

**“Assessment of health related quality of life
in HIV positive children”**

*... It took a disease we could not cure
To teach us the true meaning of healing.
It is our hope that these lessons will not be lost
As we seek to help them and their loved ones
Navigate the complex trajectory of this disease
And its changing impact on their lives...*

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University of Cape Town

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Abstract

Background

Quality of life is an important concept because it is the essence of health as defined by the WHO. Pain and other distressing symptoms affect children's quality of life. There is very little published information on pain in children with HIV infection, its prevalence or its affect on their quality of life. This study will add to a growing body of literature on health-related quality of life (HRQOL), but more specifically address these issues in a South African context of HIV/AIDS in children. Such data is currently not available.

Methods

A cross sectional descriptive study with an analytic component was performed on a convenience sample of 30 caregivers who attended the Paediatric HIV Clinic at Chris Hani Baragwanath Hospital, Johannesburg. All data was collected by a single investigator over a 4 month period. An established, multi-dimensional health related quality of life assessment tool (The PedsQL™ 4.0) designed for children, was used to measure HRQOL.

Results

Mean HRQOL scores were evaluated as well as those for physical and psychosocial health. Scores resembled those of children with other chronic diseases. Disease progression affected the scores with lower values for those children with advanced disease. Where no disclosure of HIV status occurred scores were lower for all dimensions.

The prevalence of pain in HIV-affected children was 83%. Caregivers reported 55 individual pains in 12 different regions of the body. On average each patient had 2.3 pain sites. Parents often had difficulty describing the nature of the children's pain. Moderate to severe pain was associated with decreased HRQL scores.

Discussion

This study is the first to examine pain and HRQOL in HIV-infected children in South Africa. As the nature of HIV changes to a chronic disease with the availability of antiretroviral treatment, HRQOL will become more important as a medical outcome measure. The PedsQL inventory is brief, easy to understand and takes only about 10 minutes to complete. This makes it an ideal tool for a busy clinic setting. Comprehensive, multidisciplinary health services will be required to minimize long-term illness and disability and to maximize children's potential as they move into adolescence and adulthood. The small study number lent itself to a descriptive study of exploratory nature. A follow up study which includes children's self report in their first language would be valuable.

TITLE

Assessment of health related quality of life in HIV positive children

What is the health related quality of life in children with HIV attending a paediatric HIV outpatient service at a tertiary public sector hospital in Johannesburg?

1. BACKGROUND

1.1 Introduction

Children are extremely vulnerable to HIV infection and its effect not only on their own lives, but on that of their entire families. Worldwide in 2003, 2.5 million children were living with HIV/AIDS and half a million deaths occurred in children. Sub-Saharan Africa is particularly severely affected with about 600 000 to 800 000 annual new infections in children <15 years occurring in this region. ¹ In this setting there is an overwhelming need for palliative care as it aims to improve the quality of life of a patient. ²

Quality of life is an important concept because it is the essence of health as defined by the World Health Organization (WHO), which states that health is not simply the absence of disease, but rather wellbeing in all spheres of life that include psychosocial domains. ³

This emphasis is echoed in the definition of palliative care for children as "the active total care of the child's body, mind and spirit, and also involves giving support to the family." ⁴

Assessing the quality of life of patients is not just important for research, but has important clinical implications. It has the potential to improve the quality of care by making care more patient-orientated with greater emphasis on communication and the assessment of outcomes such as treatment effects and functionality. ⁵

Pain and other distressing symptoms affect children's quality of life. In the management of HIV, especially in resource poor countries, where there is currently no cure and HIV treatments are often unavailable, interventions that maintain quality of life are vital. These often fall outside the traditional biomedical paradigm of treatment and are therefore often neglected. ⁶

The advent of new treatments such as antiretroviral treatment will not diminish the central role of quality of life. As the lives of children with HIV are prolonged quality rather than quantity of life has become increasingly important as a medical outcome measure.

Assessment of quality of life and appropriate palliative care needs to be integrated into comprehensive plans for treatment of children with HIV in order to ensure support and relief of suffering throughout their illness. ⁷

The comprehensive management of HIV infected children is the aim of the Harriet Shezi Children's Clinic at Chris Hani Baragwanath Hospital. The Hospital is a large, tertiary and secondary hospital in Soweto, Johannesburg and caters for about 3 million people living in the area. Approximately 600 children over the age of 2 years are followed up at the clinic. A multidisciplinary team manages the patients. Since 2001 antiretroviral treatment has become available through research grants although, at the time of the study the majority of patients still had no access to this treatment.

1.2 Problem statement:

How does HIV infection affect the quality of life of children in Johannesburg, South Africa?

Does pain affect children with HIV infection and does this affect quality of life? Are medical interventions successful in improving quality of life for these patients?

This study will establish local data on the prevalence of pain and quality of life scores in HIV infected children, which are currently not available. It is hoped that this data will lead to an increased awareness of these issues in aiming to improve the health of these children.

1.3. Literature review:

The assessment and improvement of a person's quality of life is the goal of palliative care. This is clearly stated in the most commonly cited definition coined by the WHO in 2002 which states that "palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." ⁴

Even though the concept of "Quality of life" plays such a pivotal role the term and its measurement has been fraught with difficulty and misunderstanding as it is not as clearly defined or as easily measured as a physiological value e.g. blood pressure. "However, the idea that the patient's perspective is as valid as that of the clinician when it comes to evaluating outcomes has a great deal of legitimacy and should certainly not be abandoned". ⁸ Because the impact of a disease cannot simply be measured by the disease status, but has to take psychosocial factors, cognitive and functional impairment into consideration, the term "health related quality of life (HRQOL)" was coined in order to study the effect that an illness has on daily life for a patient. ⁹

Quality of life is inherently multidimensional. Measuring HRQOL seeks to answer two questions: What is the objective functioning of a patient and what is that individual's subjective/perceived wellbeing? ⁹

HRQOL has become an important outcome measure in clinical research in recent years. Especially in the study of HIV/AIDS it has taken on a special significance as symptom management and psychosocial issues play such a vital role in the treatment of this disease. For the assessment of adult patients with HIV/AIDS numerous generic and disease specific measurement tools are available. Webb et al quote 8 and 9 measures respectively. ¹⁰ For children such tools are currently not available.

Measuring quality of life in children differs from adult assessments, as it has to take factors such as development into consideration. The PedsQL 4.0 Pediatric Quality of Life Inventory has been shown to be a reliable and valid measuring instrument to assess generic health related quality of life for paediatric patients with chronic conditions and can be used in a clinical setting. ¹¹ Furthermore, this tool demonstrated the ability to identify an increasing degree of morbidity, a response to clinical change and demonstrated an impact on clinical decision-making in a variety of different paediatric settings ¹².

There is very little published information on pain in children with HIV infection, its prevalence or its affect on their quality of life. Barriers to recognition and treatment of pain are considerable. Despite increasing research to the contrary, myths regarding children's pain persist. ¹³ Until recently children's nervous systems were regarded as immature and as such not capable of feeling or remembering pain as adults do. Misconceptions, such as children's inability to communicate pain or the addictive nature of opioids, have lead to misassessment and inadequate treatment of children's pain. It is now recognized that children not only feel and remember pain from before birth and that repeated pain episodes increase the magnitude of pain, but also that children's pain can be assessed, monitored and treated much like adult pain. ¹⁴

Initially work on pain in children was completed in the USA. Two important studies shed light on the pain experiences of children with HIV. ^{15&16} Estimates from these studies are that 30%-50% of HIV infected children may be experiencing pain. An increasing prevalence of pain was associated with female gender, increased immunosuppression and severity of disease. Pain was often gastrointestinal or limb pain. Pain in these children arose from a variety of sources, which included medical treatment. Importantly, pain in children adversely affected their lives..

It was also found in these studies that pain was poorly recognized and poorly treated. Even though pain was very prevalent caregivers often underestimated the children's pain. This highlights the problem of using proxy reports to assess QOL. As the assessment of HRQOL is always subjective proxy-reports have their

limitations and it has been rightfully said that the results of proxy reports must be carefully evaluated.

Parent proxy reporting has been recognized as a valid method of assessing children's quality of life if its limits are recognized.^{17&18}

Evaluating the PedsQL in paediatric cancer in a large study of 339 families of oncology patients showed that parent/child correlations were medium to high. However, neither report is redundant as both offer complementary evaluations and should be evaluated together where ever possible.¹⁹

The quality of parent proxy reporting using the PEDSQL specifically has been evaluated and it has been found that parents were moderate to good proxies of their children's HRQOL. In the setting of chronic conditions this correlation is even higher. This has been evaluated for conditions such as arthritis, irritable bowel syndrome, asthma, diabetes and cancer^{20&21}

Quality of life has been shown to impact directly on immunological status, with negative life events leading to immune suppression in children with HIV.²²

Work conducted in developing countries showed similar results. In a study of pain in children with HIV from Thailand 44% reported pain, especially those with advanced disease and, as in the USA, pain was insufficiently taken into account and treated.²³

A HRQL study conducted on children with cancer in Latin America demonstrated the feasibility of conducting such measurements in developing countries, and revealed similarities of health status and HRQOL to populations in more privileged societies.²⁴

The prevalence and duration of pain in children with HIV has been compared to that of children living with cancer.¹⁶ Interestingly, HRQOL research conducted on paediatric cancer patients suggested that both pain and emotional distress should be treated concurrently to enhance HRQOL in the long term. The same need could therefore be present in children living with HIV.¹²

This study will add to a growing body of literature on HRQOL, but more specifically address these issues in a South African context of HIV/AIDS in children. Such data is currently not available.

