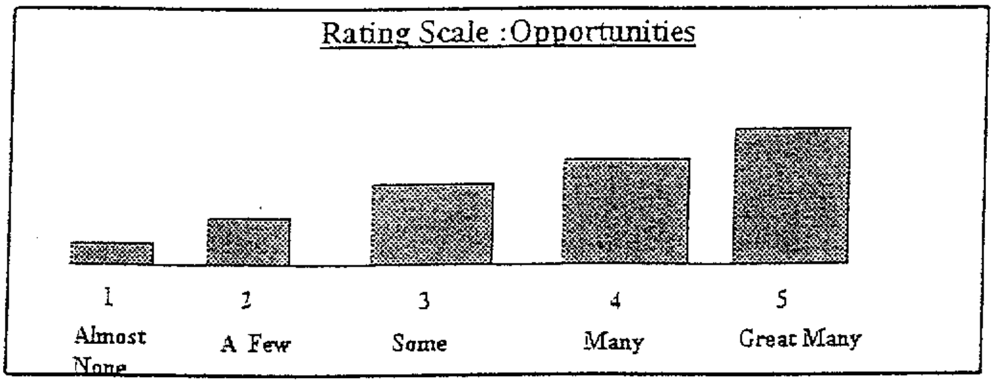
The last question to ask yourself is:

"Are there opportunities for me to improve this part of my life?"

If you need to think about the question another way, try: "Do I have choices available to me about this aspect of my life?"

Please place the number that describes how you feel on the line using the scale shown below:

- Write the number 5 on the line if you have a **great many opportunities** in that part of your life
- Write the number 4 on the line if you have **many opportunities** in that part of your life
- Write the number 3 on the line if you think you have **some opportunities** in that part of your life
- Write the number 2 on the line if you think you have a **few opportunities** in that part of your life
- Write the number 1 on the line if you have **almost no opportunities** in your life.



Are there opportunities for me to improve:

64. My physical health ______
65. My thoughts and feelings ______
66. My beliefs and values ______
67. The places where I spend my time (home, school, work) ______
68. Who I spend my time with ______
69. Being able to use what my community has to offer ______
70. The everyday things I can do in my life ______
71. The things I can do for fun and enjoyment ______
72. The things I do to better myself ______

LAST, CAN YOU TELL ME A BIT MORE ABOUT YOURSELF. Your answers will be kept strictly confidential.

Please tick the box ☐ or fill in the appropriate information on the line provided.

73. Are you :

☐.... Male
☐.... Female

74. What is your age?

____________ years.

75. Do you live with :

☐.... Both parents
☐....Mother
☐....Father
☐....Grandparents
☐.... Other (Please describe)

____

76. How many brothers do you have altogether (don't count yourself)?

☐....One
☐....Two
☐....Three
☐....More than three

77. How many sisters do you have altogether (don't count yourself)?

☐....One
☐....Two
☐....Three
☐....More than three

78. What suburb do you live in?

______________________.

79. What country were you born in?

- ☐.... Australia
- ☐.... England
- ☐.... Scotland
- ☐.... New Zealand
- ☐.... Other- Please specify

____

80. What school do you attend?

____.

81. What year are you in at school?

Year _____.

JUST A FEW MORE FACTS ABOUT YOU AND HOW YOU WOULD DESCRIBE YOUR HEALTH.

82. How would you describe your health?

- ☐.... Excellent
- ☐..... Very Good
- ☐.... Good
- ☐.... Fair
- ☐.... Poor

82. In the last 14 days have you had to reduce your activities or miss school due to illness or injury?

☐....Yes Go to Question 84.
☐....No Go to Question 88.

84. Please tell me about this illness/injury.

____

____

85. How many days altogether were you off school during the last 14 days?

____________________days.

86. How many days altogether did you spend in bed sick during the last 14 days?

____________________days.

87. Did you have to spend any time in the hospital as a result of your illness/injury during the last 14 days?

____________________days.

88. Please describe in your own words what quality of life means to you?

____

____

89. How would you describe your quality of life?

☐....Excellent
☐....Very Good
☐....Good
☐....Fair
☐....Poor

JUST A FEW MORE FACTS ABOUT YOU AND HOW YOU WOULD DESCRIBE YOUR HABITS WITH SMOKING AND DRINKING ALCOHOL.

90. Have you ever tried cigarettte smoking?

☐....Yes, just a few puffs
☐....Yes, - a whole cigarette
☐....Yes, more than a whole cigarette
☐....No

91. Have you ever tried to drink alcohol?

☐....Yes
☐....Yes, but I have only had sips
☐....Yes. I have had one whole drink
☐....Yes, I have had more than one drink
☐....Yes, I drink all the time
☐....No

THE END

93. What is your Mother's present occupation?

____

94. What is your father's present occupation?

____

95. What is the highest level of education that your mother has completed? (Circle one number only)

Primary school.............................. ☐
Year 10 at secondary school................ ☐
Year 11 at secondary school.............. ☐
Year 12 at secondary school.............. ☐
Trade qualification......................... ☐
Tafe course.................................. ☐
Business college............................ ☐
University degree.......................... ☐
Other. (Please describe below)............ ☐

____

96. What is the highest level of education that your father has completed? (Circle one number only)

Primary school.............................. ☐
Year 10 at secondary school.............. ☐
Year 11 at secondary school.............. ☐
Year 12 at secondary school.............. ☐
Trade qualification......................... ☐
Tafe course.................................. ☐
Business college............................ ☐
University degree.......................... ☐
Other. (Please describe below)............ ☐

____

97. What is the main language spoken at home?

English.................................... ☐
Other (Please specify below)........... ☐

____

Appendix B

Adolescent Health Study

To the Parent/Guardian,

A health study is being conducted by the School of Public Health at Curtin University of Technology. Mr. ____, the school principal has approved the recruitment of teenagers aged 10-19 from _____ Senior High School. The study is looking at the quality of life for the adolescent over a 6 month period. It is hoped that the results of the study will enhance our understanding of the problems encountered by adolescents, which in turn will assist in the development of policies to assist them.

We would like to recruit adolescents aged between 10-19 to participate in this study. It would involve sending two questionnaires to your home – that is one questionnaire at the start and one questionnaire at six months. All answers provided will be kept completely confidential and will be used for research purposes only.

To encourage participation in the study everyone who completes a questionnaire will receive a voucher for a free McMuffin egg and bacon burger from McDonald's.

If you allow your son/daughter to participate in the study please sign the enclosed consent form and have it returned to the front school office by _______ .The questionnaire will then be sent to your home address within the following two weeks. If you have any queries regarding the study please do not hesitate to contact either Dr. Andy Lee at 9266-4180 or myself (9266-2817).

Thank you for your time and your anticipated contribution to this important research.

Yours Sincerely,

Lynn Meuleners,
B.A., R.N., MSc., Ph.D. Cand.

( ) Yes, I am willing to allow my son/daughter to participate in the study entitled "Quality of Life of the Adolescent with a Chronic Condition"

Parent's Name: ________________________________

Address: ________________________________

Suburb: ________________________________

Postcode: ________________________________

TelephoneNumber: ________________________________

Parent's Signature: ________________________________

Teenager's Name ________________________________

Age : ________________________________

Teenager's Signature: ________________________________

( ) Yes, my son/daughter has a chronic illness.

Please describe what your son/daughter's chronic illness is. Thank you.

____

( ) No, my son/daughter does not have a chronic illness.

Appendix C

School of
Public Health

GPO Box U1987 Perth
Western Australia 6845

TELEPHONE +61 8 9266 7927
FACSIMILE +61 8 9266 2958
EMAIL enquiry@health.curtin.edu.au
WEB PAGE http://www.curtin.edu.au/
curtin/dept/health/

Dear ,

Thank you for your participation in the "Quality of Life Study for the Adolescent with a Chronic Illness". Your support is very important to us and without your participation the project would not be able to continue.

I appreciate you taking the time to complete the questionnaire. This is the first of a total of two questionnaires which will be sent to you over the next six months. The information you provide will remain strictly confidential. For this reason your name has not been included on the questionnaire

I need to know what your feelings are when answering the questions, so please answer as honestly as possible. Please understand there is no right or wrong answer. When you have finished filling in the questionnaire, return it in the prepaid envelope accompanying the questionnaire.

If you have any questions or would like to talk in more detail about the questionnaire please contact me by telephone at 9266-2817.

Don't forget when you have completed both questionnaires your name will be placed in the draw for the movie tickets and dinner. There will also be a draw for a $50.00 gift voucher for Just Jeans. So there are two great prizes to be won. So don't forget to mail your questionnaire back.

Thank you for your time.

Yours sincerely,

Lynn Meuleners,
B.A., R.N., M.Sc, Ph.D. Cand.
Project Coordinator

School of
Public Health

GPO Box U1987 Perth
Western Australia 6845

TELEPHONE +61 8 9266 7927
FACSIMILE +61 8 9266 2958
EMAIL enquiry@health.curtin.edu.au
WEB PAGE http://www.curtin.edu.au/
curtin/dept/health/

Dear ,

Thank you very much for your quick response to the first questionnaire, which you filled out six months ago. Time has gone by quickly and I am now sending you the second and last questionnaire for this study. This questionnaire is very important because it allows us to see if there has been any change in your perceptions of different aspects of your life over the last six months.

I appreciate you taking the time to complete the questionnaire. The information you provide will continue to remain strictly confidential. For this reason your name has not been included on the questionnaire. The questionnaire has been numbered to ensure your identity is kept confidential, and to allow the results to be processed anonymously.

Again, I need to know what your feelings are when answering the questions so please answer as honestly as possible. Please understand there is no right or wrong answer. When you have finished filling in the questionnaire, return it in the **prepaid** envelope accompanying the questionnaire.

Remember if you complete both questionnaires your name will go in a draw and you will have the chance of winning one of several prizes. We are pleased to add a gift certificate worth over $50.00 for Just Jeans or two free movie tickets and dinner at your local movie theater.

We are also pleased to be able to send you a free voucher for a McDonald's bacon and egg McMuffin when you have completed and return the questionnaire.

If you have any questions or would like to talk in more detail about the questionnaire please contact me by telephone at 9266-2817.

Thank you for your continued enthusiasm and support in this important project. time.

Yours sincerely,

Lynn Meuleners,
B.A., R.N., M.Sc, Ph.D. Cand.
Project Coordinator

Appendix D

School of Public Health

curti
University of Techno
Western Australia

GPO Box U 1987
Perth 6845
Western Australia
Fax (08) 9266 2958

The Principal Name,
School's Name,
Address.

Dear ,

A study is being undertaken through Curtin University of Technology to assess the quality of life for adolescents over a two-year period. We would like to invite your school to participate in the study. The part your school would play is the distribution of letters of invite (plus consent forms) to all students between the ages of 10-19 by the class teacher. If the student is interested in participating in the study the letter has to be signed by a parent (and the adolescent) then returned to the school where I will collect the completed consents. That is all your school would be required to do.

I will then send the questionnaires to their home address which they will answer and return to me. The questionnaire will ask them questions regarding their perceptions of their quality of life. It will take approximately twenty to thirty minutes to complete. A reply-paid envelope will be provided to return the completed questionnaire. All information obtained from the questionnaire will be kept totally confidential and anonymity will be maintained throughout the study. This study has been approved by the Curtin University Human Research Ethics Committee.

I shall telephone you within a week to confirm if you agree to participate in this important project. We will provide muffins for the teaching staff to show our appreciation for their assistance if you agree to participate. Should you require further details or clarification of the nature of the project, please do not hesitate to contact me at Curtin University on 9266-4180.

Thank you and looking forward to your participation.

Yours Sincerely,

Dr. Andy Lee

Appendix E

**School of
Public Health**

GPO Box U1987 Perth
Western Australia 6845

TELEPHONE +61 8 9266 7927
FACSIMILE +61 8 9266 2958
EMAIL enquiry@health.curtin.edu.au
WEB PAGE http://www.curtin.edu.au/
curtin/dept/health/

Dear ,

Approximately three weeks ago you received a questionnaire as part of the study examining the Quality of Life of the Adolescent with a Chronic Illness.

You may have already returned the questionnaire. If so, thank you, and please disregard this reminder letter.

If you have not yet completed the questionnaire could I ask you to do so and return it as soon as possible. If you have mislaid the questionnaire, please contact me on 9266-2817 and I will supply you with another copy.

The information that you provide is very important to the study and your assistance is greatly appreciated.

Yours Sincerely,

Mrs. Lynn Meuleners
Ph.D. Student
School of Public Health
Curtin University.

Appendix F

Office Use Only
CASE NO ____

PLEASE RESPOND TO EVERY QUESTION (1-58)

Thank you very much for your participation in this study. Your answers will be confidential so we encourage you to be as honest as possible. There are no right or wrong answers to this questionnaire. It is your experience and thoughts that are most important to us. This questionnaire is the first stage of the process. Your answers will help us to understand the different perceptions that people have of the quality of life of the adolescent with a chronic illness. Results from this questionnaire will be provided before completing the second questionnaire. Below are the definitions this study will use for a chronic illness and an adolescent.

This study defines a young person or young person as being between the ages of 11 to 19 years.

This study defines a chronic illness as one that has lasted longer than three months and has resulted in a level of physical impairment or requires medical care greater than expected of a young person of the same age.

The following questions relate to your personal opinions about quality of life and how you think a chronic illness might affect the quality of life of an adolescent with a chronic condition.

1. Please describe in your own words what "**Quality of Life**" means to you?

____

____

____

2. How important do you think physical health is to the quality of life of the adolescent with a chronic condition? (Please circle one number)

Not Important At All	1
Not Important	2
Important	3
Very Important	4
Extremely Important	5

3. If you have circled 1 or 2 please explain WHY/HOW physical health is important to the quality of life of the young person with a chronic illness. (Please write your answer in the space below).

4. How important do you think friendships with the same age group are to the quality of life of the young person with a chronic illness? (Please circle one number)

Not Important At All	1
Not Important	2
Important	3
Very Important	4
Extremely Important	5

5. If you have circled 1 or 2 please explain WHY/HOW friendships with the same age group are important to the quality of life of the young person with a chronic illness (Please write your answer in the space below)

6. How important do you think friendships with the opposite sex are to the quality of life of the young person with a chronic illness? (Please circle one answer)

Not Important At All	1
Not Important	2
Important	3
Very Important	4
Extremely Important	5

7. If you have circled 1 or 2 please explain HOW/WHY friendships with the opposite sex are important to the quality of life of the young person with a chronic illness. (Please write your answer in the space below.)

____

____

____

8. How important do you think family relationships are to the quality of life of the young person with a chronic illness? (Please circle one number)

Not Important At All	1
Not Important	2
Important	3
Very Important	4
Extremely Important	5

9. If you have circled 1 or 2 please explain WHY/HOW family relationships are important to the quality of life of the young person with a chronic illness. (Please write your answer in the space below)

____

____

____

10. How important do you think hobbies/interests are to the quality of life of the young person with a chronic illness? (Please circle one number)

Not Important At All	1
Not Important	2
Important	3
Very Important	4
Extremely Important	5

11. If you have circled 1 or 2 please explain WHY/HOW hobbies/ interests are important to the quality of life of the young person with a chronic illness? (Please write your answer in the space below)

____

____

____

12. How important do you think participation in school sports/activities is to the quality of life of the young person with a chronic illness? (Please circle one number.)

Not Important At All	1
Not Important	2
Important	3
Very Important	4
Extremely Important	5

13. If you have circled 1 or 2 please explain WHY/HOW participation in school/sports activities is important to the quality of life of the young person with a chronic illness? (Please write your answer in the space below)

____

____

____

14. How important do you think school and academic achievements are to the quality of life of the young person with a chronic illness? (Please circle one number)

Not Important At All	1
Not Important	2
Important	3
Very Important	4
Extremely Important	5

15. If you have circled 1 or 2 please explain HOW/WHY school and academic achievements are important to the quality of life of the young person with a chronic illness? (Please write your answer in the space below.)

____

____

____

16. How important do you think independence is to the quality of life of the young person with a chronic illness? (Please circle one number)

Not Important At All	1
Not Important	2
Important	3
Very Important	4
Extremely Important	5

17. If you have circled 1 or 2 please explain WHY/HOW independence is important to the quality of life of the teenager with a chronic illness? (Please write your answer in the space below)

____

____

____

18. How important do you think making plans for the future is to the quality of life of the young person with a chronic illness? (Please circle one answer)

Not Important At All	1
Not Important	2
Important	3
Very Important	4
Extremely Important	5

19. If you have circled 1 or 2 please explain WHY/HOW planning for the future is important to the quality of life of the young person with a chronic illness? (Please write your answer in the space below)

____

____

____

20. How important do you think it is to the quality of life of the young person with a chronic illness to make their own decisions about their illness and the management of their medical care. (Please circle one answer.)

Not Important At All	1
Not Important	2
Important	3
Very Important	4
Extremely Important	5

21. If you have circled 1 or 2 please explain WHY/HOW making decisions about their illness and management of their own care is important to the quality of life of the young person with a chronic illness? (Please write your answer in the space below)

____

____

____

22. How important do you think spiritual beliefs are to the quality of life of the young person with a chronic illness? (Please circle one answer)

Not Important At All	1
Not Important	2
Important	3
Very Important	4
Extremely Important	5

23. If you have circled 1 or 2 please explain WHY/HOW spiritual beliefs are important to the quality of life of the young person with a chronic illness? Please write your answer in the space below)

____

____

____

24. How important do you think it is to the quality of life of the young person with a chronic illness to being treated by family and friends as a " normal person" and not differently because they have a chronic illness? (Please circle one answer)

Not Important At All	1
Not Important	2
Important	3
Very Important	4
Extremely Important	5

25. If you have circled 1 or 2 please explain HOW/WHY it is important to the quality of life of the young person to be treated as a "normal person" and not differently because of their chronic illness. (Please write your answer in the space below)

____

____

____

For the next question please place only one tick in the appropriate box to the answer that best describes the way you feel?

A person's health often affects the way they feel about life. Do you think that a young person with a chronic illness feels that:

	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
26 They are discriminated against because of their health.					
27. Their health interferes with their satisfaction with life.					
28. Their health has made them a burden to society.					
29. Their health has made them a burden to their family.					
30. Their health prevents them from making long term plans.					
31. Their quality of life is impaired because of their illness.					
32. Their illness makes them different to everyone else.					

There are different types of chronic conditions that can have different effects on the young person and their quality of life. Please circle the answer that best describes how you feel.

33. How important do you think the severity of the chronic illness is to the quality of life of the young person with a chronic illness? (Please circle one answer)

Not Important At All	1
Not Important	2
Important	3
Very Important	4
Extremely Important	5

34. If you have circled 1 or 2 please explain WHY/HOW the severity of the chronic condition is important to the quality of life of the young person? (Please write your answer in the space below)

____

____

____

35. How important do you think the physical visibility (for example: a limp) of the chronic illness is to the quality of life of the young person? (Please circle one number)

Not Important At All	1
Not Important	2
Important	3
Very Important	4
Extremely Important	5

36. If you have circled 1 or 2 please explain WHY/HOW the physical visibility of the chronic illness is important to the quality of life of the young person with a chronic illness. (Please write your answer in the space below)

____

____

____

37. How important do you think a physical limitation is to the quality of life of the young person with a chronic illness? (Please circle one number)

Not Important At All	1
Not Important	2
Important	3
Very Important	4
Extremely Important	5

38. If you have circled 1 or 2 please explain WHY/HOW a physical limitation is important to the quality of life of the young person? (Please write your answer in the space below)

____

____

____

39. How important do you think the young person's attitude towards their chronic illness is to their quality of life? (Please circle one number)

Not Important At All	1
Not Important	2
Important	3
Very Important	4
Extremely Important	5

40. If you have circled 1 or 2 please explain WHY/HOW the young person's attitude to their chronic illness is important to their quality of life. (Please write your answer in the space below)

____

____

____

41. How important do you think the family's attitude towards the chronic illness is to the young person's quality of life? (Please circle one answer)

Not Important At All	1
Not Important	2
Important	3
Very Important	4
Extremely Important	5

42. If you have circled 1 or 2 please explain WHY/HOW the family's attitudes is important to the quality of life of the young person? (Please write your answer in the space below)

____

____

____

43. How would you rate the quality of life of a young person with a chronic illness to the quality of life of a healthy young person?

☐ Better than a healthy young person
☐ The same as a healthy young person
☐ Worse than a healthy young person

44. Please explain your answer in greater detail?

____

____

____

____

45. What other things, which have not been mentioned in this questionnaire, do you believe to be important to the quality of life of the young person with a chronic illness?

____

____

____

____

46. What do you think that you, as a teacher, can do to improve the quality of life of the young person with a chronic illness while they attend school?

____

____

____

____

Lastly, you are invited to share a little information about yourself. This information will help us to understand the experiences that you have/have not with young persons with a chronic condition. Please tick one answer.

47. Are you: ☐ Male ☐ Female

48. What is your age? ____________ years.

49. What is your marital status?

☐	Married	☐	Widowed
☐	De Facto	☐	Never Married
☐	Separated	☐	Divorced

50. In what country were you born? __________________________

51. What is your occupation? ______________________

52. If you are a teacher, what year do you teach? ________________

53. What is the highest level of education that you have completed? Please tick only one answer.

Left school before the end of year 12	☐
Completed year 12	☐
Completed an apprenticeship	☐
Completed a TAFE course	☐
Completed a university degree	☐
Other (please explain)	☐

54. Do you have a young person between the ages of 10 to 19 living with you at present?

☐ Yes ☐ No

55. Is there a child or young person (age 10-19) with a chronic illness living in your house at the present time?

☐ Yes ☐ No

56. If you answered yes to the last question please describe the chronic illness.

____

____

____

57. Do you have any other close relatives who have a chronic illness?

☐ Yes ☐ No

58. If you answered yes to the above question what is their relationship to you?

____

____

THANK YOU VERY MUCH FOR YOUR PATIENCE AND YOUR COOPERATION.

Appendix G

Curtin
University of Technology
Western Australia

A Parent's Perceptions of the Quality of Life of an Adolescent with a Chronic Illness

What does Quality of Life Mean?

O.K let me try and explain....

Contact Details
Lynn Meuleners
School of Public Health
Curtin University of Technology
Direct Phone: 9266-2817

Office Use Only
Case No ______

The Quality of Life of the Adolescent with a Chronic Illness
Questionnaire Number 2
Parent's perspective

The **questions (1-22) listed here** have originated from the comments made in the first questionnaire that you have already completed. They represent **key aspects of Quality of Life** which were **identified by parents in their responses to their perceptions of the quality of life of the adolescent with a chronic illness.**

Each page has a **question(s)**, which is **comprised** of **several items which are related to a particular aspect of Quality of Life.** Please **read all the items first, then rank each of them based on your perception OF THEIR IMPORTANCE to that particular aspect of Quality of Life.**

An example is provided below:

What factors are important to you when choosing to dine out at a restaurant?

Read all the items listed below. Then rank each item on a scale of 1-4 by placing a number in each box. **Please number each item in order of importance with 1 representing the most important and 4 the least important. Remember to only use each number (1-4) once.**

Choosing to Dine at a Restaurant	Your Rank
Financial cost	3
Location	1
Type of Food	2
Reputation of the restaurant	4

Please return the completed questionnaire by, Friday, September 10, 1999.

SECTION 1

The questions (1-8) in this section ask you to rank the importance of several items related to different aspects of Quality of Life. These aspects were found to be EXTREMELY IMPORTANT to the quality of life of the adolescent with a chronic illness based on your responses from the first questionnaire. Please read all the items related to that particular aspect of Quality of Life and then indicate your perception of the relative importance of each item.

Enter (1) for the item you feel is the MOST IMPORTANT;
Enter (2) for the SECOND MOST IMPORTANT item;
Enter (3) for the THIRD MOST IMPORTANT item and so on.

Please remember to use each number only once.

1. **The following items were found to be extremely important to the Quality of Life of the adolescent with a chronic illness. (Please rank them on a scale of 1-7)**

Extremely Important Items	Your Rank
Physical health	
Friendships with their peers	
Family relationships	
The attitude of the adolescent towards their chronic illness	
Managing their own medical care and making decisions about their illness	
Being treated as "normal"	
The attitude of the family towards the adolescent with a chronic illness	

Other Comments:____

____

2. **How important are the following aspects of physical health to the adolescent with a chronic illness. (Please rank them on a scale of 1-5)**

Physical Health	Your Rank
Need good health to participate in everyday life	
Good health will help the adolescent to deal with the pressure of their illness	
Need good health to enjoy life	
Need good physical health to keep pace with their peers	
Poor health can damage self-esteem	

Other Comments:____

____

3. **How important are the following aspects of <u>relationships with the same age group</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-6)**

Relationships with Peers	**Your Rank**
To be able to relate with people their own age	
Friend can provide support and encouragement	
Friends would help the adolescent to not " feel different"	
Someone to share their feelings with	
Illness can isolate the adolescent, friends can help prevent this from happening	
Friends would encourage the adolescent to do more things	

Other Comments:____

____

4. **How important are the following aspects of <u>family relationships</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-4)**

Family Relationships	**Your Rank**
Can provide emotional support to the adolescent with a chronic illness	
Family can help the adolescent through the "downers" of their illness	
Positive energy from the love of the family can aid recuperation	
To know that you are loved "unconditionally" by your family	

Other Comments:____

____

5. **How important are the following aspects of the <u>adolescent's attitude</u> towards their illness to their quality of life? (Please rank them on a scale of 1-4)**

Adolescent's Attitude	**Your Rank**
A positive attitude can help the adolescent cope with their illness	
A positive attitude can help make recovery easier	
A positive attitude can help the adolescent to live life to the fullest	
A positive attitude can improve the quality of life	

Other Comments:____

____

6. **How important are the following aspects of the <u>family's attitude</u> towards the adolescent's chronic illness to his/her quality of life? (Please rank them on a scale of 1-4)**

Family's Attitude	**Your Rank**
A positive family attitude should provide hope, support and encouragement to the adolescent	
A positive family attitude is essential to the normal development of the adolescent	
A positive family attitude can help the adolescent feel part of the family	
A positive family attitude can help in recovery of episodes of the chronic illness	

Other Comments:____

____

7. **How important are the following aspects of being treated as a <u>"normal person"</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-4)**

Treated as a "Normal Person"	**Your Rank**
Encourages a feeling of "belonging" or "fitting in" with peers and family	
The adolescent is accepted for themselves and not their illness	
Can have a positive effect on their self-esteem	
Can have a negative effect on their illness	

Other Comments:____

____

8. **How important are the following aspects of <u>managing medical care and making decisions about their illness</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-3)**

Managing Medical care and making Decisions about their Illness	**Your Rank**
Allows the adolescent to take some control over their illness	
Helps the adolescent to be aware of the limits imposed by their illness	
By making decisions themselves they will not become resentful of decisions made by the family since it is their own body	

Other Comments:____

____

SECTION 2

The questions (9-16) in this section ask you to rank the importance of several items related to different aspects of Quality of Life. These aspects were found to be VERY IMPORTANT to the quality of life of the adolescent with a chronic illness based on your responses from the first questionnaire. Please read all the items related to that particular aspect of Quality of Life and then indicate your perception of the relative importance of each item.