2. AIMS AND OBJECTIVES

2.1 Aim:

To assess the health related quality of life of HIV infected children attending a paediatric HIV outpatient service at a tertiary public sector hospital in Johannesburg.

2.2. Specific objectives:

To assess the prevalence of pain in paediatric HIV infection

To assess the effect of pain on quality of life by using a specific paediatric pain questionnaire.

To make recommendations for the use of the PedsQL assessment tool in the clinical management of children with HIV and other chronic conditions

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3. METHODOLOGY

3.1 Study design:

A cross sectional descriptive study with an analytic component was chosen for this research project. This allowed the subjective nature of the dimensions studied to be described whilst at the same time allowing statistical and numerical analysis of quality of life scores and pain scores.

3.2 Sampling:

3.2.1 Sample:

A convenience sample of a total number of 30 caregivers were interviewed. Possible study participants were chosen from those patients who had checked in for their appointment but before being seen by their health care provider.

3.2.2 Inclusion criteria:

A parent/caregiver attending the Harriet Shezi Children's clinic for a follow-up appointment of their child

Able to communicate in English

Child has been diagnosed as HIV-infected on a previous visit

Child currently not receiving antiretroviral treatment

Willingness to sign informed consent

Child age 5 -18 years

3.3 Study site:

The Paediatric HIV Clinic (Harriet Shezi Clinic) at Chris Hani Baragwanath Hospital, Johannesburg. This clinic is run by the Wits Paediatric HIV Working Group and offers an outpatient-based service for HIV infected children and their families in the Soweto area. Children receive medical care and also have access to allied health care workers such as social workers, dietician etc. The " Friday " clinic follows up those children who are HIV infected and currently not receiving antiretroviral treatment.

3.4 Data collection:

All data was collected by a single investigator, the author of the dissertation, over a 4 month period.

An established health related quality of life assessment tool specifically designed for children was used. The PedsQL™ 4.0 Measurement Model is a modular approach to measuring HRQOL in children and adolescents. These questionnaires were developed and validated by Dr. James Varni and are administered by the MAPI Research Institute.^{11&25} The questionnaires are available free of charge for non-funded academic research.

The PedsQL has been applied widely in research in a variety of settings, has been translated into many languages and has been used in 32 countries, including developing countries such as South America, India and Eastern

Europe, many of which face similar socioeconomic and health challenges as the participants in this study.²⁶

The PedsQL™ 4.0 consists of brief, practical, generic core scales suitable for use in pediatric populations with acute and chronic health conditions. PedsQL™ condition-specific modules complement the generic core scales for use in designated clinical populations.

Unfortunately, no HIV/AIDS specific questionnaire is currently available. Therefore 2 modules were chosen for the purposes of this dissertation: The PedsQL 4.0 Generic Core Scale (UK version) and the PedsQL Pediatric Pain Questionnaire.

3.4.1 PedsQL Pediatric Quality of Life Generic Core Scales:

The 23-item PedsQL™ 4.0 Generic Core Scales were designed to measure the core dimensions of health as delineated by the WHO, as well as role (school) functioning. Thus, the multidimensional PedsQL™ 4.0 Generic Core Scales encompass the essential core domains for pediatric HRQOL measurement: 1) Physical Functioning (8 items), 2) Emotional Functioning (5 items), 3) Social Functioning (5 items), and 4) School Functioning (5 items).

3.4.2 PedsQL Pediatric Pain Questionnaire:

The Paediatric Pain Questionnaire is a structured pain assessment tool to facilitate a standardized assessment of pain in children. The retrospective interview, which is conducted with the child and/or parent using a written questionnaire containing structured questions, gives a retrospective review of current and past pain.²⁷ The questionnaire chosen for this study consisted of a structured questionnaire that asked parents to recall the child's current pain experience and that in the last 7 days through various assessment tools:

- 1) Descriptions (parents are asked to note the words they would use to describe the child's pain)
- 2) Visual Analogue Scales (VAS) (parents are asked to mark a scale ranging from not hurting, no discomfort, no pain to hurting a whole lot, very uncomfortable, severe pain)
- 3) Drawings (a schematic drawing of the body is used to note the site of pain) are used to assess both current and past pain.

The PedsQL™ 4.0 Measurement Model consists of developmentally appropriate forms for children of different ages. Forms for children in 3 age categories were chosen: 5-7, 8-12, and 13-18 years.

Both self-report and parent proxy-report of child HRQOL are available. The parent proxy questionnaires were chosen because the copyright holders require a lengthy and costly linguistic validation for translation of the questionnaires. Items on the proxy- and self reports are essentially identical, differing only in developmentally appropriate language and in the first or third person tense.²¹

Most parents or caregivers are able to communicate in English, whereas most children are only able to speak their mother tongue, in most cases isiZulu. The questionnaires are written in very simple, everyday language and caregivers had no difficulty in understanding and answering questions. The investigator sat with each one of them and went through the questions slowly and offered explanations if any question was unclear. This is the recommended method for conducting the interviews and completing the questionnaires. Many caregivers enjoyed the additional opportunity the interview afforded them to discuss concerns around their child's health. Any problems encountered such were referred with the parent's permission e.g. on being questioned about disclosure one mother confided that her daughter was asking questions she felt she could not truthfully answer and was referred to the clinic's counsellor.

See Appendix A1,2,3 and Appendix B1,2,3 for examples of the questionnaires used for the different age categories.

3.5 Ethical considerations:

3.5.1 GCP:

The investigator completed training in ICH-GCP in 2002.

Children are recognized as a vulnerable group when it comes to participation in clinical trials due to their dependent nature. Any group that has decreased autonomy requires and deserves protection from exploitation. Although children can assent to participation in a study, they cannot give consent, which has to be obtained from a legal guardian. In this study all caregivers had to complete written informed consent prior to answering the questionnaire even though the questions were of such a nature as may be asked during a routine clinic visit and questioning could be stopped at any time if the parent felt uncomfortable.

The ethical guidelines of the FDA state that children should not become a commodity and that there should be a potential for children to benefit from participating in a study i.e. the principle of beneficence. In this study the increase awareness of QOL will benefit children in the future, but because problems picked up during the interview were referred appropriately each child also had an immediate benefit.²⁸

Despite these added responsibilities that makes research using children as participants more difficult, the declaration of Helsinki actively encourages it where a drug or procedure will need to be applied in a paediatric setting. QOL assessments will need to be applied to children and because of the specific nature of these assessments in children it is important to study them in this particular setting.²⁹

3.5.2 Confidentiality:

Written informed consent was obtained from each parent or caregiver prior to completing the questionnaire (patient consent and patient information sheets attached as appendix C) with assurance that they could choose not to take part or to withdraw without influencing the quality of care their child would receive. Each participant was allocated a unique study number. The identifying data (appendix D) and the patient record is linked by this number for confidentiality during analysis and presentation of the data.

3.5.3 Permission for the study:

Ethics approval for the study was obtained by the Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town (REC REF 126/2004)

Permission for conducting the research on the premises of the clinic was granted by Dr. Tammy Meyers, Paediatrician and Head, Wits Paediatric HIV Working Group and Harriet Shezi Children's Clinic, Chris Hani Baragwanath Hospital. Permission to conduct the research during working hours was granted by the researcher's employer, Dr. Gayle Sherman, Consultant Paediatric Haematologist, University of the Witwatersrand and NHLS, in her capacity as the director for CHOMP (Children's Homes Outreach Medical Programme), a project of the Wits Paediatric HIV Working Group.

3.5.4 Language barriers:

The parent proxy questionnaires were chosen because the copyright holders require a lengthy and costly linguistic validation for translation of the questionnaires. Most parents or caregivers attending this particular clinic are able to communicate in English, whereas most children are only able to speak their mother tongue, in most cases isiZulu. The questions are not of an intrusive or offensive nature, but may be questions asked during a routine visit to a clinic.

3.5.5 Funding:

Non-funded academic research

3.6 Data Analysis:

3.6.1 PedsQL Pediatric Quality of Life Inventory :

Scaling and scoring of the Pediatric Quality of Life Inventory PedsQL Version 4.0 was completed according to instructions issued by the author and the copyright holders.

The 23 items contained in the questionnaire comprise 4 dimensions. The parent proxy-report version uses a 5-point Likert scale in which parents rate how much a problem each of the items has been for their child over the past one month. (0=never a problem, 1=almost never a problem, 2=sometimes a problem, 3=often a problem, and 4 =almost always a problem).

Dimensions	Number of Items	Cluster of Items	Reversed scoring	Direction of Dimensions
Physical functioning	8	1-8	1-8	Higher scores indicate better HRQOL
Emotional functioning	5	1-5	1-5	
Social functioning	5	1-5	1-5	
School functioning	5	1-5	1-5	

3.6.1.1: Scoring of dimensions:

Item scaling	5-point Likert scale from 0 (never) to 4 (Almost always)
Weighting of items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100
Scoring Procedure	<p>Step 1: Transform score</p> <p>Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p>Step 2: Calculate scores</p> <p><u>Score by dimensions:</u></p> <ul style="list-style-type: none"> If more than 50% of the items in the scale are missing, the scale scores should not be computed Mean score= Sum of the items over the number of items answered <p><u>Psychological health Summary Score</u> = Sum of the items over the number of items answered in the Emotional, Social, and School Functioning Scales.</p> <p><u>Physical Health Summary Score</u> = Physical Functioning Scale Score</p> <p>Total score: Sum of all the items over the number of items answered on all the Scales</p>
Interpretation and Analysis of missing data	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale</p>

The PedsQL generic core scale scores were compared to results from the literature that used the same PedsQL generic core Inventory to assess HRQOL scores for children with cancer compared to a healthy age-matched group.¹⁹

3.6.2 PedsQL paediatric pain questionnaire :

The PedsQL paediatric pain questionnaire assessed pain in 3 different ways:

3.6.1 Verbal description:

The descriptions were evaluated to ascertain whether specific words were used by parents to describe their children's pain.