Enter (1) for the item you feel is the MOST IMPORTANT;
Enter (2) for the SECOND MOST IMPORTANT item;
Enter (3) for the THIRD MOST IMPORTANT item and so on.
Remember to use each number only once

9. The following items were found to be <u>very important</u> to the Quality of Life of the adolescent with a chronic illness. (Please rank them on a scale of 1-7)

Very Important Items	**Your Rank**
Participation in school/sports activities	
School and academic achievements	
Making plans for the future	
Severity of the chronic illness	
Physical visibility of the illness	
Hobbies/Interests	
Independence	

Other Comments:____

____

10. How important are the following aspects of the <u>physical visibility</u> of the chronic illness to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-4)

Physical Visibility	**Your Rank**
The adolescent would be treated differently by people since people are often judged on first appearances	
It could effect their self-esteem	
It could add to the isolation felt by the adolescent	
It could effect their self-confidence	

Other Comments:____

____

11. **How important are the following aspects of <u>making plans for the future</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-5)**

Making Plans for the Future	**Your Rank**
Allow them to live as normal a life as possible	
Provides them with a future to work towards	
Is a positive step towards recovery	
Helps them work towards developing a set of values in life	
Allow them to live life to the fullest	

Other Comments:____

____

12. **How important are the following aspects of the <u>severity of the chronic illness</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-3)**

Severity of the Chronic Illness	**Your Rank**
Would seriously effect the adolescent's quality of life	
The adolescent cannot plan for the future	
The adolescent becomes totally absorbed in their illness and treatment	

Other Comments:____

____

13. **How important are the following aspects of <u>hobbies/interests</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-6)**

Hobbies/Interests	**Your Rank**
Can be therapeutic to the adolescent with a chronic illness	
Can provide an interest in life	
Takes the adolescent's mind off their illness	
Gives the adolescent something to "aim for"	
Provide opportunities to meet new people	
Provides a sense of achievement to the adolescent	

Other Comments:____

____

14. **How important are the following aspects of <u>independence</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-4)**

Independence	**Your Rank**
Can give the adolescent confidence	
Independence is essential for the adolescent to manage their life	
Can help provide a positive self-esteem	
Can keep the adolescent from feeling dependent on their family	

Other Comments:____

____

15. **How important are the following aspects of <u>participation in school/sports activities</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-5)**

Participation in School/Sports Activities	**Your Rank**
Is important so that adolescent does not feel "different" from other adolescents	
Is important for the adolescent to interact with their "peers"	
Activities can be very therapeutic	
Can provide positive energy which can help the adolescent feel better	
Provides exposure to different people and activities	

Other Comments:____

____

16. **How important are the following aspects of <u>school and academic achievements</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-5)**

School/Academic Achievements	**Your Rank**
It proves that they can achieve things	
Can provide positive energy which can help the adolescent feel better	
Is a confidence booster	
Provides a sense of purpose and a goal to work towards	
Helps the adolescent to realize that they have a future to work towards	

Other Comments:____

____

SECTION 3

The questions (17-19) in this section ask you to rank the importance of different aspects of Quality of Life which you found to be IMPORTANT to the quality of life of the adolescent with a chronic illness. Please read all the items related to that particular aspect of Quality of Life and then indicate your perception of the relative importance of each aspect.

Enter (1) for the item you feel is the MOST IMPORTANT;
Enter (2) for the SECOND MOST IMPORTANT item;
Enter (3) for the THIRD MOST IMPORTANT item and so on .
Remember to use each number only once

17. The following items were found to be important to the quality of life of the adolescent with a chronic illness. (Please rank them on a scale of 1-2)

Important Questions	Your Rank
Friendships with the opposite sex	
Spiritual beliefs	

Other Comments:____

____

18. How important are the following aspects of spiritual beliefs to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-5)

Spiritual beliefs	Your Rank
Can have a calming influence on the adolescent	
Can provide inner strength to the adolescent	
Faith provides hope for a brighter tomorrow	
Faith can aid in the recovery process	
Can provide a sense of stability to the adolescent	

Other Comments:____

____

19. How important are the following aspects of <u>friendships with the opposite sex</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-4)

Friendships with the Opposite Sex	Your Rank
Can help the adolescent to feel "accepted" by peers	
Can help to build confidence in the adolescent	
Can help the adolescent to feel "normal" and not different to their peers	
Can help the adolescent to feel attractive and desirable	

Other Comments:____

____

SECTION 4

The last three questions are concerned with other aspects for the Quality of Life of the Adolescent with a chronic illness. Please read each question and follow the instructions that are given with the question.

20. Aspects of Quality of Life which parents found important in defining what Quality of Life means to <u>them</u> are given below. How important do you think these aspects are to your definition of Quality of Life? Please rank them on a scale of 1-13 with the number 1 representing the most important and 13 the least important. Remember to use each number (1-13) only once.

Quality of Life means.....	Your Rank
Good health	
Lead a full and happy life	
Able to do the things you want to do	
Personal independence	
Enjoyable occupation	
Satisfaction with your life	
A good standard of living	
Having a loving and caring family	
Belief in God and that God has everything under control	
Self-confidence	
Enjoying what you are doing with your life	
A pain free life	
Consistent state of well-being in all areas of life- physical, mental and emotional	

Other Comments:____

____

21. The majority of parents ranked the Quality of Life of the adolescent with a chronic illness as poorer than the quality of life of the healthy adolescent. The reasons for this rating are based on the results from the first questionnaire which are given below. Please number each item in order of importance with 1 representing the most important and 2 the least important. Remember to only use each number (1-2) only once.

Reasons for a poorer rating for the Quality of Life of the Adolescent with a Chronic Illness	Your Rank
They may not be able to do the things that a healthy adolescent can do	
A poor attitude due to the chronic illness can effect their quality of life	

Other Comments:____

____

22. The following items were identified by parents as ways they can help to improve the Quality of Life of the adolescent with a chronic illness. Please number each item in order of importance with 1 representing the most important and 9 the least important. Remember to only use each number (1-9) once.

Ways Parents can Improve the Quality of Life of the Adolescent with a Chronic Illness	Your Rank
Support and encouragement	
By learning as much as possible about the illness	
Being there when the adolescent needs them	
Positive attitude towards the adolescent and the illness	
Keeping home life as normal as possible	
Encouraging independence	
Keeping them informed of all aspects of their illness and treatment	
Making them realize that they are important individuals in society	
Lots of love	

Other Comments:____

____

THANK YOU FOR YOUR TIME AND PATIENCE

curtin
University of Technology
Western Australia

- **Information gathered from this questionnaire will remain confidential**
- **All respondents will remain anonymous**
- **Your participation in this study is appreciated**

THANK YOU FOR YOUR PATIENCE
AND COOPERATION

curtin
University of Technology
Western Australia

A Health Professional's Perceptions of the Quality of Life of an Adolescent with a Chronic Illness

What does Quality of Life Mean?

O.K let me try and explain....

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Office Use Only
Case No ______

The Quality of Life of the Adolescent with a Chronic Illness
Questionnaire Number 2
Health Professional's Perspective

The **questions (1-23) listed here** have originated from the comments made in the first questionnaire that you have already completed. They represent **key aspects of Quality of Life** which were **identified by Health Professionals in their responses to their perceptions of the quality of life of the adolescent with a chronic illness.**

Each page has a **question(s)**, which is **comprised of several items that are related to a particular aspect of Quality of Life.** Please **read all the items first, then rank each of them based on your perception OF THEIR IMPORTANCE to that particular aspect of Quality of Life.**

An example is provided below:

What factors are important to you when choosing to dine out at a restaurant?

Read all the items listed below. Then rank each item on a scale of 1-4 by placing a number in each box. **Please number each item in order of importance with 1 representing the most important and 4 the least important. Remember to only use each number (1-4) once.**

Choosing to Dine at a Restaurant	**Your Rank**
Financial cost	3
Location	1
Type of Food	2
Reputation of the restaurant	4

Please return the completed questionnaire by Friday, October 1 1999.

SECTION 1

The questions (1-6) in this section ask you to rank the importance of several items related to different aspects of Quality of Life. These aspects were found to be EXTREMELY IMPORTANT to the quality of life of the adolescent with a chronic illness based on your responses from the first questionnaire. Please read all the items related to that particular aspect of Quality of Life and then indicate your perception of the relative importance of each item.

Enter (1) for the item you feel is the MOST IMPORTANT;
Enter (2) for the SECOND MOST IMPORTANT item;
Enter (3) for the THIRD MOST IMPORTANT item and so on.

Please remember to use each number only once.

1. **The following items were found to be extremely important to the Quality of Life of the adolescent with a chronic illness. (Please rank them on a scale of 1-5)**

Extremely Important	**Your Rank**
Severity of the illness	
Adolescent's Attitude towards their illness	
Friendships with the same age group	
Physical health	
Family relationships	

Other Comments:____

____

2. **How important are the following aspects of the severity of the chronic illness to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-5)**

Severity of the Chronic Illness	**Your Rank**
May hinder the adolescent from participating in activities that adolescents do everyday	
May impair quality of life	
May affect any goal setting	
May hinder the adolescent from having a "normal" life	
May affect the adolescent's attitude	

Other Comments:____

____

3. **How important are the following aspects of the <u>adolescent's attitude</u> towards their illness to their quality of life? (Please rank them on a scale of 1-5)**

Adolescent's Attitude	**Your Rank**
A positive attitude helps the adolescent to cope with his/her illness	
A positive attitude helps to improve the quality of life	
A positive attitude will determine how the adolescent experiences life	
A positive attitude will help the adolescent accept the illness	
A positive attitude can help strengthen the body's immune system	

Other Comments:____

____

4. **How important are the following aspects of <u>friendships with the same age group</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-5)**

Friendships with the Same Age Group	**Yours Rank**
The adolescent needs to feel that he/she "belongs"	
Helps to increase independence from the family	
Helps to develop/refine their self-concept	
Friendships with their peers help the adolescent to learn adult behaviour	
Friendships with the same age group are a normal adolescent developmental task	

Other Comments:____

____

5. **How important are the following aspects of family relationships to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-8)**

Family Relationships	**Your Rank**
Provide love especially when the adolescent is ill	
Provide long term emotional and physical support	
Provide the adolescent with a relatively "normal" life	
Help maintain a good attitude	
Provide security	
Supportive family can help to attain optimal health	
Family often has a greater understanding of the illness	
Supportive family can help the adolescent cope with the illness	

Other Comments:____

____

6. **How important are the following aspects of physical health to the adolescent with a chronic illness. (Please rank them on a scale of 1-5)**

Poor Physical Health	**Your Rank**
Can interfere with the adolescent achieving personal goals	
May exclude the adolescent from participating in activities	
Could affect the development of friendships because of the inability to interact with others in usual adolescent activities	
Does not allow full enjoyment of life	
May make the adolescent feel as if they are "different"	

Other Comments:____

____

SECTION 2

The questions (7-14) in this section ask you to rank the importance of several items related to different aspects of Quality of Life. These aspects were found to be VERY IMPORTANT to the quality of life of the adolescent with a chronic illness based on your responses from the first questionnaire. Please read all the items related to that particular aspect of Quality of Life and then indicate your perception of the relative importance of each item.

Enter (1) for the item you feel is the MOST IMPORTANT;
Enter (2) for the SECOND MOST IMPORTANT item;
Enter (3) for the THIRD MOST IMPORTANT item and so on.
Remember to use each number only once

7. The following items were found to be very important to the Quality of Life of the adolescent with a chronic illness. (Please rank them on a scale of 1-7)

Very Important Items	Your Rank
Hobbies/Interests	
Physical visibility of the illness	
Making plans for the future	
Making decisions about their illness and management of their own medical care	
Independence	
Family's attitude towards the chronic illness	
Being treated as a "normal" person by family	

Other Comments____

____

8. How important are the following aspects of hobbies/interests to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-5)

Hobbies/Interests	Your Rank
Can provide the adolescent with a distraction from his/her illness	
Can provide feelings of satisfaction and accomplishment through his/her productivity	
Can provide intellectual stimulation	
Provide opportunities to achieve goals within his/her area of interest	
Helps the adolescent to define and discover who they are	

Other Comments:____

____

9. **How important are the following aspects of the <u>physical visibility</u> of the chronic illness to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-5)**

Physical Visibility of the Chronic Illness	**Your Rank**
Physically identifies the adolescent as "different"	
Can reduce the independence of the adolescent	
Can damage their self-image depending on the response of others	
May make the adolescent feel a burden to others	
Can reduce the self-confidence of the adolescent	

Other Comments:____

____

10. **How important are the following aspects of <u>making plans for the future</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-4)**

Making Plans for the Future	**Your Rank**
Provides hope that there is a future	
Enables the adolescent to set goals for the future	
Gives the adolescent the will to achieve their goals	
Is vital in maintaining optimal health	

Other Comments:____

____

11. **How important are the following aspects of <u>managing medical care and making decisions about their illness</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-5)**

Managing Medical Care and Making Decisions about Their Illness	**Your Rank**
Provides a feeling of control over their illness	
Provides a feeling of self-worth about their own capabilities	
Provides a feeling of independence	
Could reduce the fear and anxiety of their illness	
Provides relevant information about their illness	

Other Comments:____

12. How important are the following aspects of independence to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-7)

Independence	**Your Rank**
Enables the adolescent to pursue the things he/she wants to do	
Is a normal adolescent developmental task that needs to be accomplished whether the adolescent has a chronic illness or not	
Reduces the feelings that the adolescent may have of being a burden to the family	
Provides positive feelings of self-worth	
Allows the adolescent to do as much as possible for him/herself	
Allows the adolescent to cope with life and their illness	
Helps the adolescent's emotional growth	

Other Comments:____

____

13. How important are the following aspects of being treated as a "normal person" to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-4)

Treated as a "Normal Person"	**Your Rank**
Help to lessen the feelings the adolescent may have of being "different"	
Help the adolescent to "fit in" with their peers	
It is damaging psychologically to self-image if family focuses on illness	
Help the adolescent to put their illness in perspective and not become "obsessed" about it	

Other Comments:____

____

14. How important are the following aspects of the family's attitude towards the adolescent's chronic illness to his/her quality of life? (Please rank them on a scale of 1-6)

Family's Attitude	**Your Rank**
Can affect the adolescent's health and well-being	
Can determine if the adolescent feels part of the family	
Can determine if the adolescent sees him/herself as an "invalid" or "normal"	
Can determine how good their quality of life is	
Can determine how autonomous the adolescent becomes	
Positive attitude of the family can be "health enhancing"	

Other Comments:____

____

SECTION 3

The questions in this section (15-19) ask you to rank the importance of different aspects of Quality of Life which you found to be IMPORTANT to the quality of life of the adolescent with a chronic illness. Please read all the items related to that particular aspect of Quality of Life and then indicate your perception of the relative importance of each aspect.

Enter (1) for the item you feel is the MOST IMPORTANT;
Enter (2) for the SECOND MOST IMPORTANT item;
Enter (3) for the THIRD MOST IMPORTANT item and so on .
Remember to use each number only once

15. The following items were found to be important to the quality of life of the adolescent with a chronic illness. (Please rank them on a scale of 1-4)

Important Questions	**Your Rank**
Participation in school/sports activities	
School/academic achievements	
Friendships with the opposite sex	
Spiritual beliefs	

Other comments:____

____

16. **How important are the following aspects of <u>participation in school/sports activities</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-6)**

Participation in School/Sports Activities	**Your Rank**
Helps the adolescent to feel accepted by their peers	
Can affect social acceptance by their peers if they cannot participate in school/sport activities	
Helps the adolescent to be active physically	
Provides the opportunity to mix and compete with their peers on equal terms	
Can increase self-confidence	
Can have a negative effect on the adolescent if unable to participate in school/sport activities	

Other Comments:____

____

17. **How important are the following aspects of <u>school and academic achievements</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-5)**

School/Academic Achievements	**Your Rank**
Can help the adolescent prepare for a career	
Can help the adolescent to acquire a feeling of independence through his/her accomplishments	
Help the adolescent to not feel "different" from their classmates	
Provide a sense of self-worth through his/her accomplishments	
Can be pursued in spite of the chronic illness by the adolescent	

Other Comments:____

____

18. How important are the following aspects of friendships with the opposite sex to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-4)

Friendships with the Opposite Sex	**Your Rank**
Provide a feeling of 'belonging" and doing the same things that other adolescents are doing	
Are part of normal adolescent development tasks that need to be accomplished by the adolescent	
Help the adolescent to feel comfortable with the changes of puberty	
Provide a feeling of being special to someone other than the family	

Other Comments:____

____

19. How important are the following aspects of spiritual beliefs to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-4)

Spiritual beliefs	**Your Rank**
Can provide hope and comfort for the future	
Can provide the strength to endure the illness	
Can provide a sense of fulfillment	
Can help the adolescent come to terms with the illness	

Other Comments:____

____

SECTION 4

The last four questions are concerned with other aspects for the Quality of Life of the Adolescent with a chronic illness. Please read each question and follow the instructions that are given with the question.

20. Aspects of Quality of Life which Health Professionals found important in defining what Quality of Life means to them are given below. How important do you think these aspects are to your definition of Quality of Life? Please rank them on a scale of 1-9 with the number 1 representing the most important and 9 the least important. Remember to use each number (1-9) only once.

Quality of Life means……	**Your Rank**
The ability to do what you want to do without physical, mental and social impairment	
Independence	
Having personal and professional goals and being able to attain these goals	
Meaningful relationships	
Good physical health	
Good mental health	
Maintain a standard of lifestyle chosen by oneself	
To live life with dignity	
Appreciate and participate in life's pleasures	

Other Comments:____

____

21. **The majority of Health Professionals ranked the Quality of Life of the adolescent with a chronic illness as <u>poorer</u> than the quality of life of the healthy adolescent. The reasons, given below, are based on the results from the first questionnaire. Please number each item in order of importance with 1 representing the most important and 5 the least important. Remember to only use each number (1-5) only once.**

Reasons for a poorer rating for the Quality of Life of the Adolescent with a Chronic Illness	**Your Rank**
The adolescent with a chronic illness has greater obstacles to overcome which are added to their normal developmental tasks	
The adolescent with a chronic illness may have physical limitations	
The adolescent with a chronic illness may have emotional limitations	
Chronic illness can be debilitating and will not allow full enjoyment of life to the fullest	
The adolescent with a chronic illness may have to try harder and longer to achieve the same outcomes as an adolescent without a chronic illness	

Other Comments:____

____

22. **Other aspects of a chronic illness which Health Professionals felt were important to the adolescent's quality of life are listed below. Please number each item in order of importance with 1 representing the most important and 4 the least important. Remember to only use each number (1-4) only once.**

Other Important Aspects of Quality of Life	**Your Rank**
Better government policies	
Financial assistance to the family	
Discharge as soon as possible after hospitalization with good home support	
The environment around them	

Other Comments:____

____

23.The following items were identified by Health Professionals as ways they can help to improve the Quality of Life of the adolescent with a chronic illness. Please number each item in order of importance with 1 representing the most important and 8 the least important. Remember to only use each number (1-8) once.

Ways Health Professional can Improve the Quality of Life of the Adolescent with a Chronic Illness	**Your Rank**
Treat them as you would any other adolescent so they do not feel different from other "healthy" adolescents	
Provide support and encouragement to the adolescent and the family so they can achieve a good quality of life	
Understand the illness of the adolescent and how it effects them	
Educate the adolescent of the importance of their medications	
Help the adolescent to take responsibility for the illness and management of their care	
Allow time for individual assessment in clinical settings	
In-depth knowledge of resources available for the adolescent and their family	
Setting reasonable goals for the adolescent	

Other Comments:____

____

Curtin University of Technology Western Australia

A Teacher's Perceptions of the Quality of Life of an Adolescent with a Chronic Illness

What does Quality of Life Mean?

O.K let me try and explain....

Contact Details
Lynn Meuleners
School of Public Health
Curtin University of Technology
Direct Phone: 9266-2817

Office Use Only
Case No ______

The Quality of Life of the Adolescent with a Chronic Illness
Questionnaire Number 2
Teacher's perspective

The **questions (1-22) listed here** have originated from the comments made in the first questionnaire that you have already completed. They represent **key aspects of Quality of Life** which were **identified by teachers in their responses to their perceptions of the quality of life of the adolescent with a chronic illness.**

Each page has a **question(s)**, which is **comprised of several items which is related to a particular aspect of Quality of Life.** Please **read all the items first, then rank each of them based on your perception OF THEIR IMPORTANCE to that particular aspect of Quality of Life.**

An example is provided below:

What factors are important to you when choosing to dine out at a restaurant?

Read all the items listed below. Then rank each item on a scale of 1-4 by placing a number in each box. **Please number each item in order of importance with 1 representing the most important and 4 the least important. Remember to only use each number (1-4) once.**

Choosing to Dine at a Restaurant	**Your Rank**
Financial cost	3
Location	1
Type of Food	2
Reputation of the restaurant	4

Please return the completed questionnaire by Monday, August 2, 1999.

SECTION 1

The questions (1-6) in this section ask you to rank the importance of several items related to different aspects of Quality of Life. These aspects were found to be EXTREMELY IMPORTANT to the quality of life of the adolescent with a chronic illness based on your responses from the first questionnaire. Please read all the items of a particular aspect of Quality of Life and then indicate your perception of the relative importance of each item.

Enter (1) for the item you feel is the MOST IMPORTANT;
Enter (2) for the SECOND MOST IMPORTANT item;
Enter (3) for the THIRD MOST IMPORTANT item and so on.
Please remember to use each number only once.

1. The following items were found to be extremely important to the Quality of Life of the adolescent with a chronic illness. (Please rank them on a scale of 1-5)

Extremely Important	**Your Rank**
Family relationships	
Making plans for the future	
Attitude of the adolescent with a chronic illness	
Being treated as a "normal person"	
Attitude of the family.	

Other Comments:____

____

2. How important are the following aspects of <u>family relationships</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-6)

Family Relationships	**Your Rank**
Provide critical emotional support	
Provide critical physical support	
Stable influence in the adolescent's life	
Family provides the additional care the adolescent may need due to the chronic illness	
Family can affect the choices the adolescent with a chronic illness makes	
Family relations affect the development of the adolescent as an individual	

Other Comments:____

____

3. **How important are the following aspects of making plans for the future to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-5)**

Making Plans for the Future	**Your Rank**
Goal setting is important	
Gives the adolescent control over their destiny	
Provides a motivator for their dreams, goals and a future	
Making plans involves hope and not dwelling on the limitations of the illness	
Important to plan in order to teach appropriate goals	

Other Comments:____

____

4. **How important are the following aspects of the adolescent's attitude towards their illness to their quality of life? (Please rank them on a scale of 1-4)**

Adolescent's Attitude	**Your Rank**
A positive attitude will assist the adolescent to cope on a daily basis to the best of their abilities	
A positive attitude can influence their health	
A positive attitude can help the adolescent find meaning in life	
Adolescent's attitude effects behavior	

Other Comments:____

____

5. **How important are the following aspects of the <u>family's attitude</u> towards the adolescent's chronic illness to his/her quality of life? (Please rank them on a scale of 1-4)**

Family's Attitude	**Your Rank**
Effects how the young person feels about themselves	
Effects how independent the adolescent becomes	
Family's attitude can influence quality of life	
Family's attitude helps encourage a positive attitude in the adolescent	

Other Comments:____

____

6. **How important are the following aspects of being treated as a <u>"normal person"</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-4)**

Treated as a "Normal Person"	**Your Rank**
The adolescent does not want to be seen or treated as "different"	
Being seen as "different" can be a constant reminder of the chronic illness	
Being seen as different can cause stress on the adolescent	
Being seen as "different" can cause poor self-image	

Other Comments:____

____

SECTION 2

The questions (7-14) in this section ask you to rank the importance of several items related to different aspects of Quality of Life. These aspects were found to be VERY IMPORTANT to the quality of life of the adolescent with a chronic illness based on your responses from the first questionnaire. Please read all the items of a particular aspect of Quality of Life and then indicate your perception of the relative importance of each item.

Enter (1) for the item you feel is the MOST IMPORTANT;
Enter (2) for the SECOND MOST IMPORTANT item;
Enter (3) for the THIRD MOST IMPORTANT item and so on.
Remember to use each number only once

7. **The following items were found to be very important to the Quality of Life of the adolescent with a chronic illness. (Please rank them on a scale of 1-7)**

Very Important Items	**Your Rank**
Physical health	
Friendships with the opposite sex	
Managing their own medical care and making decisions about their illness	
Severity of the chronic illness	
Spiritual beliefs	
Hobbies/Interests	
Independence	

Other Comments:____

____

8. **How important are the following aspects of <u>physical health</u> to the adolescent with a chronic illness. (Please rank them on a scale of 1-6)**

Poor Physical Health	**Your Rank**
Poor physical health can effect self-esteem	
Poor physical health can effect the attitude of the adolescent	
Poor physical health can effect emotional health	
Poor physical health can limit work and leisure activities/opportunities	
Poor physical health can limit independence	
Poor physical health can inhibit feeling part of the "group"	

Other Comments:____

____

9. **How important are the following aspects of <u>friendships with the opposite sex</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-4)**

Friendships with the Opposite Sex	**Your Rank**
Help to develop a normal and healthy attitude to the opposite sex	
Are part of normal adolescent development	
Help to boost the morale of the adolescent	
The opposite sex can give a different perspective on life	

Other Comments:____

____

10. How important are the following aspects of managing medical care and making decisions about their illness to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-6)

Managing Medical Care and Making Decisions about their Illness	**Your Rank**
Helps the adolescent to feel control over their life	
Makes them responsible for their health- for example being aware of risks	
Helps develop self-confidence and a positive self esteem	
Helps to alleviate feeling of being scared of their illness by being fully informed	
Helps develop independence in the adolescent	
Helps the adolescent understand the importance of their medical care and adhering to their treatment	

Other Comments:____

____

11. How important are the following aspects of the severity of the chronic illness to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-6)

Severity of the Chronic Illness	**Your Rank**
Limit ability to participate in sports/leisure activities	
Limit type of work pursued	
Limit enjoyment of activities	
Can have a negative effect on personality	
Limit the independence of the adolescent	
Limit self-confidence	

Other Comments:____

____

12. How important are the following aspects of spiritual beliefs to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-5)

Spiritual beliefs	Your Rank
Provide hope and encouragement to keep going	
Provide a way to help cope with their illness	
Help to overcome obstacles	
Help to find "peace"	
Help to make sense of the illness and put it into perspective	

Other Comments:____

____

13. How important are the following aspects of hobbies/interests to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-6)

Hobbies/Interests	Your Rank
Provide distraction from illness	
Provide feelings of self-worth by learning additional skills	
Provide opportunity to socialize and extend friendship base	
Provides opportunity for a role-model to "look up to"	
Provides opportunity for involvement in activities which are not limited by their illness	
Provide an outside interest apart from school	

Other Comments:____

____

14. How important are the following aspects of independence to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-7)

Independence	Your Rank
Helps the adolescent to cope better in life	
Is a normal developmental task that needs to be mastered	
Increases a positive self-image	
Helps increase a positive attitude	
Dependence on the family decreases as their independence increases	
Helps the adolescent plan for the future	
Allows the adolescent to do things for hi/her self	

Other Comments:____

____

SECTION 3

The questions in this section ask you to rank the importance of different aspects of Quality of Life which you found to be IMPORTANT to the quality of life of the adolescent with a chronic illness. You are asked to review these aspects and then indicate your views of the relative importance of each aspect.