3.6.2 Visual Analogue Scale:

The PedsQL Pediatric Pain Questionnaire Visual analogue scales were interpreted according to guidelines for VAS pain scales. The first scale rated how much pain the child was having at the present time, the second rated the worst pain experienced in the last week. The point of the mark made by the parent on the scale was measured in cm and converted into a score with 1cm=1point. Pain was classified according to 3 categories: Mild(0-3), moderate(4-7),severe(8-10).

3.6.3 Site drawing:

All the sites indicated on the drawings were counted up and classified according to 12 regions in the body.

Patient information, answers and scores for the questionnaires were entered into a Microsoft Excel spreadsheet, which was used to generate tables for summation of the data recorded.

Statistical analysis was performed using Microsoft Excel. Simple spreadsheet calculations were used to evaluate numerical data in order to establish averages, minimum and maximum values and to compare values across the different groups.

Results were converted into graphic representations using Microsoft PowerPoint.

Because of the descriptive nature of the study and the small number of the convenience sample the study was not designed to analyze statistical significance.

4. RESULTS

30 caregivers or parents of children attending the Harriet Shezi Children's clinic were interviewed at the clinic over a 4-month period from May to August 2004.

Both a PedsQL Generic Core Scale Parent proxy report and a PedsQL Pediatric Pain Questionnaire were completed by each caregiver. For each age group an age appropriate version of the questionnaires was chosen. 15 (50%) questionnaires for a young child (age 5-7), 14 (46,7%) for a child (age 8-12) and one (3,3%) for a teenager (age13-18) were completed.

4.1 Demographic details:

The caregivers had a variety of relationships to the children. These consisted of 17 mothers (56,7%), 0 (0%) fathers, 3 (10%) grandmothers, 1 (3,3%) sibling, 9 (30%) other relatives-8 aunts and 1 cousin and no (0%) unrelated foster parents.

Data was collected for 30 children age 5 -18. The group consisted of 14 (46,7%) male and 16 (53,3%) female children. The average age was 8.23 years with the minimum and maximum ages being 5.01 and 14.03 years respectively.

4.2 Medical details:

All children had been previously diagnosed as HIV infected. On average the diagnosis of HIV was made at 4.5 years with the earliest diagnosis at one month and the latest at 11 years of age. On average the children had been attending the clinic 1,9 years at the time of the interview with the shortest period being 14 days and the longest being 7.4 years. As record keeping is very poor, some of these results were not recorded in file and were estimates by the caregiver interviewed.

Disclosure of the HIV status to the child occurred in 5 (16,7%) children. 24 (80%) children did not have any disclosure and one (3,3%) child, although never formally disclosed to, knew about her HIV status by overhearing an adult conversation.

The children had all been classified according to CDC clinical and immunological categories³⁰ (Table 1). CD4 count results were available for 29 patients. The average CD4 Lymphocyte count was 450,6 cells $\times 10^6$ ranging from 9 cells $\times 10^6$ – 1056 cells $\times 10^6$. In children measurement of CD4 % of total lymphocyte count is more useful. 18, 22% was the average CD4% with a range of 2% to 48%. None of the children were currently receiving any antiretroviral therapy and were all managed symptomatically for HIV related symptoms and the recommended prophylactic medication e.g. cotrimoxazole according to recommended guidelines.³¹

Immunological and clinical classification of study participants

Clinical category (n=30)		Immunological category (n=29)	
A	6 (20%)	Mild ($\geq 25\%$)	15 (51,7%)
B	19 (63,3%)	Moderate (15-24%)	6 (20,7%)
C	5 (16,7%)	Severe (<15%)	8 (27,6%)

Table 1

4.3 Pediatric Quality of Life Inventory:

4.3.1 Mean and Subscores:

30 caregivers completed the PedsQL Parent Proxy Generic Core Scale for 30 children. Mean, Physical Health Score and Psychological Health Score were all evaluated and subscores for emotional, social and school function were calculated (Table 2).

A wide variation of scores can be seen with maximum scores approaching the 100 or maximum score. On average the children had lower Physical Health (62.28) than Psychosocial Health scores (71.56). Graphic representations of the scores are seen in Figure 1.

When analyzing Psychosocial health Subscores (Figure 2) for the different functional components, school function had a far lower average score (64.17) than the other 2 dimensions (73.00 and 77.50). No child scored a maximum score for school functioning.

Mean Scores and Subscores of the PedsQL Generic Core Scales Parent Proxy Questionnaire in 30 HIV infected Children

PedsQL questionnaire evaluation						
Study numbers	Mean Score	Psycho-logical Health Score	Emotional score	Social Score	School Score	Physical Health Score
0001KP	73.91	68.33	75.00	90.00	40.00	84.38
0002NM	80.43	83.33	80.00	95.00	75.00	75.00
0003NF	76.09	80.00	80.00	85.00	75.00	68.75
0004TS	23.91	28.33	60.00	10.00	15.00	15.63
0005TZ	77.17	71.67	90.00	60.00	65.00	87.50
0006TG	84.78	78.33	75.00	80.00	80.00	96.88
0007TM	57.61	66.67	55.00	90.00	55.00	40.63
0008TM	50.00	53.33	55.00	40.00	65.00	43.75
0009MK	83.70	81.67	65.00	100.00	80.00	87.50
0010NT	75.00	81.67	70.00	100.00	75.00	62.50
0011TS	88.04	90.00	90.00	90.00	90.00	84.38
0012VN	70.65	71.67	85.00	90.00	40.00	68.75
0013SN	32.61	41.67	45.00	10.00	70.00	15.63
0014SM	77.17	75.00	90.00	100.00	35.00	81.25
0015WM	69.57	73.33	90.00	70.00	60.00	62.50
0016JD	81.52	83.33	75.00	90.00	85.00	78.13
0017NM	64.13	76.67	80.00	100.00	50.00	40.63
0018NN	56.52	70.00	70.00	80.00	60.00	31.25
0019MM	93.48	93.33	100.00	100.00	80.00	93.75
0020ZM	66.30	78.33	60.00	90.00	85.00	43.75
0021MD	78.26	76.67	80.00	85.00	65.00	81.25
0022KT	63.04	76.67	55.00	100.00	75.00	37.50
0023PM	57.95	75.00	80.00	70.00	75.00	21.43
0024GP	61.96	60.00	70.00	35.00	75.00	65.63
0025SD	83.70	81.67	75.00	90.00	80.00	87.50
0026SN	54.35	46.67	45.00	65.00	30.00	68.75
0027KB	64.13	75.00	75.00	80.00	70.00	43.75
0028PK	88.04	85.00	85.00	80.00	90.00	93.75
0029TG	57.61	65.00	80.00	80.00	35.00	43.75
0030SM	59.78	58.33	55.00	70.00	50.00	62.50
Average	68.38	71.56	73.00	77.50	64.17	62.28
Minimum	23.91	28.33	45.00	10.00	15.00	15.63
Maximum	93.48	93.33	100.00	100.00	90.00	96.88

Table 2

PedsQL GCS mean score, physical health score and psychological health score

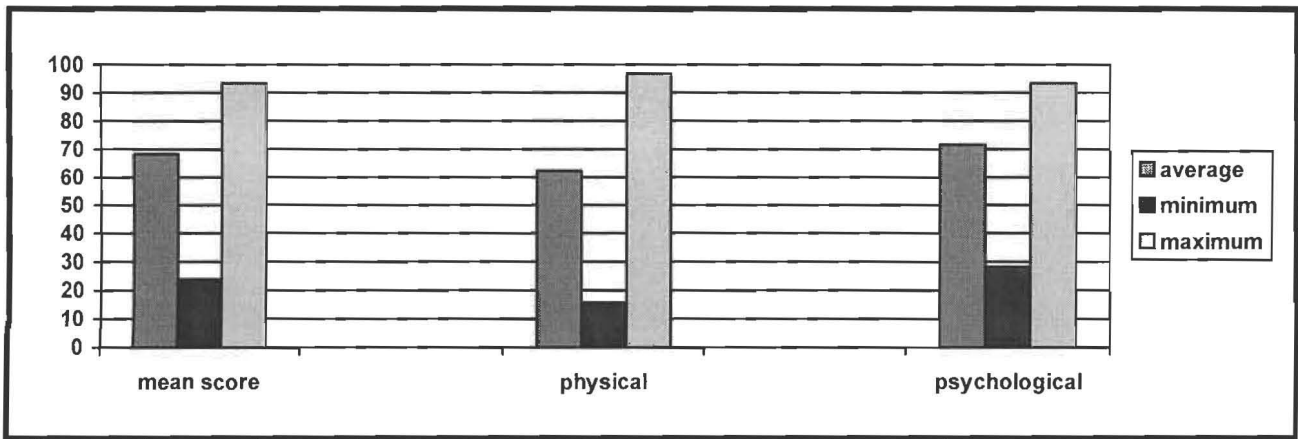


Figure 1

PedsQL GCS psychosocial health subscores

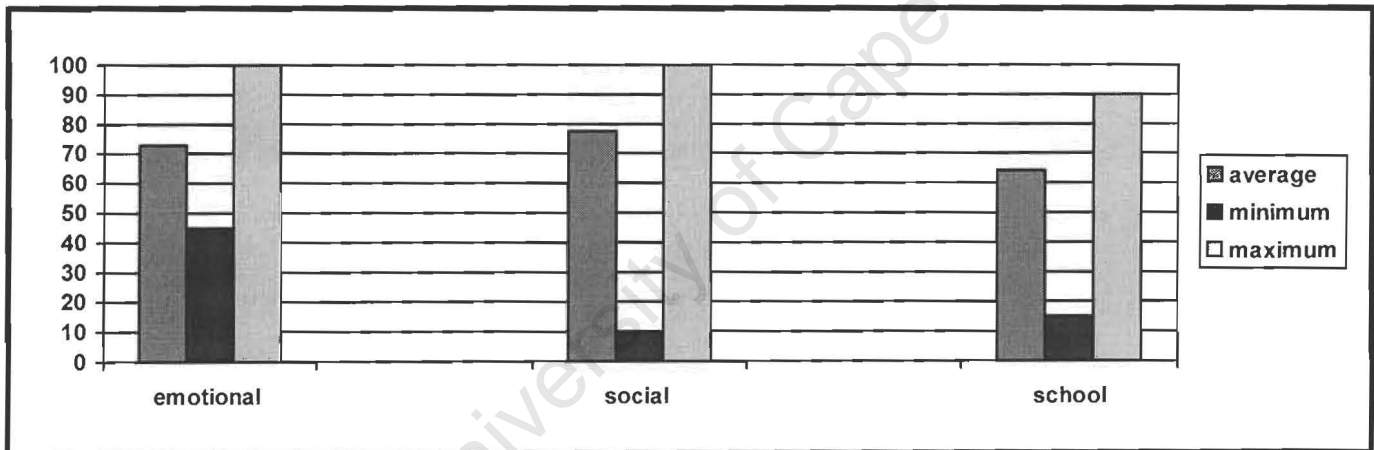


Figure 2

4.3.2 Comparison with literature

The scores for the different dimensions making up the HRQOL inventory were compared with results of cohorts from the literature. Varni et al¹⁹ used the same PedsQL generic core Inventory to assess HRQOL scores for children with cancer compared to a healthy age-matched group.

Both in terms of mean, physical and psychosocial health average scores for the HIV group (68,38/62.28/71.56) and the oncology group (69,70/68.75/70.31) fall below those of healthy children (87.61/89.32/89.58). The same pattern is seen when comparing psychosocial subscores. The score for emotional, social and school functioning for the HIV sample (73.00 /77.50/64.17) again resembled that of the oncology group (67.53/75.64/66.40) and was markedly lower than that of healthy children(82.64/91.56/85.47). Figure 3 and 4 illustrate these differences.

PedsQL GCS scores of study cohort compared to oncology and healthy group

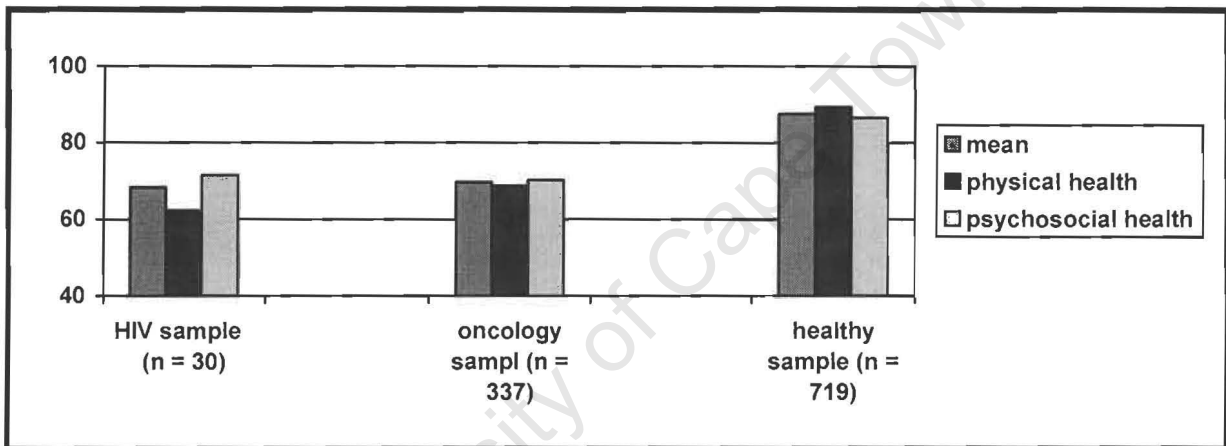


Figure 3

PedsQL GCS subscores of study cohort compared to oncology and healthy group

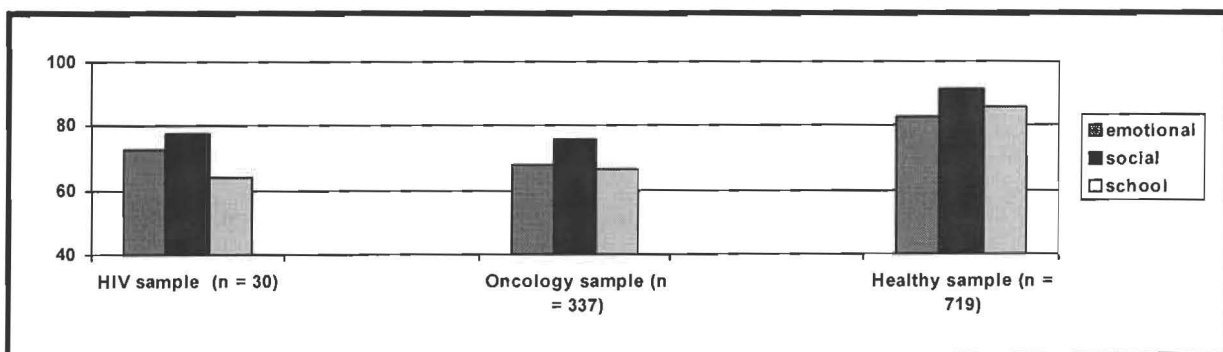


Figure 4

4.3.3 Effect of Clinical Category on PedsQL scores:

The PedsQL scores also varied according to CDC clinical category with a definite trend towards lower values for those children with worse clinical categories. This trend was not observed when looking at CD4 counts or % (Figure 5).

PedsQLscore GCS scores for CDC clinical categories

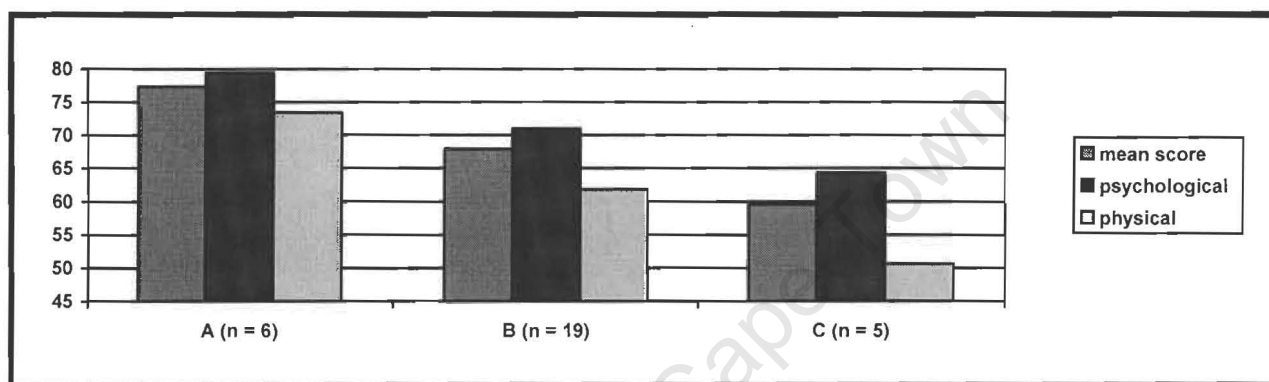


Figure 5

4.3.4 Effect of Disclosure of HIV status on PedsQL scores:

Disclosure of his or her HIV status to the child occurred in 5 (16,7%) children and these children had PedsQL scores that were higher compared to the 25 (83,3%) children who did not have any disclosure or knew about their HIV status by overhearing an adult conversation. In figure 6 average scores for mean QOL, psychosocial functioning and physical functioning are compared. Because all of the children who knew their HIV status fell into clinical category B only those children were evaluated to eliminate any bias due to different clinical categorization. Again small numbers do not allow evaluation of statistical significance, but the trend is noticeable. Where no disclosure occurred scores were lower for all 3 dimensions (64.93/67.62/59.57) and (76.09/80.33/68.13)

PEDSQL scores in children with and without disclosure of HIV status:

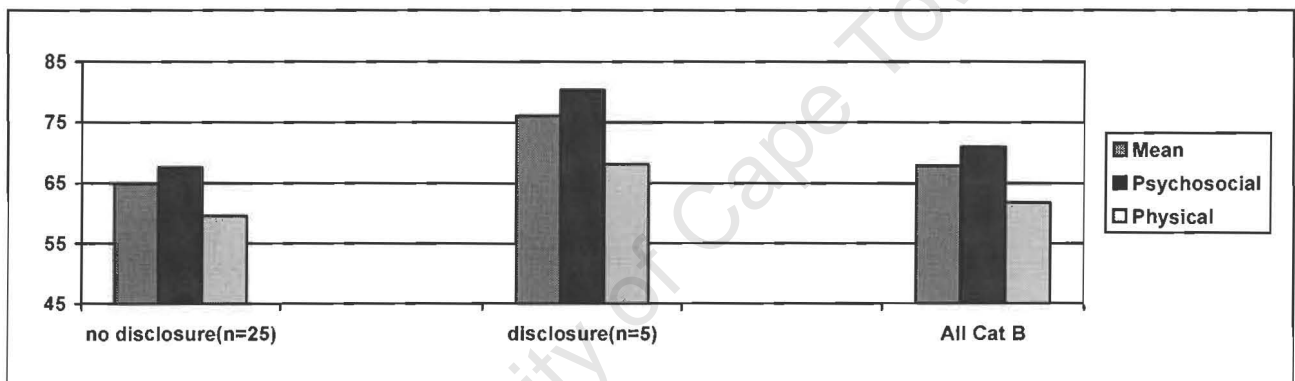


Figure 6

4.4 Pediatric Pain Questionnaire:

The PedsQL paediatric pain questionnaire assessed pain in 3 different ways: Description, VAS and site drawing

4.4.1 Verbal description:

Parents often had difficulty describing the nature of the children's pain. Usually the site of the pain was mentioned and not the nature of the pain.