Enter (1) for the item you feel is the MOST IMPORTANT;
Enter (2) for the SECOND MOST IMPORTANT item;
Enter (3) for the THIRD MOST IMPORTANT item and so on .
Remember to use each number only once

15. The following items were found to be important to the quality of life of the adolescent with a chronic illness. (Please rank them on a scale of 1-3)

Important Questions	**Your Rank**
School and academic achievement	
Participation in sports/school activities	
Physical visibility of the chronic illness	

Other comments:____

____

16. How important are the following aspects of the <u>physical visibility</u> of the chronic illness to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-3)

Physical Visibility	**Your Rank**
Visibility of the illness sets them apart from their peers and they are seen as "different"	
People tend to make judgements based on what they see – physical visibility can be seen to impose limitation	
An "invisible" illness is often overlooked – "there is nothing wrong with them"	

Other Comments:____

____

17. How important are the following aspects of <u>participation in school/sports activities</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-7)

Participation in School/Sports Activities	**Your Rank**
Helps provide a positive self-image	
Adolescent is seen to "fit in" or accepted as "normal"	
Creates opportunities to socialize with peers	
Participation in sport help the adolescent feel needed and involved	
Provides outlet to help them through the difficult times	
Helps develop team spirit in the adolescent	
Sports may help strengthen the adolescent against illness	

Other Comments:____

____

18. How important are the following aspects of <u>school and academic achievements</u> to the quality of life of the adolescent with a chronic illness? (Please rank them on a scale of 1-4)

School/Academic Achievements	**Your Rank**
Help to develop a positive self-esteem	
Help provide future employment prospects	
Provides goals for the adolescent to work towards	
Help provide feelings of being "normal" and "fitting in"	

Other Comments:____

____

SECTION 4

The last four questions are concerned with other aspects for the Quality of Life of the Adolescent with a chronic illness. Please read each question and follow the instructions that are given with the question.

19. Aspects of Quality of Life which teachers found important in defining what Quality of Life means to them are given below. How important do you think these aspects are to your definition of Quality of Life? Please rank them on a scale of 1-10 with the number 1 representing the most important and 10 the least important. Remember to use each number (1-10) only once.

Quality of Life means......	**Your Rank**
Good health	
Good relationships with family/friends/colleagues	
Able to enjoy all aspects of your life both physically and mentally	
Having goals in life and being able to attain them	
Being able to attain these goals in life	
Being stimulated and challenged both mentally and physically	
Having control over your life	
Having a good sense of self-esteem	
You are loved and valued as a person	
Ability to participate in activities – educational, sports and social	

Other Comments:____

____

20. The majority of teachers ranked the Quality of Life of the adolescent with a chronic illness as poorer than the quality of life of the healthy adolescent. The reasons for this rating are based on the results from the first questionnaire which are given below. Please number each item in order of importance with 1 representing the most important and 7 the least important. Remember to only use each number (1-7) only once.

Reasons for a poorer rating for the Quality of Life of the Adolescent with a Chronic Illness	**Your Rank**
Choices (goals/activities) are limited when a chronic illness is involved	
Peer attitudes can contribute to a lesser Quality of Life	
Attitude of the adolescent themselves can contribute to a lesser QOL	
Attitude of the family towards the chronically ill adolescent	
Attitude of the community towards the chronically ill adolescent	
Physical health can effect Quality of Life	
Independence of the adolescent may be limited	

Other Comments:____

____

21. **Other aspects of a chronic illness which teachers felt were important to the adolescent's quality of life are listed below. Please number each item in order of importance with 1 representing the most important and 6 the least important. Remember to only use each number (1-6) only once.**

Other Important Aspects of Quality of Life	**Your Rank**
Better provision of services – community and respite facilities	
Better provision of equipment at schools – wheelchairs, ramps	
Income supplement to low income families	
Better transport facilities for people needing to use wheelchairs	
Schools having a more positive attitude to accepting students which require additional facilities due to their illness	
Quality medical care	

Other Comments:____

____

22. **The following items were identified by teachers as ways they can help to improve the Quality of Life of the adolescent with a chronic illness. Please number each item in order of importance with 1 representing the most important and 8 the least important. Remember to only use each number (1-8) once.**

Ways Teacher can Improve the Quality of Life of the Adolescent with a Chronic Illness	**Your Rank**
Help the adolescent acquire skills which will allow greater independence	
Help improve self-esteem by providing information about the choices the adolescent can make in their life	
Encourage other students to assist the adolescent with a chronic illness	
Schools should have a written policy for disabled and chronically ill students	
Tailoring the workload of the student to meet the limitations of his/her illness	
Acknowledge the skills the chronically ill adolescent has	
Have recent information (symptoms, treatment and medications) about the illness of an adolescent with a chronic illness in your class	
Educate peers so that positive attitudes are encouraged towards the adolescent with a chronic illness	

Other Comments:____

____

THANK YOU FOR YOUR PATIENCE
AND COOPERATION

Appendix H

curtin
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A Health Professional's Perceptions of the Quality of Life of an Adolescent with a Chronic Illness

What does Quality of Life Mean?

O.K let me try and explain....

Contact Details
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Office Use Only
Case No. _____

The Quality of Life for the Adolescent with a Chronic Illness
Questionnaire Number 3
Health Professional's Perspective

This is the **FINAL QUESTIONNAIRE** in a series of three, which aim to identify Health Professional's (as a group/panel) **PERCEPTIONS** of the **Quality of Life for the Adolescent with a Chronic Condition.**

This questionnaire has two main purposes:

1. To show you how the **Panel of Health Professionals** (as a group) **RANKED** the various items relating to aspects of Quality of Life which was presented to you in the previous (second) questionnaire. These rankings are based on the statistical average of the ranks for each item. This is how we were able to achieve consensus of the Panel (group).
2. To offer you the opportunity to think about the rankings of the **Panel** as a group and decide if you **AGREE** or **DISAGREE** with these rankings. If you disagree with the rankings then you have this last opportunity to reorder the items according to your personal preference, if desired.

YOUR CONTINUED PARTICIPATION WILL BE SINCERELY APPRECIATED!

Please return the completed questionnaire by Monday, November 22, 1999

Each question is divided into two **parts- A and B.**

Part A: There are three columns. The first column is called **Panel Rank** and this column shows how the panel/group ranked different aspects of quality of life for the adolescent with a chronic illness based on the responses from the second questionnaire. **Number 1** is the item the panel felt was the most important; item **number 2** was the second most important, item **number 3** is the third most important and so on.

The second column called **Your Previous Rank** is how you, as an individual ranked each item from the second questionnaire. This is just to remind how you ranked each item compared to the Panel (group).

The third column called **Your New Rank** is **only to be used** if you don't **agree** with the panel/group rank.

Part B asks if you **agree** or **disagree** with the rankings of the panel as a group. Please circle the response, which best describes how you feel. If you **disagree** or **strongly disagree** with the rankings of the group please go back to **Part A** and **reorder** the rankings in the box labeled **YOUR NEW RANK.** If you **agree** with the rankings then please proceed to the next question. Circle **Neutral** if you don't agree or disagree with the rankings.

1.(A). The following items were found to be <u>extremely important</u> to the Quality of Life for the adolescent with a chronic illness. This is how the panel ranked the items in order of importance (1-5).

Extremely Important	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Adolescent's Attitude towards their illness	1		
Severity of the illness	2		
Family Relationships	3		
Physical Health	4.5		
Friendships with the same age group	4.5		

1.(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 1A only if you disagree or st disagree.

2(A) **This is how the panel RANKED the items relating to aspects of <u>family relationships</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-8).**

Family Relationships	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Provide long term emotional and physical support	1		
Supportive family can help the adolescent cope with the illness	2		
Provide the adolescent with a relatively "normal" life	3		
Provide love especially when the adolescent is ill	4		
Provide security	5		
Supportive family can help to attain optimal health	6		
Help maintain a good attitude	7		
Family often has a greater understanding of the illness	8		

2(B) **To WHAT EXTENT do you AGREE with the ABOVE order of rankings?**
(Please circle one number ONLY)

1-------------------2 -----------------3------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 2A only if you disagree or strongly disagree.

3(A) **This is how the panel RANKED the items relating to aspects of the <u>adolescent's attitude</u> towards their illness in order of importance (1-5).**

Adolescent's Attitude	**Group Rank**	**Your Previous Rank**	**Your New Rank**
A positive attitude helps the adolescent to cope with his/her illness	1		
A positive attitude will determine how the adolescent experiences life	2		
A positive attitude helps to improve the quality of life	3		
A positive attitude will help the adolescent accept the illness	4.5		
A positive attitude can help strengthen the body's immune system	4.5		

3(B) **To WHAT EXTENT do you AGREE with the ABOVE order of rankings?**
(Please circle one number ONLY)

1-------------------2 -----------------3------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 3A only if you disagree or strongly disagree.

4(A) This is how the panel RANKED the items relating to aspects of friendships with the same age group to the quality of life for the adolescent with a chronic illness in order of importance (1-5).

Friendships with the Same Age Group	**Group Rank**	**Your Previous Rank**	**Your New Rank**
The adolescent needs to feel that he/she "belongs"	1		
Helps to develop/refine their self-concept	2.5		
Friendships with the same age group are a normal adolescent developmental task	2.5		
Helps to increase independence from the family	4		
Friendships with their peers help the adolescent to learn adult behavior	5		

4(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 4A only if you disagree or strongly disagree

5(A) This is how the panel RANKED the items relating to aspects of physical health to the quality of life for the adolescent with a chronic illness in order of importance.

Poor Physical Health	**Group Rank**	**Your Previous Rank**	**Your New Rank**
May exclude the adolescent from participating in activities	1		
Could affect the development of friendships because of the inability to interact with others in usual adolescent activities	2		
May make the adolescent feel as if they are "different"	3		
Does not allow full enjoyment of life	4		
Can interfere with the adolescent achieving personal goals	5		

5(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 5A only if you disagree or strongly disagree

6(A) **This is how the panel RANKED the items relating to aspects of the severity of the chronic illness to the quality of life for the adolescent with a chronic illness in order of importance (1-5).**

Severity of the Chronic Illness	**Group Rank**	**Your Previous Rank**	**Your New Rank**
May hinder the adolescent from having a "normal" life	1		
May hinder the adolescent from participating in activities that adolescents do everyday	2.5		
May impair quality of life	2.5		
May affect the adolescent's attitude	4		
May affect any goal setting	5		

6(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1-------------------2 -----------------3------------------- 4 --------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 6A only if you disagree or strongly disagree.

7(A) **This is how the panel RANKED the items which were found to be very important to the quality of life for the adolescent with a chronic illness in order of importance (1-7).**

Very Important Items	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Being treated as a "normal" person	1		
Independence	2		
Family's attitude towards the chronic illness	3		
Making decisions about their illness and management of their own medical care	4		
Physical visibility of the illness	5		
Making plans for the future	6		
Hobbies/Interests	7		

7(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1-------------------2 -----------------3------------------- 4 --------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 7A only if you disagree or strongly disagree.

8(A) This is how the panel RANKED the items relating to aspects of being treated as a "normal person" to the quality of life for the adolescent with a chronic illness in order of importance (1-4).

Treated as a "Normal" Person	Group Rank	Your Previous Rank	Your New Rank
Help to lessen the feelings the adolescent may have of being "different"	1		
Help the adolescent to "fit in" with their peers	2		
Help the adolescent to put their illness in perspective and not become "obsessed" about it.	3		
It is damaging psychologically to self-image if family focuses on illness	4		

8(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 8A only if you disagree or strongly disagree.

9(A) This is how the panel RANKED the items relating to aspects of the family's attitude towards the adolescent's chronic illness in order of importance (1-6).

Family's Attitude	Group Rank	Your Previous Rank	Your New Rank
Can determine if the adolescent sees him/herself as an "invalid" or "normal"	1		
Can affect the adolescent's health and well-being	2		
Can determine how good their quality of life is	2		
Positive attitude of the family can be "health enhancing"	4		
Can determine how autonomous the adolescent becomes	5		
Can determine if the adolescent feels part of the family	6		

9(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 9A only if you disagree or strongly disagree

10(A) This is how the panel RANKED the items relating to aspects of making plans for the future to the quality of life for the adolescent with a chronic illness in order of importance (1-4).

Making Plans for the Future	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Provides hope that there is a future	1		
Gives the adolescent the will to achieve their goals	2		
Enables the adolescent to set goals for the future	3		
Is vital in maintaining optimal health	4		

10(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1------------------2 -----------------3------------------- 4 --------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 10A only if you disagree or strongly disagree.

11(A) This is how the panel RANKED the items relating to managing medical care and making decisions about their illness to the quality of life for the adolescent in order of importance (1-5).

Managing Medical Care and making Decisions about their Illness	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Provides a feeling of control over their illness	1		
Could reduce the fear and anxiety of their illness	2		
Provides a feeling of self-worth about their own capabilities	3		
Provides a feeling of independence	4		
Provides relevant information about their illness	5		

11(B) To WHAT EXTENT do you AGREE with the ABOVE order of ranking
(Please circle one number ONLY)

1------------------2 -----------------3------------------- 4 --------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 11A only if you disagree or strongly disagree.

12(A) This is how the panel RANKED the items relating to aspects of <u>hobbies/interests</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-5).

Hobbies/Interests	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Can provide feelings of satisfaction and accomplishment through his/her productivity	1		
Provide opportunities to achieve goals within his/her area of interest	2		
Helps the adolescent to define and discover who they are	3		
Can provide intellectual stimulation	4		
Can provide the adolescent with a distraction from his/her illness	5		

12(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1-------------------2 -----------------3------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 12A only if you disagree or strongly disagree.

13(A) This is how the panel RANKED the items relating to aspects of <u>independence</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-7).

Independence	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Provides positive feelings of self-worth	1		
Allows the adolescent to cope with life and their illness	2		
Enables the adolescent to pursue the things he/she wants to do	3		
Allows the adolescent to do as much as possible for him/herself	4		
Helps the adolescent's emotional growth	5		
Is a normal adolescent developmental task that needs to be accomplished whether the adolescent has a chronic illness or not	6		
Reduces the feelings that the adolescent may have of being a burden to the family	7		

13(B) To WHAT EXTENT do you AGREE with the ABOVE order of ranking?
(Please circle one number ONLY)

1-------------------2 -----------------3------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 13A only if you disagree or strongly disagree.

14(A) This is how the panel RANKED the items relating to aspects of physical visibility of the chronic illness to the quality of life for the adolescent in order of importance (1-5).

Physical Visibility	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Physically identifies the adolescent as "different"	1		
Can damage their self-image depending on the response of others	2		
Can reduce the self confidence of the adolescent	3		
Can reduce the independence of the adolescent	4		
May make the adolescent feel a burden to others	5		

14(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1-------------------2 -----------------3------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 14A only if you disagree or strongly disagree.