Parents described the children's pain in terms of the behaviours they observed rather than verbal descriptions e.g. "rubs eyes" -0001KP, "doesn't want to cough"-0012VN, "points at pain"-0030SM. Behaviours such as feeling tired, wanting to go to sleep or crying were also mentioned by numerous patients.

In 3 instances the children were described as not complaining of pain even though the parents felt they were experiencing it. e.g. "tries to be strong" - 0013SN.

4.4.2 Visual Analogue Scale:

The VAS scale asked participants to score the child's pain at two time points, pain at the present time of the interview and the worst pain experienced in the previous week.

The prevalence of pain as reported by the children's caregivers was 83,3% for the present time and 86,6% for the previous week.

The 2 simple visual analogue scales were completed by all 30 parents as summarized in table 3.

Caregivers VAS assessments of their children's pain

	Pain at the present time	Worst pain last week
No pain	5 (16,7%)	4 (13,3%)
Mild (0-3)	15 (50%)	10 (33,3%)
Moderate (4-7)	10 (33,3%)	3 (10%)
Severe (8-10)	0 (0%)	13 (43,3%)
Average	2.86	5.96
Minimum	0.00	0.00
Maximum	7.00	10.00

Table 3

Figure 7 illustrates the differences in the perception of pain at the 2 different time points. Most patients experienced worse pain during the week than on the day of

the interview and clinic visit as only 8 patients had an unchanged or a lower score on the second VAS.

Comparison of VAS pain scores at 2 time intervals for each of 30 participants
 Current pain: pain at the present time of the interview. Past pain: worst pain experienced in the previous week.

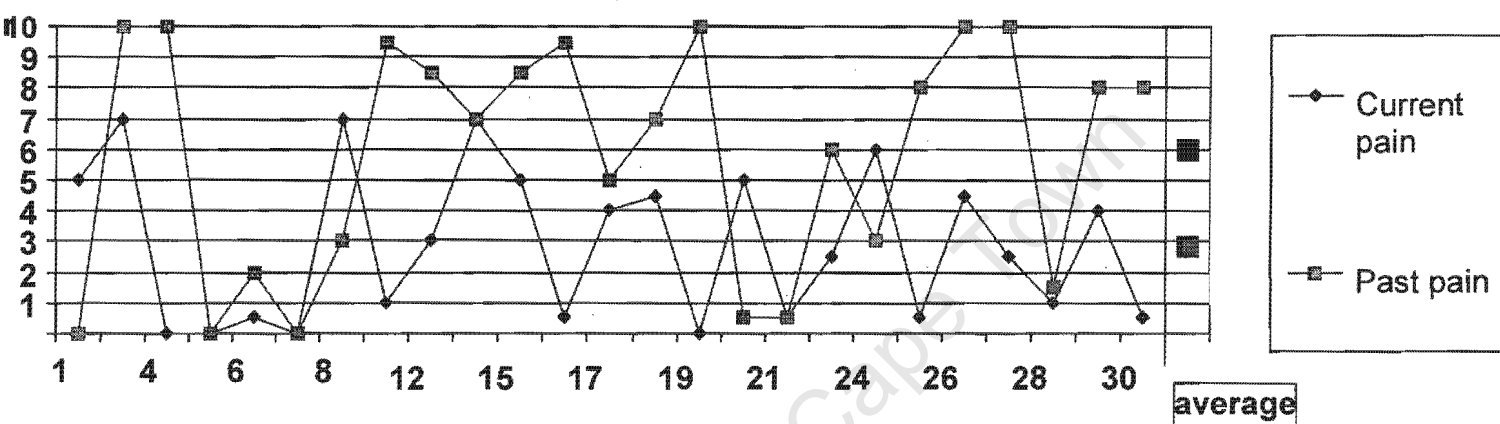


Figure 7

4.4.3. Site of pain:

29 caregivers completed the question. 5 patients were not experiencing any pain 55 individual pains were described in 12 different regions of the body. On average each patient had a 2.3 pain sites with a minimum of one site in 11 patients and a maximum of 6 sites in 2 patients (Table 4).

Sites of pain described by study cohort

Number of pain sites	Number of patients (n=24)
1	11(45,8%)
2	6 (25,0%)
3	1(4,2%)
4	3 (12,5%)
5	1 (4,2%)
6	2 (8,3%)

Table 4

Ear-Nose-Throat (ENT) was the most common pain in 9 (16,4%) patients, closely followed by headache, chest and lower limb pain in 8 (14,5%) patients respectively. Also commonly reported were abdominal pain and upper limb pain, 7 (12,7%) and 5 (9,1%). Less common sites were retrosternal chest pain (3/ 5,5%), mouth(2/ 3,6%), back(2/ 3,6%), face/parotid pain, genital and eyes (1each /1,8%) (Figure 8).

Sites of pain of study cohort

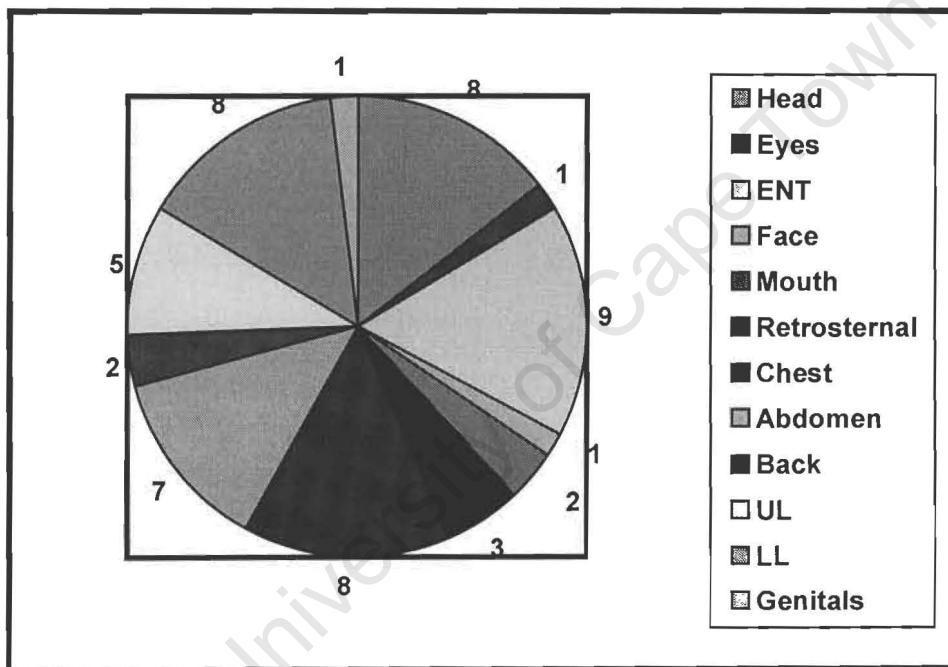


Figure 8

The severity of pain was compared to the mean, physical and psychosocial Health score on the PedsQL Generic Core scale. Moderate to severe pain was associated with decreased Life Inventory HRQL scores, especially the physical health subscore (Figure 9).

Pain scores compared to PedsQL GCS scores

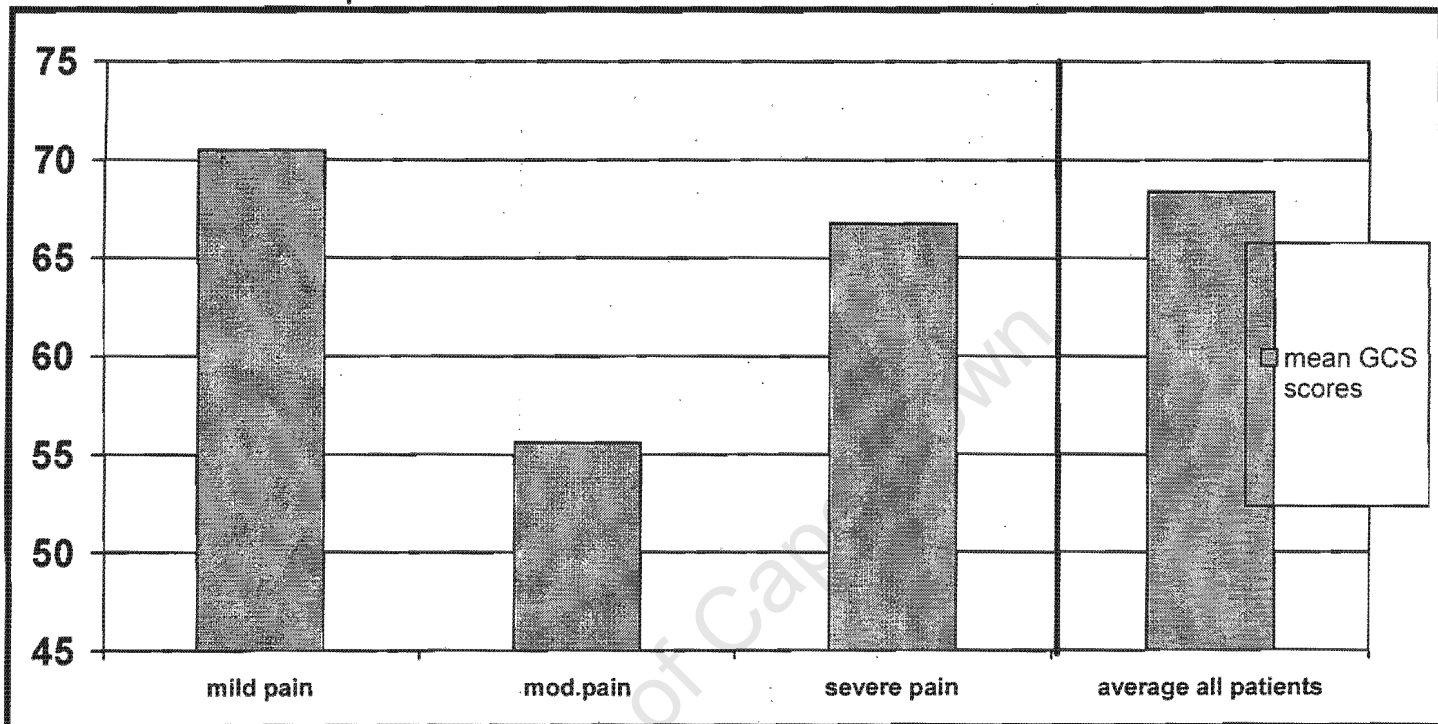


Figure 9a

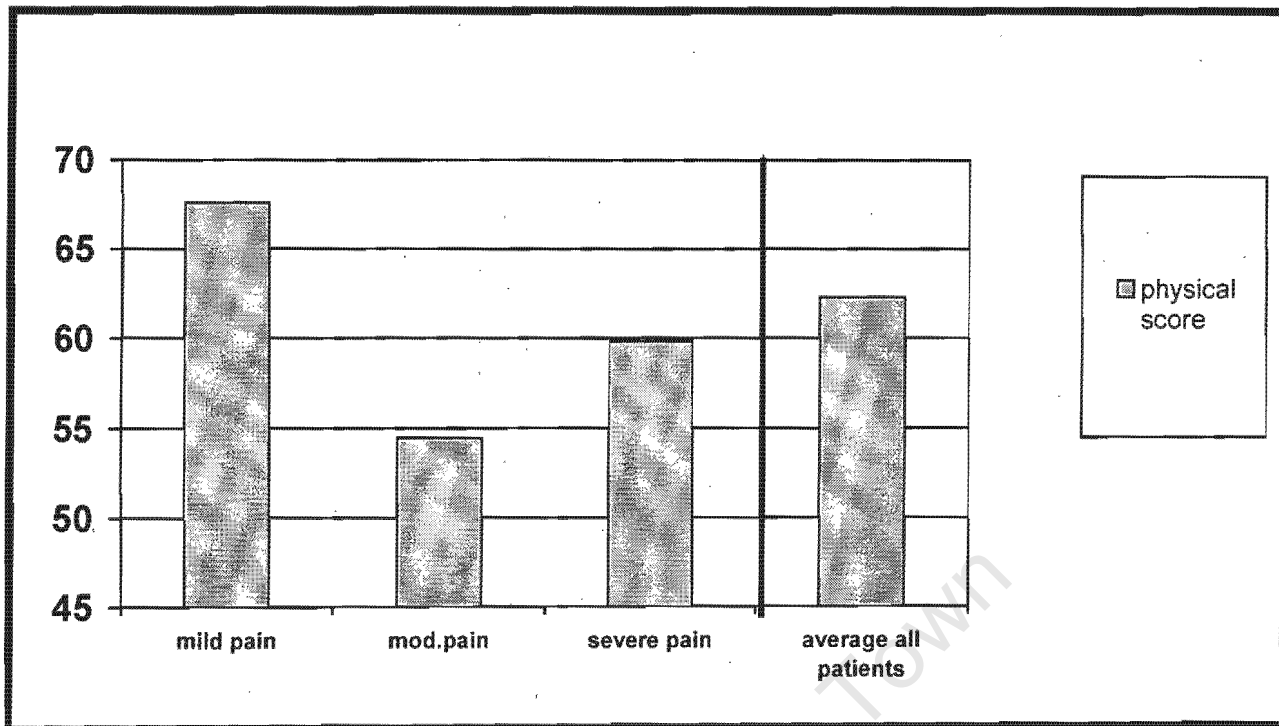


Figure 9b

University of Cape Town

5. DISCUSSION

Paediatric HIV infection has become a global crisis. In 2003 a National Department of Health Report on HIV prevalence in South Africa estimated that 250 children a day were being infected with HIV through mother-to-child-transmission. Currently, more than a quarter of a million children under the age of 15 in South Africa are HIV infected. However, HIV does not only affect children themselves by infection, but also by disrupting families through orphanhood. More than 600 000 children in South Africa have been orphaned due to HIV/AIDS.³²

We have only begun to realize the magnitude and diversity of problems that face children with a life threatening illness such as HIV and their families. The child's needs range from treatment and symptom control, to education, recreation, affection and access to a life with all its challenges and rewards.³³

THE ACT Charter developed jointly by the "Royal College of Paediatrics" in the UK and the "Association for Children with Life threatening and Terminal conditions and their Families" challenges the current management of children by setting a "gold standard of care", that includes physical and psychosocial care for both child and family (see appendix E).

This approach is at the heart of palliative care for children as defined by the WHO as the active total care of the child's body, mind and spirit, which also involves giving support to the family.

Although some people may feel that such care is not appropriate in third world countries the WHO stresses that palliative care can be successfully implemented even where resources are limited and is the responsibility of every health care worker at all levels of health care.⁴ We should not accept a lower quality of care for our patients especially as the key resource to offering quality palliative care is knowledge. This knowledge will challenge the current overriding attitude in the health care sector that patients with HIV require less care when in fact these families and children require more support and access to the best resources.

5.1 HRQOL

HRQOL has been defined as the measurement and study of a patient's personal morbidity i.e. the effect that illnesses and treatments have on daily life and life satisfaction.⁹

Because symptoms and their management is so important in HIV, assessment of HRQOL has taken on a special importance in this field.

Although HRQOL assessments grew out of the research setting, many authors now recognize that assessing HRQL can have practical, clinical applications. Benefits of monitoring HRQOL such as choosing therapies, improving communication, ensuring adherence and optimizing long-term management of chronic disease have all been described.¹⁰

HIV infected adults have reported lower HRQOL than the general population or patients with other chronic conditions such as cancer.

Little is known about the effect of HIV on the HRQOL in children as few formal studies exist in the literature as they do for other chronic conditions in childhood such as cancer or juvenile rheumatoid arthritis.

5.1.1 Critical assessment of the PedsQL as an assessment tool for HRQOL

The PedsQL inventory is brief, easy to understand and takes only about 10 minutes to complete. This makes it an ideal tool for a busy clinic setting.

It takes into consideration that childhood development has to be taken into account when assessing paediatric HRQOL. 3 age-specific questionnaires allow clinicians to chose the most appropriate for a particular child's developmental stage and cognitive ability. However, the items selected for the PedsQL inventory, both in content and wording, reflect issues that are important across all age groups and can thus be used to track concerns longitudinally or to evaluate differences between groups.²⁵

Although originally developed with paediatric cancer patients, the broad range of concerns covered in the generic core scales allows for the use of the inventory for a diverse range of chronic conditions.

Further research is still required to understand HRQOL in HIV infected children better. With the use of a tool such as the PedsQL, which is reliable over time, long term effects of treatments such as HAART could be studied.²⁵

Because this tool is standardized it allows comparison with different groups and could be used to compare HRQOL amongst children in different socio-economic conditions such as urban vs. rural environments.

Developing a disease specific module for HIV/AIDS would assist in achieving improved symptom control as the core scale does not include assessment of some distressing symptoms seen commonly in HIV such as loss of appetite and weight or skin manifestations.

5.1.1.1 Use of proxy assessments

Due to the language barriers and the difficulty in accessing translation, the parent-proxy-report was used as the measurement tool. It has been shown that caregivers underestimate children's distress and pain and therefore cross-informant variance is expected. The correlation of the self and proxy reports will depend on the quality of the proxy. Those of caregiver or parent are of a high quality as they are more likely to share information with each other.²¹

Studies have shown the validity for using parent proxy reports to evaluate a chronic health condition in children. In a study on chronic arthritis in children it was found that parents were moderate to good reporters of the HRQOL of their children²⁰ and in a large study to validate the UK version of the PedsQL correlation between children and parents was higher where the children had a chronic health problem.²¹

A reliable proxy report such as that of a caregiver is important as it is the adult caregivers that are responsible for making health care decisions for the child and it is the parents perspective of their children's health that determines health-seeking behaviour.³⁴ Thus parent-proxy reports of HRQOL in children predicted the cost of health care with those reporting lower scores using 12 times more funds. This could assist in planning services and ensuring quality of care for children with chronic diseases.¹⁸

A second consideration is that a proxy report allows for the assessment of a child who is developmentally impaired as would be the case in a child with HIV encephalopathy or physically ill such as during a hospital admission.¹⁷ This was shown in study of children with brain tumours which included children who were physically ill and had cognitive impairment due to the nature of their disease.