15(A) This is how the panel RANKED the items that were found to be important to the quality of life for the adolescent with a chronic illness in order of importance (1-4)

Important	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Friendships with the opposite sex	1		
Participation in school/sports activities	2		
School/academic achievements	3		
Spiritual beliefs	4		

15(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1-------------------2 -----------------3------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 15A only if you disagree or strongly disagree.

16(A) **This is how the panel RANKED the items relating to <u>friendships with the opposite sex</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-4).**

Friendships with the Opposite Sex	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Provide a feeling of "belonging" and doing the same things that other adolescents are doing	1		
Are part of normal adolescent developmental tasks that need to be accomplished by the adolescent	2		
Provide a feeling of being special to someone other than the family	3		
Help the adolescent to feel comfortable with the changes of puberty	4		

16(B) **To WHAT EXTENT do you AGREE with the ABOVE order of rankings?**
(Please circle one number ONLY)

1-------------------2 -----------------3------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 16A only if you disagree or strongly disagree.

17(A) **This is how the panel RANKED the items relating to aspects of <u>spiritual beliefs</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-4).**

Spiritual Beliefs	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Can provide the strength to endure the illness	1		
Can provide hope and comfort for the future	2		
Can help the adolescent come to terms with the illness	3		
Can provide a sense of fulfillment	4		

17(B) **To WHAT EXTENT do you AGREE with the ABOVE order of rankings?**
(Please circle one number ONLY)

1-------------------2 -----------------3------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 17A only if you disagree or strongly disagree.

18(A) This is how the panel RANKED the items relating to aspects of <u>participation in school/sports activities</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-6).

Participation in School /Sports Activities	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Helps the adolescent to feel accepted by their peers	1		
Can increase self-confidence	2		
Can affect social acceptance by their peers if they cannot participate in school/sport activities	3		
Helps the adolescent to be active physically	4		
Provides the opportunity to mix and compete with their own age group on equal terms	5		
Can have a negative effect on the adolescent if unable to participate in school/sport activities	6		

18(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1------------------2 ----------------3------------------ 4 -------------------- 5

Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 18A only if you disagree or strongly disagree.

19(A) This is how the panel RANKED the items relating to aspects of <u>school and academic achievements</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-5).

School and Academic Achievements	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Provides a sense of self-worth through his/her accomplishments	1		
Help the adolescent to not feel "different" from their classmates	2		
Can help the adolescent to acquire a feeling of independence through his/her accomplishments	3		
Can be pursued in spite of the chronic illness by the adolescent	4		
Can help the adolescent prepare for a career	5		

19(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1------------------2 ----------------3------------------ 4 -------------------- 5

Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 19A only if you disagree or strongly disagree.

20(A) This is how the panel RANKED aspects which they felt to be important in defining what Quality of Life means to them in order of importance (1-9).

Quality of Life means….	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Good physical health	1		
Meaningful relationships	2		
Good mental health	3		
Maintain a standard of lifestyle chosen by oneself	4.5		
The ability to do what you want to do without physical, mental and social impairment	4.5		
Having personal and professional goals and being able to attain these goals	6		
To live life with dignity	7		
Independence	8		
Appreciate and participate in life's pleasures	9		

20(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 20A only if you disagree or strongly disagree.

21(A) This is how the panel RANKED the items relating to reasons for a poorer <u>quality of life</u> for the adolescent with a chronic illness in order of importance (1-5).

Reasons for a Poorer Rating for the Quality of Life for the Adolescent with a Chronic Illness	**Group Rank**	**Your Previous Rank**	**Your New Rank**
The adolescent with a chronic illness has greater obstacles to overcome which are added to their normal developmental tasks	1		
The adolescent with a chronic illness may have to try harder and longer to achieve the same outcomes as an adolescent without a chronic illness	2		
Chronic illness can be debilitating and will not allow enjoyment of life to the fullest	3		
The adolescent with a chronic illness may have physical limitations	4.5		
The adolescent with a chronic illness may have emotional limitations	4.5		

21(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1-------------------2 -----------------3------------------- 4 -------------------- 5

Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 21A only if you disagree or strongly disagree.

22(A) This is how the panel RANKED <u>additional items</u> not mentioned in the first questionnaire which they felt were important to the quality of life for the adolescent with a chronic illness in order of importance (1-4).

Other Important Aspects of Quality of Life	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Discharge as soon as possible after hospitalization with good home support	1		
The environment around them	2		
Financial assistance to the family	3		
Better government policies	4		

22(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1-------------------2 -----------------3------------------- 4 -------------------- 5

Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 22A only if you disagree or strongly disagree.

23(A) This is how the panel RANKED ways they could help improve the quality of life for the adolescent with a chronic illness in order of importance (1-8).

Ways that Health Professionals can Improve the Quality of Life for the Adolescent with a Chronic Illness	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Provide support and encouragement to the adolescent and the family so they can achieve a good quality of life	1		
Treat them as you would any other adolescent so they do not feel different from other "healthy" adolescents	2		
Understand the illness of the adolescent and how it affects them	3		
Help the adolescent to take responsibility for the illness and management of their care	4		
In-depth knowledge of resources for the adolescent and their family	5		
Educate the adolescent about the importance of their medications	6		
Allow time for individual assessment in clinical settings	7		
Setting reasonable goals for the adolescent	8		

23(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 23A only if you disagree or strongly disagree.

THE END

THANK YOU FOR YOUR PATIENCE AND COOPERATION

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A Teacher's Perceptions of the Quality of Life of an Adolescent with a Chronic Illness

What does Quality of Life Mean?

O.K let me try and explain....

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Office Use Only
Case No. 2

The Quality of Life for the Adolescent with a Chronic Illness
Questionnaire Number 3
Teacher's Perspective

This is the **FINAL QUESTIONNAIRE** in a series of three, which aim to identify teacher's (as a group/panel) **PERCEPTIONS** of the **Quality of Life for the Adolescent with a Chronic Condition.**

Findings shown in this questionnaire are based on the statistical average **RANKINGS** for each item which you ranked in order of importance from the second questionnaire.

This questionnaire has two main purposes:

1. To show you how the Panel of Teachers (as a group) **RANKED** the various items relating to aspects of Quality of Life which was presented to you in the previous questionnaire.
2. To offer you the opportunity to **AGREE** or **DISAGREE** with these rankings and to reorder the items according to your personal preference, if desired.

YOUR CONTINUED PARTICIPATION WILL BE SINCERELY APPRECIATED!

Please return the completed questionnaire by

Each question is divided into two **parts- A and B**.

Part A of each question will show how the group/panel ranked different aspects of quality of life for the adolescent with a chronic illness based on the responses from the second questionnaire. This information is provided in column one labelled **Group Rank. Number 1** is the item the panel felt was the most important; item **number 2** was the second most important, item **number 3** is the third most important and so on. The second column entitled **Your Previous Rank** is to remind you how you ranked the items in the second questionnaire.

Part B asks if you **agree** or **disagree** or feel **neutral** towards the rankings of the panel/group . Please circle the response, which best describes how you feel. If you **disagree** or **strongly disagree** with the rankings of the group please go back to **Part A** and **reorder** the rankings in the column labeled **Your New Rank**. If you agree with the rankings then please proceed to the next question.

1.(A). The following items were found to be <u>extremely important</u> to the Quality of Life for the Adolescent with a chronic illness. This is how the panel the ranked the items in order of importance (1-6).

Extremely Important	Group Rank	Your Previous Rank	Your New Rank
Attitude of the Adolescent with a Chronic Illness	1		
Attitude of the Family towards the Adolescent with a Chronic Illness	2		
Family relationships	3		
Being treated as a "normal" person	4		
Making Plans for the future	5		
Relationships with the same age group	6		

1.(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 1A only if you disagree or strongly disagree.

2(A) This is how the panel RANKED the items relating to aspects of <u>family relationships</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-6).

Family Relationships	Group Rank	Your Previous Rank	Your New Rank
Provide critical emotional support	1		
Stable influence in the adolescent's life	2		
Family relations effect the development of the adolescent as an individual	3		
Provide critical physical support	4		
Family provides the additional care the adolescent may need due to the chronic illness	5		
Family can effect the choices the adolescent with a chronic illness makes	6		

2(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1--------------------------- 2 --------------------3---------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 2A only if you disagree or strongly disagree.

3(A) This is how the panel RANKED the items relating to aspects of <u>making plans for the future</u> to the quality of life for the adolescent with a chronic illness on order of importance (1-5).

Making Plans for the Future	Group Rank	Your Previous Rank	Your New Rank
Goal setting is important	1		
Provides motivation for their dreams, goals and a future	2		
Making plans involves hope and not dwelling on the limitations of the illness	3		
Gives the adolescent control over their destiny	4		
Important to plan in order to teach appropriate goals	5		

3(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1--------------------------- 2 --------------------3---------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 3A only if you disagree or strongly disagree.

4(A) This is how the panel RANKED the items relating to aspects of the <u>adolescent's attitude</u> towards their illness in order of importance (1-4).

Adolescent's Attitude	Group Rank	Your Previous Rank	Your New Rank
A positive attitude will assist the adolescent to cope on a daily basis to the best of their abilities	1		
The adolescent's attitude effects behavior	2		
A positive attitude can influence their health	3		
A positive attitude can help the adolescent find meaning in health	4		

4(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1--------------------------- 2 --------------------3---------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 4A only if you disagree or strongly disagree.

5(A) This is how the panel RANKED the items relating to aspects of the <u>family's attitude</u> towards the adolescent chronic illness in order of importance (1-4).

Family's Attitude	Group Rank	Your Previous Rank	Your New Rank
Affects how the young person feels about themselves	1		
Helps encourage a positive attitude in the adolescent	2		
Can influence quality of life	3		
Affects how independent the adolescent becomes	4		

5(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1--------------------------- 2 --------------------3---------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 5A only if you disagree or strongly disagree

6(A) This is how the panel RANKED the items relating to aspects of being treated as a <u>"normal person"</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-4).

Treated as a "Normal" Person	Group Rank	Your Previous Rank	Your New Rank
Being seen as "different" can cause a poor self-image	1		
The adolescent does not want to be seen or treated as "different"	2		
Being seen as "different" can be a constant reminder of the chronic illness	3		
Being seen as "different" can cause stress for the adolescent	4		

6(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1--------------------------- 2 --------------------3---------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 6A only if you disagree or strongly disagree.

7(A) This is how the panel RANKED the items relating to aspects of <u>relationships with the same age group</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-3).

Relationship with Adolescent their own Age	Group Rank	Your Previous Rank	Your New Rank
Help the adolescent to feel "normal"	1		
Friendships with own age group provides someone the adolescent can talk and relate to	2		
Bonds of friendship can help overcome difficulties of having a chronic illness	3		

7(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1--------------------------- 2 --------------------3---------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 7A only if you disagree or strongly disagree

8(A) This is how the panel RANKED the items which were found to <u>very important</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-7).

Very Important Items	Group Rank	Your Previous Rank	Your New Rank
Physical health	1		
Severity of the chronic illness	2		
Independence	3		
Managing their own medical care and making decisions about their illness	4		
Hobbies/interests	5		
Friendships with the opposite sex	6		
Spiritual beliefs	7		

8(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 8A only if you disagree or strongly disagree.

9(A) This is how the panel RANKED the items relating to aspects of <u>physical health</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-6).

Physical Health	Group Rank	Your Previous Rank	Your New Rank
Can effect self-esteem	1		
Can effect emotional health	2		
Can inhibit feeling part of the group	3		
Can effect the attitude of the adolescent	4		
Can limit independence	5		
Poor physical health can limit work and leisure activities/opportunities	6		

9(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 9A only if you disagree or strongly disagree

10(A) This is how the panel RANKED the items relating to <u>friendships with the opposite sex</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-4).

Friendships with the Opposite Sex	Group Rank	Your Previous Rank	Your New Rank
Are part of normal adolescent development	1		
Help to develop a normal and healthy attitude to the opposite sex	2		
Help to boost the morale of the adolescent	3		
The opposite sex can give a different perspective on life	4		

10(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1-------------------------- 2 --------------------3---------------------4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 10A only if you disagree or strongly disagree.

11(A) This is how the panel RANKED the items relating to <u>managing medical care and making decisions about their illness</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-6).

Managing Medical Care and making Decisions about their Illness	Group Rank	Your Previous Rank	Your New Rank
Helps the adolescent to feel control over their life	1		
Helps the adolescent understand the importance of their medical care and adhering to their treatment	2		
Makes them responsible for their health- for example being aware of risks	3		
Helps develop self-confidence and a positive self-esteem	4		
Helps to alleviate feelings of being scared of their illness by being fully informed	5		
Helps develop independence in the adolescent	6		

11(B) To WHAT EXTENT do you AGREE with the ABOVE order of ranking (Please circle one number ONLY)

1-------------------------- 2 --------------------3---------------------4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 11A only if you disagree or strongly disagree.

12(A) **This is how the panel RANKED the items relating to aspects of the <u>severity of the chronic illness</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-6).**

Severity of the Chronic Illness May	Group Rank	Your Previous Rank	Your New Rank
Limit the independence of the adolescent	1		
Limit self-confidence	2		
Have a negative affect on personality	3		
Limit enjoyment of activities	4		
Limit ability to participate in sport/leisure activities	5		
Limit type of work pursued	6		

12(B) **To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)**

1--------------------------- 2 --------------------3---------------------- 4 -------------------- 5

Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 12A only if you disagree or strongly disagree.

13(A) **This is how the panel RANKED the items relating to aspects of <u>spiritual beliefs</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-5).**

Spiritual Beliefs	Group Rank	Your Previous Rank	Your New Rank
Provide hope and encouragement to keep going	1		
Provide a way to help cope with their illness	2		
Help to find "peace"	3		
Help to make sense of the illness and put it into perspective	4		
Help to overcome obstacles	5		

13(B) **To WHAT EXTENT do you AGREE with the ABOVE order of rankings. (Please circle one number ONLY)**

1--------------------------- 2 --------------------3---------------------- 4 -------------------- 5

Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 13A only if you disagree or strongly disagree.

14(A) This is how the panel RANKED the items relating to aspects of <u>hobbies/interests</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-6).

Hobbies/Interests	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Provide opportunity to socialize and extend friendship base	1		
Provide feelings of self-worth by learning additional skills	2		
Provides opportunity for involvement in activities which are not limited by their illness	3		
Provide an outside interest apart from school	4		
Provide distraction from illness	5		
Provide opportunity for a role-model for the adolescent to "look up to"	6		

14(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 14A only if you disagree or strongly disagree.

15(A) This is how the panel RANKED the items relating to aspects of <u>independence</u> to the quality of life for the adolescent with a chronic illness in order of importance(1-7).

Independence	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Increases a positive self-image	1		
Helps increase a positive attitude	2		
Allows the adolescent to do things for his/herself	3		
Helps the adolescent to cope better in life	4		
Is a normal developmental task that needs to be mastered	5		
Can decrease dependence on the family	6		
Helps the adolescent plan for the future	7		

15(B) To WHAT EXTENT do you AGREE with the ABOVE order of ranking? (Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 15A only if you disagree or strongly disagree.

16(A) This is how the panel RANKED the items that were found to be <u>important</u> to the quality of life for the adolescent with a chronic illness in order of importance.

Important	Group Rank	Your Previous Rank	Your New Rank
Participation in sports/school activities	1		
Physical visibility of the illness	2		
School and academic achievements	3		

16(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 16A only if you disagree or strongly disagree.

17(A) This is how the panel RANKED the items relating to aspects of <u>physical visibility</u> of the chronic illness to the quality of life for the adolescent in order of importance (1-3).

Physical Visibility	Group Rank	Your Previous Rank	Your New Rank
People tend to make judgments based on what they see- physical visibility can be seen to impose limitation	1		
Visibility of the illness sets them apart from their peers and they are seen as different	2		
An "invisible" illness is often overlooked- "there is nothing wrong with them"	3		

17(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 17A only if you disagree or strongly disagree.

18(A) This is how the panel RANKED the items relating to aspects of <u>school/ sports activities</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-7).

Participation in School /Sports Activities	Group Rank	Your Previous Rank	Your New Rank
Help the adolescent to "fit in" with peers	1		
Help to create opportunities to socialize with peers	2		
Help provide a positive self-image	3		
Help the adolescent to feel needed and involved	4		
Help to develop team spirit in the adolescent	5		
Provide an outlet to help them through the difficult times	6		
May help strengthen the adolescent against illness	7		

18(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1--------------------------- 2 --------------------3---------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 18A only if you disagree or strongly disagree.

19(A) This is how the panel RANKED the items relating to aspects of <u>school and academic achievements</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-4).

School and Academic Achievements	Group Rank	Your Previous Rank	Your New Rank
Provide goals for the adolescent to work towards	1		
Help to develop a positive self-esteem	2		
Help the adolescent to "fit in" with peers	3		
Help provide future employment prospects	4		

19(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1--------------------------- 2 --------------------3---------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 19A only if you disagree or strongly disagree.

20(A) This is how the panel RANKED aspects which they felt to be important in <u>defining what Quality of Life</u> means to them in order of importance(1-10).

Quality of Life means....	Group Rank	Your Previous Rank	Your New Rank
You are loved and valued as a person	1		
Good relationships with family/friends/colleagues	2		
Having a good sense of self-esteem	3		
Able to enjoy all aspects of your life both physically and mentally	4		
Good health	5		
Having control over your life	6		
Having goals in life and being able to attain them	7		
Being stimulated and challenged both mentally and physically	8		
Being able to live life to the fullest	9		
Ability to participate in activities-educational, sports, and social	10		

20(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 20A only if you disagree or strongly disagree.

21(A) This is how the panel RANKED the items relating to reasons for a <u>poorer quality of life</u> for the adolescent with a chronic illness in order of importance (1-7).

Reasons for a Poorer Rating for the Quality of Life for the Adolescent with a Chronic Illness	Group Rank	Your Previous Rank	Your New Rank
Attitude of the adolescent themselves can contribute to a lesser quality of life	1		
Attitude of the family towards the chronically ill adolescent	2		
Peer attitudes can contribute to a lesser quality of life	3		
Choices(goals/activities) are limited when a chronic illness is involved	4		
Attitude of the community towards the chronically ill adolescent	5		
Physical health can effect quality of life	6		
Independence of the adolescent may be limited	7		

21(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 21A only if you disagree or strongly disagree.

22(A) This is how the panel RANKED additional items not mentioned in the first questionnaire which they felt were <u>important to the quality of life</u> for the adolescent with a chronic illness in order of importance (1-6).

Other Important Aspects of Quality of Life	Group Rank	Your Previous Rank	Your New Rank
Better provision of services-community and respite areas	1		
Schools have a more positive attitude to accepting students which require additional facilities due to their illness	2		
Quality medical care	3		
Income supplement to low income families	4		
Better provision of equipment at schools-wheelchairs, ramps	5		
Better transport facilities for people needing to use wheelchairs	6		

22(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1--------------------------- 2 --------------------3--------------------- 4 ------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 22A only if you disagree or strongly disagree.

23(A) This is how the panel RANKED ways they could help <u>improve</u> the quality of life for the adolescent with a chronic illness in order of importance (1-8).

Ways that Teachers can Improve the Quality of Life for the Adolescent with a Chronic Illness	Group Rank	Your Previous Rank	Your New Rank
Help improve self-image by providing information about the choices the adolescent can make in their life	1		
Educate peers so that positive attitudes are encouraged towards the adolescent with a chronic illness	2		
Help the adolescent acquire skills which will allow greater independence	3		
Tailoring the workload of the student to meet the limitations of his/her illness	4		
Acknowledge the skills the chronically ill adolescent has	5		
Have recent information (symptoms, treatment, and medications) about the illness of an adolescent with a chronic illness in your class	6		
Schools should have a written policy for disabled and chronically ill students	7		
Encourage other students to assist the adolescent with a chronic illness	8		

23(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1--------------------------- 2 --------------------3--------------------- 4 ------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 23A only if you disagree or strongly disagree.

THE END

THANK YOU FOR YOUR PATIENCE
AND COOPERATION

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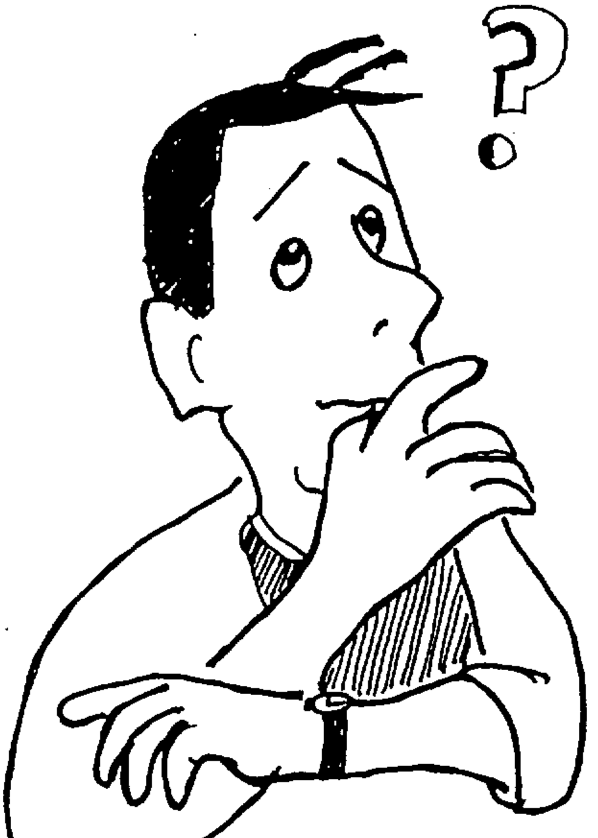
University of Technology
Western Australia

A Parent's Perceptions of the Quality of Life of an Adolescent with a Chronic Illness



What does Quality of Life Mean?

O.K let me try and explain....

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Case No.______

The Quality of Life for the Adolescent with a Chronic Illness
Questionnaire Number 3
Parent's Perspective

This is the **FINAL QUESTIONNAIRE** in a series of three, which aim to identify teacher's (as a group) **PERCEPTIONS** of the **Quality of Life for the Adolescent with a Chronic Condition.**

Findings shown in this questionnaire are based on the statistical average **RANKINGS** for each item which you ranked in order of importance from the second questionnaire.

This questionnaire has two main purposes:

1. To show you how the Panel of Teachers (as a group) **RANKED** the various items relating to aspects of Quality of Life which was presented to you in the previous questionnaire.
2. To offer you the opportunity to **AGREE** or **DISAGREE** with these rankings and to reorder the items according to your personal preference, if desired.

YOUR CONTINUED PARTICIPATION WILL BE SINCERELY APPRECIATED!

Please return the completed questionnaire by

Each question is divided into two **parts- A and B.**

Part A of each question will show how the panel ranked different aspects of quality of life for the adolescent with a chronic illness based on the responses from the second questionnaire. **Number 1** is the item the panel felt was the most important; item **number 2** was the second most important, item number 3 is the third most important and so on.

Part B asks if you **agree** or **disagree** with the rankings of the panel as a group. Please circle the response, which best describes how you feel. If you **disagree** or **strongly disagree** with the rankings of the group please go back to **Part A** and **reorder** the rankings in the box labeled **YOUR RANK.** If you agree with the rankings then please proceed to the next question.

1.(A). The following items were found to be extremely important to the Quality of Life for the Adolescent with a chronic illness. This is how the panel the ranked the items in order of importance (1-7).

Extremely Important	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Being treated as "normal"	1		
Family Relationships	2		
Physical Health	3		
The attitude of the adolescent towards their chronic illness	4		
The attitude of the family towards the adolescent with a chronic illness	5		
Friendships with their own age group	6		
Managing their own medical care and making decisions about their illness	7		

1.(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1--------------------------- 2 --------------------3---------------------- 4 ------------------- 5
Strongly Disagree   Disagree   Neutral   Agree   Strongly Agree

Please reorder the rankings in the space provided in question 1A only if you disagree or strongly disagree.

2(A) **This is how the panel RANKED the items relating to aspects of <u>family relationships</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-4).**

Family Relationships	**Group Rank**	**Your Previous Rank**	**Your New Rank**
To know that you are loved "unconditionally" by your family	1		
Positive energy from the love of the family can aid recuperation	2		
Can provide emotional support to the adolescent with a chronic illness	3		
Family can help the adolescent through the "downers" of their illness	4		

2(B) **To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 2A only if you disagree or strongly disagree.

3(A) **This is how the panel RANKED the items relating to aspects of the <u>adolescent's attitude</u> towards their illness in order of importance (1-4).**

Adolescent's Attitude	**Group Rank**	**Your Previous Rank**	**Your New Rank**
A positive attitude can help the adolescent cope with their illness	1		
A positive attitude can improve the quality of life	2		
A positive attitude can help the adolescent to live life to the fullest	3		
A positive attitude can help make recovery easier	4		

3(B) **To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 4A only if you disagree or strongly disagree.

4(A) This is how the panel RANKED the items relating to aspects of the family's attitude towards the adolescent chronic illness in order of importance (1-4).

Family's Attitude	Group Rank	Your Previous Rank	Your New Rank
A positive family attitude should provide hope, support, and encouragement to the adolescent	1		
A positive family attitude is essential to the normal development of the adolescent	2		
A positive family attitude can help in recovery of episodes of the chronic illness	3		
A positive family attitude can help the adolescent to feel part of the family	4		

4(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1-------------------------- 2 -------------------3--------------------- 4 ------------------- 5

Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 5A only if you disagree or strongly disagree

5(A) This is how the panel RANKED the items relating to aspects of physical health to the quality of life for the adolescent with a chronic illness in order of importance (1-5).

Physical Health	Group Rank	Your Previous Rank	Your New Rank
Need good health to participate in everyday life	1		
Good health will help the adolescent to deal with the pressure of their illness	2		
Poor health can damage self-esteem	3		
Need good health to enjoy life	4		
Need good health to keep pace with their peers	5		

5(B) WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1--------------------------- 2 -------------------3--------------------- 4 ------------------- 5

Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 9A only if you disagree or strongly disagree

6(A) This is how the panel RANKED the items relating to aspects of being treated as a <u>"normal person"</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-4).

Treated as a "Normal" Person	**Group Rank**	**Your Previous Rank**	**Your New Rank**
The adolescent is accepted for themselves and not their illness	1		
Encourages a feeling of "belonging" or "fitting in" with their own age group and family	2		
Can have a positive effect on their self-esteem	3		
Can have a positive effect on their illness	4		

6(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1--------------------------- 2 --------------------3---------------------- 4 -------------------- 5

Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 6A only if you disagree or strongly disagree.

7(A) This is how the panel RANKED the items relating to aspects of <u>relationships with the same age group</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-6).

Relationship with Adolescent their own Age	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Someone to share their feelings with	1		
Friends can provide support and encouragement	2		
Illness can isolate the adolescent , friends can help prevent this From happening	3		
Friends would help the adolescent to not feel "different"	4		
To be able to relate with people their own age	5		
Friends would encourage the adolescent to do more things	6		

7(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1--------------------------- 2 --------------------3---------------------- 4 -------------------- 5

Strongly Disagree Disagree Neutral Agree Strongly Agree

9(A) This is how the panel RANKED the items relating to managing medical care and making decisions about their illness to the quality of life for the adolescent with a chronic illness in order of importance (1-3).

Managing Medical Care and making Decisions about their Illness	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Allows the adolescent to take some control over their illness	1		
By making decisions themselves they will not become resentful of decisions made by the family since it is their own body	2		
Helps the adolescent to be aware of the limits imposed by their illness	3		

9(B)To WHAT EXTENT do you AGREE with the ABOVE order of ranking (Please circle one number ONLY)

1---------------------------- 2 ---------------------3----------------------- 4 -------------------- 5
Strongly Disagree   Disagree   Neutral   Agree   Strongly Agree

Please reorder the rankings in the space provided in question 11A only if you disagree or strongly disagree.