Because HRQOL is a broad construct that does not simply refer to physical functioning, any measurement tool has to be by definition multi-dimensional. For this study the PedsQL inventory was chosen as it assesses physical and psychosocial functioning, with the latter subdivided into emotional, social and school functioning.

5.1.1.2 Cross cultural adaptation

The concern in using the same questionnaire in different countries is that of the cross cultural validity of the measure. Most questionnaires have guidelines for translations, however, the concept of HRQOL may be diverse in different cultures.³⁵

The ideal methods for adapting measurement instruments is still under review³⁶. Although there is certainly a place for culture-specific assessments, some authors are advocating the development and use of internationally applicable assessment tools. In a study of 7 generic quality of life tools applied internationally no prominent differences were found in HRQOL between countries.³⁷

The PedsQL questionnaire was recently assessed as one of the promising measure for childhood HRQOL and is widely used in clinical settings and research in both developed and developing countries²¹ although no specific references on cross-cultural validity for this tool were found in the literature.

5.1.1.3 Comparison with literature

The scores for the different dimensions making up the HRQOL inventory were compared with results of cohorts from the literature. Varni et al¹⁹ used the same PedsQL generic core Inventory to assess HRQOL scores for children with cancer compared to a healthy age-matched group. The comparison of scores in the healthy and oncology group as quoted by Varni et al were statistically significant ($p < 0.001$) for all measured HRQOL scores. Although the sample in this study is too small to evaluate a statistical significance, when compared to children with an oncology problem and healthy children from the literature the scores of the HIV group resembled that of the oncology group.

Developing, translating, and validating this assessment instrument for the South African culture would be very valuable. The tool has not previously been evaluated in an African country. Due to the high burden of poverty and HIV/AIDS, "normal", healthy children in South Africa may have very different HRQOL scores than the controls in the literature.

5.1.2 Physical score:

The physical health scores of the children were on average the lowest scores achieved. This finding correlated with the findings that HIV infected patients are often highly symptomatic and that these symptoms cause distress. Patients with lower CDC classifications, which imply multiple chronic problems, had the lowest physical health scores. The patient with the lowest score (0004TS) is a 5-year old girl, Category B, with LIP, cor pulmonale and TB. In managing patients it would therefore be important to prevent such chronic complications by early

interventions and highlights the importance of access to highly active antiretroviral treatment HAART.

In this case, a poor physical score was associated with a very low psychological health score and thus the lowest overall mean score. This illustrates the concept of HRQOL as a multidimensional construct. This patient requires holistic interventions for all the affected dimensions and not simply prescription of drugs.

5.1.3. Psychosocial score:

Psychological health scores had an average of 71.56 which was higher than the average for the physical health score. Difficulties with physical function and distressing physical symptoms would be much easier for caregivers to identify and the higher score may thus be a reflection of caregivers underestimating psycho-social distress.

Almost half of the children were being cared for by a caregiver other than their mothers. This is an indication of the social devastation that HIV brings with it. Perinatally infected children do not only have to cope with their own disease, but also with the illness and death of mothers and other close family members. Psycho-social support is of utmost importance to the health of a child. Studies have noted the adverse effects that psychosocial stress has²² and better support has been associated with improved symptom control and health. This is consistent with the palliative care teaching of pain and symptoms as multidimensional. Thus it is vitally important that physicians treating HIV infected children take note of psychosocial stressors.³⁸

5.1.3.1 Effect of Disclosure:

Disclosure of the diagnosis to an HIV infected child poses complex issues that involve the entire family. Mode of transmission, maternal guilt, more than one family member with the virus, social stigma and isolation, amongst others, all need to be discussed.³⁹ Communication of parents and children with HIV seems to be particularly difficult as effective coping mechanisms are often absent.⁴⁰ Cultural factors may also play a great role in South Africa.⁴¹

As illustrated in other literature, disclosure of the HIV status to school aged children is difficult for parents. In a group of 35 children aged 5-10 years studied at a French Hospital only 17% had full disclosure of the diagnosis, which compares to the 16,7% in this group of similar age. Almost half the parents used secrecy as a strategy to avoid disclosure.⁴²

This is in contrast to a report on a method of disclosure that has been a successful strategy for many children cared for at the New York Hospital-Cornell University Medical Center. Consistent support by a multi-disciplinary team of providers is at the heart of this program. Of 73 perinatally HIV-infected children

who are 6 years of age or older, 41% have had complete disclosure and another 19% partial.³⁹

In a culturally diverse setting such as South Africa innovative methods for disclosure need to be found. One such programme is the use of puppets in disclosure by Creative Arts therapists at the Beautiful Gate AIDS Care Centre in Cape Town, South Africa. Here children of all cultures can use an appropriate and safe method to communicate feelings and process difficult situations through play. Disclosure is seen as a process, rather than as an event. At a young age of 6-7 years children are gradually introduced to the HIV and the implications of their own status. " I believe it is far easier to grow up with the knowledge of one's status, even when the full implications are not understood, than to hear one day in one's adolescence"⁴³

Of concern are the reports in the literature that children, where the disclosure of HIV infection is delayed, experience distress and poor psychosocial adjustment such as emotional distress, disturbed self-image, and social isolation. Further more, caregivers were often unaware of this situation and could not adequately support the children.^{32&44}

This is also the experience of the study population. Poor HRQOL scores seems to be related to lack of disclosure. This seems to not only affect psychosocial, but physical function as well. In this setting, the palliative care approach is again invaluable. The multi disciplinary team that has a central role to play in all palliative care interventions is suited to take on the responsibility to guide families through the process of disclosure.

As the pattern of HIV disease in paediatric patients will change due to the increasing use of highly active anti-retroviral therapy (ART) and patients survive into adolescence and beyond, the issue of disclosure of diagnosis becomes more significant and part of their comprehensive medical care. As this population matures, the importance of disclosure relates directly to medication adherence, treatment compliance, sexual exploration, fears associated with premature death, and the child's developing autonomy.³⁹

5.1.3.2 School functioning:

It is interesting to note that school functioning was the most negatively affected of the psycho-social dimensions with an average score of only 64.17. Perhaps school functioning is a more objective measure of a child's psycho-social function that is less influenced by parents perceptions.

As children with HIV live to adolescence and adulthood it will be important to facilitate learning in order to maximize their full potential. Research from many countries of the world emphasizes that health and nutritional problems make a significant impact on school participation and performance.⁴⁵

The South African Department of Education has committed itself to ensuring quality education for those who are ill and distressed, but the practical implication of this will be a challenge.⁴⁶

Schools will however also be able to play an important role in assisting children with HIV. Through the acceptance of HIV positive children within schools and the creation of a caring, secure environment stigmatization in the community can be overcome. Because of the relative accessibility of schools and the amount of time that children spend there they can assist in identifying learners in need of medical and social support, which would in turn improve their ability to concentrate and learn.⁴⁷

An active school health system will need to play a central role in preventative and promotive health care to ensure continuity of care for children who require long-term follow up of their chronic condition and can assist in ensuring adherence to medication.⁴⁵

5.1.4 Disease progression and QOL:

The mean score is the multidimensional indicator of QOL as it incorporates physical, psychological and social functioning. This study found that severity of illness as measured by clinical staging was associated with a lower HRQOL score. This finding has been confirmed by other studies. In a study on the predictors of change in the functional status of HIV infected children, poor growth parameters and immunosuppression were found to influence functional status.³⁸

Because HAART slows disease progression and improves immune status and clinical outcomes it seems a logical conclusion that treatment with HAART can have a positive effect of HRQOL in children. Available data supports the notion. Storm et al found that treatment-mediated changes in CD4 counts were associated with a higher functionality and better health perception scores. However, they warn against ignoring the adverse effects that treatment brings with it. Not only do the drugs have physical side effects that cause distressing symptoms, they are also challenging to take because of their palatability and strict adherence regimens. Of concern is that in their study on children receiving an effective PI-based regimen physical and psycho-social dysfunction was common. Almost 40% of children reported more than 1 physical symptom, 32% experienced limitations in their daily activities of living and 23% scored poorly in a behaviour problem index.³⁴

It is clear that treatment of children with HIV requires a paradigm shift. In terms of physical and psychosocial function they are similar to children with other chronic conditions. Treatment can no longer be for an acute infectious disease with high mortality, but rather for a chronic disease with long term morbidity. Palliative care service with their holistic approach and emphasis on QOL will play an important role in this changing nature of management.

"Comprehensive health services will continue to be required to minimize long-term illness and disability and to maximize children's potential as they move into adolescence and adulthood" ³⁴

5.2 The experience of Pain:

Pain is a complex symptom that is by its very nature subjective and therefore difficult to assess and treat. In palliative care, pain is understood not simply as a physical symptom, but rather a manifestation of physical, emotional, psycho-social and spiritual factors that all need to be considered if relief from pain is to be achieved.

Pain in children has been very misunderstood in the past and only slowly is scientific evidence changing the misconceptions and myths that have prevented adequate management of children's pain.

Several studies of adults infected with HIV have shown that although pain is highly prevalent and associated with physical and psychological morbidity it is alarmingly underreported and undertreated. ⁴⁸

South African data on pain in HIV/AIDS is not common. One of the most comprehensive assessments of pain and other symptoms in HIV infected adults was reported by Norval in 2004. ⁴⁹ Pain was almost universally reported by a cohort of hospice patients in Soweto. 98% experienced pain with 34% reporting that pain was the worst symptom. Although a limitation of the study was that it included only hospice patients with AIDS that are not entirely representative of the entire population of people living with HIV, the study did highlight that pain is a significant problem.