Please reorder the rankings in the space provided in question 7A only if you disagree or strongly disagree

10(A) This is how the panel RANKED the items which were found to very important to the quality of life for the adolescent with a chronic illness in order of importance (1-7).

Very Important Items	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Severity of the chronic illness	1		
Independence	2		
Physical visibility of the illness	3		
School and academic achievements	4		
Making plans for the future	5		
Participation in school/sports activities	6		
Hobbies/Interests	7		

10(B)AT EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1---------------------------- 2 ---------------------3----------------------- 4 -------------------- 5
Strongly Disagree   Disagree   Neutral   Agree   Strongly Agree

Please reorder the rankings in the space provided in question 8A only if you disagree or strongly disagree.

11(A)is is how the panel RANKED the items relating to aspects of <u>making plans for the future</u> to the quality of life for the adolescent with a chronic illness on order of importance (1-5).

Making Plans for the Future	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Provides them with a future to work towards	1		
Allows them to live as normal a life as possible	2		
Is a positive step towards recovery	3		
Helps them work towards developing a set of values in life	4		
Allows the adolescent to live life to the fullest	5		

11(A)WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 3A only if you disagree or strongly disagree.

12(A) This is how the panel RANKED the items relating to aspects of the <u>severity of the chronic illness</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-3).

Severity of the Chronic Illness May	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Would seriously effect the adolescent's quality of life	1		
The adolescent becomes totally absorbed in their illness and treatment	2		
The adolescent cannot plan for the future	3		

12(B)o WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 12A only if you disagree or strongly disagree.

13(A) This is how the panel RANKED the items relating to aspects of hobbies/interests to the quality of life for the adolescent with a chronic illness in order of importance (1-6).

Hobbies/Interests	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Can be therapeutic to the adolescent with a chronic illness	1		
Provides a sense of achievement to the adolescent	2		
Can provide an interest in life	3		
Takes the adolescent's mind off their illness	4		
Gives the adolescent something to "aim for"	5		
Provides opportunities to meet new people	6		

13(B)To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 14A only if you disagree or strongly disagree.

14(A) This is how the panel RANKED the items relating to aspects of independence to the quality of life for the adolescent with a chronic illness in order of importance(1-4).

Independence	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Can help provide a positive self-esteem	1		
Can give the adolescent confidence	2		
Independence is essential for the adolescent to manage their life	3		
Can keep the adolescent from feeling dependent on their family	4		

14(B) To WHAT EXTENT do you AGREE with the ABOVE order of ranking?
(Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 15A only if you disagree or strongly disagree.

15(A) This is how the panel RANKED the items relating to aspects of <u>physical visibility</u> of the chronic illness to the quality of life for the adolescent in order of importance (1-4).

Physical Visibility	**Group Rank**	**Your Previous Rank**	**Your New Rank**
It could add to the isolation felt by the adolescent	1		
The adolescent would be treated differently since people are often judged on first appearances	2		
It could effect their self-esteem	3		
It could effect their self-confidence	4		

15(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1--------------------------- 2 --------------------3---------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 17A only if you disagree or strongly disagree.

16(A) This is how the panel RANKED the items relating to aspects participation in school/sports activities
<u>sports activities</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-5).

Participation in School /Sports Activities	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Is important so that the adolescent does not feel "different" from other adolescents	1		
Is important for the adolescent to interact with their "peers"	2		
Activities can be very therapeutic	3		
Can provide positive energy which can help the adolescent to feel better	4		
Provides exposure to different people and activities	5		

16(B)To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1--------------------------- 2 --------------------3---------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 18A only if you disagree or strongly disagree.

17(A) This is how the panel RANKED the items relating to aspects of <u>school and academic achievements</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-5).

School and Academic Achievements	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Helps the adolescent to realize that they have a future to work towards	1		
It proves that they can achieve things	2		
Is a confidence booster	3		
Provides a sense of purpose and a goal to work towards	4		
Can provide positive energy which can help the adolescent feel better	5		

17(B) HAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1-------------------------- 2 -------------------3---------------------- 4 ------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 19A only if you disagree or strongly disagree

18(A) This is how the panel RANKED the items that were found to be <u>important</u> to the quality of life for the adolescent with a chronic illness in order of importance (1-2).

Important	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Friendships with the opposite sex	1		
Spiritual beliefs	2		

18(B)To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1-------------------------- 2 -------------------3---------------------- 4 ------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 16A only if you disagree or strongly disagree

19(A) This is how the panel RANKED the items relating to aspects of spiritual beliefs to the quality of life for the adolescent with a chronic illness in order of importance (1-5).

Spiritual Beliefs	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Can provide inner strength to the adolescent	1		
Can have a calming influence on the adolescent	2		
Faith provides hope for a brighter tomorrow	3		
Faith can aid in the recovery process	4		
Can provide a sense of stability to the adolescent	5		

19(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings. (Please circle one number ONLY)

1--------------------------- 2 -------------------3--------------------- 4 ------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 13A only if you disagree or strongly disagree.

20(A) This is how the panel RANKED aspects which they felt to be important in defining what Quality of Life means to them in order of importance(1-13).

Quality of Life means....	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Good health			
Having a loving and caring family			
Lead a full and happy life			
Consistent state of well-being in all areas of life – physical, mental, and emotional			
Satisfaction with your life			
Self-confidence			
Personal independence			
A pain free life			
Able to do the things you want to do			
Enjoying what you are doing with your life			
Enjoyable occupation			
Belief in God and that God has everything under control			
A good standard of living			

20(B) T EXTENT do you AGREE with the ABOVE order of rankings? (Please circle one number ONLY)

1--------------------------- 2 -------------------3--------------------- 4 ------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 20A only if you disagree or strongly disagree.

21(A) This is how the panel RANKED the items relating to reasons for a poorer quality of life for the adolescent with a chronic illness in order of importance (1-2).

Reasons for a Poorer Rating for the Quality of Life for the Adolescent with a Chronic Illness	**Group Rank**	**Your Previous Rank**	**Your New Rank**
They may not be able to do things that a healthy adolescent can do	1		
A poor attitude due to the chronic illness can effect their quality of life	2		

21(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1--------------------------- 2 -------------------3---------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 21A only if you disagree or strongly disagree.

22(A) This is how the panel RANKED additional items not mentioned in the first questionnaire which they felt were important to the quality of life for the adolescent with a chronic illness in order of importance (1-9).

Other Important Aspects of Quality of Life	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Lots of love	1		
Support and encouragement	2		
Keeping home life as normal as possible	3		
Making them realize that they are important individuals in society	4		
Being there when the adolescent needs them	5		
Positive attitude towards the adolescent and the illness	6		
By learning as much as possible about the illness	7		
Encouraging independence	8		
Keeping them informed of all aspects of their illness and treatment	9		

22(B) To WHAT EXTENT do you AGREE with the ABOVE order of rankings?
(Please circle one number ONLY)

1--------------------------- 2 -------------------3---------------------- 4 -------------------- 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

Please reorder the rankings in the space provided in question 22A only if you disagree or strongly disagree.

23(A) **This is how the panel RANKED ways they could help improve the quality of life for the adolescent with a chronic illness in order of importance (1-8).**

Ways that Teachers can Improve the Quality of Life for the Adolescent with a Chronic Illness	**Group Rank**	**Your Previous Rank**	**Your New Rank**
Help improve self-image by providing information about the choices the adolescent can make in their life	1		
Educate peers so that positive attitudes are encouraged towards the adolescent with a chronic illness	2		
Help the adolescent acquire skills which will allow greater independence	3		
Tailoring the workload of the student to meet the limitations of his/her illness	4		
Acknowledge the skills the chronically ill adolescent has	5		
Have recent information (symptoms, treatment, and medications) about the illness of an adolescent with a chronic illness in your class	6		
Schools should have a written policy for disabled and chronically ill students	7		
Encourage other students to assist the adolescent with a chronic illness	8		

23(B) **To WHAT EXTENT do you AGREE with the ABOVE order of rankings?**
(Please circle one number ONLY)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please reorder the rankings in the space provided in question 23A only if you disagree or strongly disagree.

THE END

THANK YOU FOR YOUR PATIENCE
AND COOPERATION

Appendix I

School of Public Health

curtin
University of Technology
Western Australia

GPO Box U 1987
Perth 6845
Western Australia
Fax (08) 9266 2958

Telephone
(08) 9266 7927

Dear Healthcare Professional,

I am writing to invite you to participate in a research project, which is looking at the quality of life of the adolescent with a chronic illness and comparing it to the quality of life of a healthy adolescent. The study is also interested in the perceptions that parents, teachers and health care professional have of the adolescent with a chronic illness. This research is being conducted as a PhD degree project in the School of Public Health, Curtin University of Technology. Permission to seek your assistance with this project has been obtained from the ethics committee at Curtin University.

To obtain a HEALTHCARE PROFESSIONAL'S perspective a sample of nurses, occupational therapists, physiotherapists and physicians from different areas in Perth are invited to form a panel that is capable of giving expert or informed opinion on this topic. You, as one of these individuals are considered well placed to offer a rich source of practical and expertise information.

Your participation in this project would involve completing three thirty minute Delphi questionnaires, over a period of five to six months which will be sent to your home. The Delphi Method allows panelists to remain anonymous, yet communicate with each other on questionnaire items, by viewing summarized reports of the first and subsequent questionnaires BEFORE being asked to complete further questionnaires. This method facilitates information sharing and provides the opportunity to modify opinions on questionnaire items, if desired.

It must be emphasized that any INFORMATION obtained will be kept strictly confidential and no individual person will be identified in any of the feedback reports or other results. Your participation is entirely VOLUNTARY and you may WITHDRAW at any time should you wish to do so.

Your assistance with this study would be very much appreciated. Participation also offers you a unique opportunity to collaborate with other healthcare professionals in making an important contribution towards the study of the adolescent with a chronic illness.

If you agree to participate please sign the attached consent form and the first questionnaire will be sent to your home.

Thank you in anticipation of your help

Yours Sincerely,

Lynn Meuleners

Lynn Meuleners,
B.A (Sociology),Diploma Nursing,Master of Science (Nursing),PhD Candidate- Public Health.

School of Public Health

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Western Australia

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Perth 6845
Western Australia
Fax (08) 9266 2958

Dear Teacher,

I am writing to invite you to participate in a research project, which is looking at the quality of life of the adolescent with a chronic illness and comparing it to the quality of life of a healthy adolescent. The study is also interested in the perceptions that parents, teachers and health care professional have of the adolescent with a chronic illness. This research is being conducted as a PhD degree project in the School of Public Health, Curtin University of Technology. Permission to seek your assistance with this project has been obtained from the ethics committee at Curtin University.

To obtain a teachers's perspective a sample of teachers from different areas in Perth are invited to form a panel that is capable of giving expert or informed opinion on this topic. You, as one of these individuals are considered well placed to offer a rich source of practical and expertise information.

Your participation in this project would involve completing three thirty minute Delphi questionnaires, over a period of five to six months which will be sent to your home. The Delphi Method allows panelists to remain anonymous, yet communicate with each other on questionnaire items, by viewing summarized reports of the first and subsequent questionnaires BEFORE being asked to complete further questionnaires. This method facilitates information sharing and provides the opportunity to modify opinions on questionnaire items, if desired.

It must be emphasized that any INFORMATION obtained will be kept strictly confidential and no individual person will be identified in any of the feedback reports or other results. Your participation is entirely VOLUNTARY and you may WITHDRAW at any time should you wish to do so.

Your assistance with this study would be very much appreciated. Participation also offers you a unique opportunity to collaborate with other healthcare professionals in making an important contribution towards the study of the adolescent with a chronic illness.

If you agree to participate please sign the attached consent form and the first questionnaire will be sent to your home.

Thank you in anticipation of your help

Yours Sincerely,

Lynn Meuleners,
B.A (Sociology),Diploma Nursing,Master of Science (Nursing),PhD Candidate- Public Health.

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GPO Box U 1987
Perth 6845
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Dear Parent,

I am writing to invite you to participate in a research project, which is looking at the quality of life of the adolescent with a chronic illness and comparing it to the quality of life of a healthy adolescent. The study is also interested in the perceptions that parents, teachers and health care professional have of the adolescent with a chronic illness. This research is being conducted as a PhD degree project in the School of Public Health, Curtin University of Technology. Permission to seek your assistance with this project has been obtained from the ethics committee at Curtin University.

To obtain a PARENT'S perspective a sample of parents from different areas in Perth are invited to form a panel that is capable of giving expert or informed opinion on this topic. You, as one of these individuals are considered well placed to offer a rich source of practical and expertise information.

Your participation in this project would involve completing three thirty minute Delphi questionnaires, over a period of five to six months which will be sent to your home. The Delphi Method allows panelists to remain anonymous, yet communicate with each other on questionnaire items, by viewing summarized reports of the first and subsequent questionnaires BEFORE being asked to complete further questionnaires. This method facilitates information sharing and provides the opportunity to modify opinions on questionnaire items, if desired.

It must be emphasized that any INFORMATION obtained will be kept strictly confidential and no individual person will be identified in any of the feedback reports or other results. Your participation is entirely VOLUNTARY and you may WITHDRAW at any time should you wish to do so.

Your assistance with this study would be very much appreciated. Participation also offers you a unique opportunity to collaborate with other parents, in making an important contribution towards the study of the adolescent with a chronic illness.

If you agree to participate please sign the attached consent form and the first questionnaire will be sent to your home.

Thank you in anticipation of your help

Yours Sincerely,

Lynn Meuleners

Lynn Meuleners,
B.A (Sociology),Diploma Nursing,Master of Science (Nursing),PhD Candidate- Public Health.

Appendix J

Please sign and return this sheet if you are interested in participating in this study. I will mail the first questionnaire to you within the next two weeks after all your questions regarding the study have been answered. Thank you for your interest and your support.

I, ______________________________ am interested in participating in

the study entitled "Quality of Life for Adolescents with a Chronic Condition"

Name: ______________________________

Address: ______________________________

____

Phone Number: ______________________________