Compared to the number of publications on adult pain the study of pain in children with HIV has been relatively neglected. It is clear however from the small number of text available that it is a significant clinical problem. ^{15&16} The prevalence and duration of pain in AIDS has been found to be comparable to cancer with reports ranging from 20-59%.

This study is the first to examine pain in HIV infected children in South Africa. It shows that the prevalence of pain, even in an outpatient setting, is much higher than reported elsewhere. Over 80% of caregivers complained of pain in their children. From previous work we know that parents often underestimate their children's pain which perhaps may imply that the actual prevalence is even higher.

It is also interesting to note that a third to a half of the pain was "mild" and as such may remain untreated as it is not considered significant by parent or health care provider. However, even "mild" pain has the potential to affect a child's quality of life and daily functioning.

Pain scores for the assessment of the last week's pain were higher for most patients. "Severe" pain was very common (43,3%) during the last week, however, no parents reported severe pain on the day of the study. The reasons for this is unclear. It may be a weakness of using a proxy report. Perhaps children did not disclose their pain to their parents, for fear of receiving painful treatment or having to be admitted to the hospital. and thus caregivers would not be able to report on it .

Children with HIV often have multiple sites of pain. Over half of the patients (54,8%) complained of more than one pain, with 8,3% of patients reporting as many as 6 pains ! On average each patient had 2.3 pains, which compares with adult figures of 3 pains as reported in the literature.

The sites of pain were also very diverse with almost every region of the body being involved. It is not a surprise that ENT pain is the most common pain. Infections with a multitude of organisms in this area are extremely common in HIV. Fungal infections such as oral candidiasis, Herpes virus stomatitis or a bacterial upper respiratory tract infection are often identified. Antibiotics are prescribed by the doctor, but analgesics are generally omitted. ENT examination is often skipped as it requires special equipment and is difficult in young children. However, a thorough history and clinical examination is required to ensure that no pain is missed.

Caregivers found it difficult to articulate the pain experience of their children. Language barriers are often present in the multi-cultural health care services in South Africa. Children will often have to suffer in silence because their pain cannot be expressed by them or conveyed by their caregivers. Paediatric health care workers will have to be taught innovative means of assessing children's pain that do not rely solely on self report.

Because children often do not complain of pain, health care workers need to be trained to recognize autonomic changes and behavioural clues to identify children in pain. Simple age appropriate scales, such as the Wong-Baker Faces scale, that can be used in a child as young as 3 are available to assess the level of pain and the response to treatment.

Once pain has been assessed appropriate treatment needs to be given. Drug therapy is only one aspect of managing a child's pain. Too often health care workers forget that simple, inexpensive measures can lessen a painful experience. Non-pharmacological interventions from giving age-appropriate information to guided imagery techniques can actually reduce pain. Health care professionals may simply expect children ignore their pain.

The use of pharmacological methods to reduce pain should follow the guidelines as laid out by the WHO. Drugs should be given "by the ladder, by the clock, by the child, by the mouth."⁵⁰

Parents and health care workers alike often avoid appropriate treatment due to fears about opioid drug use such as addiction without considering that most pain responds to simple analgesics, especially in HIV infected children where pain commonly has an infective cause.¹⁵

It is also important to consider that children not only suffer from physical pain but that intimidating environments and procedural pain during a hospital visit add to the pain experience.¹⁴

Importantly, the study suggests that an increasing severity of pain is associated with poorer quality of life scores. Pain influenced not only physical scores, but also psychological scores. This is in keeping with the palliative care paradigm that pain is not simply a physical symptom, but that psycho-social and emotional factors play a part. Therefore pain cannot be simply managed by a drug prescription, but requires a multidisciplinary team to deal with all aspects in a holistic manner.

Normal development, learning, school functioning all determine how the child will be able to cope with his/her illness as an adult. Because pain and its effect on quality of life interferes with all these processes, adequate pain identification, assessment and management should be systemically considered in the routine care of HIV infected children.

Of great importance is the fact that children who received treatment with HAART had a significant decrease in pain related diagnoses from 46% to 29%.¹³ It will be interesting to repeat the study in those children who now have access to HAART to confirm this finding.

5.3 Limitations of study:

The small study number lent itself to a descriptive study of exploratory nature, however, the numbers were too small to comment on statistical significance of the findings. Palliative care research is often undertaken with small numbers. Systematic reviews of other similar studies often strengthen the results by increasing study numbers. As the PedsQL has never been used in the setting of HIV a direct comparison was not possible, however, when compared to the literature, the results of this study were comparable in that children with chronic disease experience marked negative effects on their quality of life. A multi-site study, which could include far greater numbers of children could improve the results obtained.

Due to difficulties with the translation process questionnaires were completed in English, which is a second language for most respondents. Therefore, certain aspects such as pain description will not have been ideally recorded due to language barriers. To facilitate optimal understanding the investigator sat with each one of the participants and went through the questions slowly and offered explanations if any question was unclear. The respondents were also encouraged to give examples to show that they had understood the meaning of questions. E.g. when answering a question on shortness of breath the question the respondent may have been asked to describe the setting in which this happens.

Assessing HRQOL in children through parent-proxy interviews is also limited. Cross-informant variance has been consistently shown as caregivers tend to underestimate their children's symptoms. A follow up study which includes children's self report in their first language would be valuable.

Only a small proportion of children infected by HIV were sampled in this study. This cohort is not entirely representative of all children as it only investigated urban children attending a specialist clinic. Any follow up study should include children from other socio-economic circumstances.

A significant limitation is the omission of an SA control group. This would have allowed validation of the tool for the SA setting. Further studies are needed to validate the tool for use in the South African setting. As the instrument has however been widely used and translated it is highly probable that it is applicable in the setting in which it was used. As the aim of the study was to highlight the need for a holistic assessment of a patient's disease by assessing all dimensions of HRQOL rather than establishing absolute values, the study still has merit as it stands.

6. CONCLUSION

This descriptive study achieved its aim in establishing that the high prevalence of pain in HIV infected children described in the literature is also found in the South African setting as well. Despite small numbers the study clearly showed that pain had an impact on HRQOL. The PedsQL was shown to be an easy to use, valuable tool to use in clinical practice and established that as with other chronic childhood diseases children with HIV experience a decrease in their QOL scores.

Children are the hope and future of South Africa. Currently, their lives are being devastated by the effects of the HIV epidemic. Both their physical and psychosocial health status is impacting on their poor quality of life. We cannot put our hope in medication alone to mitigate the impact of this disease.

Comprehensive assessment, as implemented through the PedsQL tool, facilitates the active total care of the child's body, mind and spirit as described in the WHO definition of palliative care for children.

A palliative medicine approach with the goal of management being quality of life is the only care that will assist children reaching their full potential.

7. RECOMMENDATIONS

In line with current thinking of the importance of quality of life measures in managing patients with chronic conditions, HRQOL and pain assessments should be incorporated into the clinical assessment of patients. The availability of simple, but effective tools such as the PedsQL makes this possible.

A follow up study that would allow validation of the PedsQL tool in the South African setting by using appropriate translations of the questionnaires and comparing to a control group is recommended.

Since this study was conducted highly active antiretroviral treatment has become available to all children in the state medical service. A follow up assessment of all the children taking part in the study to assess the effect that HAART has on HRQOL would be valuable.

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ABBREVIATIONS:

AIDS: Acquired Immune Deficiency Syndrome

CDC: Centre for Disease Control

ENT: Ear-Nose-Throat

GCS: Generic Core Scales

GCP: Good Clinical Practice

HAART: Highly active antiretroviral treatment

HIV: Human Immune Deficiency Virus

HRQOL: Health Related Quality of Life

LIP: Lymphocytic Interstitial Pneumonitis

PI: Protease Inhibitor

PPQ: Pediatric Pain Questionnaire

TB: Tuberculosis

WHO: World Health Organization

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ID# _____
Date: _____

PedsQL™
Pediatric Quality of Life
Inventory (UK)

Version 4.0

Comment: UK version sent by James Varni on CD – June 2002 and by C. Eiser

Translation team: Christine Eiser Ph.D.
Sheffield, England, email:
C.Eiser@sheffield.ac.uk

Methodology of translation: They used the method described by Jim Varni in the PedsQL website and instructions he sent.

PARENT REPORT for YOUNG CHILDREN (ages 5-7)

DIRECTIONS:

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

- 0 if it is **never** a problem
- 1 if it is **almost never** a problem
- 2 if it is **sometimes** a problem
- 3 if it is **often** a problem
- 4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

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→ the past **ONE month**, how much of a **problem** has your child had with ...

PHYSICAL FUNCTIONING (<i>problems with...</i>)	Never	Almost Never	Sometimes	Often	Almost Always
1. Walking down the road a little bit	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports or running games	0	1	2	3	4
4. Lifting heavy things	0	1	2	3	4
5. Having a bath or shower by him or herself	0	1	2	3	4
6. Helping to pick up his or her toys	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Feeling very tired	0	1	2	3	4

EMOTIONAL FUNCTIONING (<i>problems with...</i>)	Never	Almost Never	Sometimes	Often	Almost Always
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad or unhappy	0	1	2	3	4
3. Feeling angry or cross	0	1	2	3	4
4. Trouble sleeping at night	0	1	2	3	4
5. Worrying about what will happen to him or her	0	1	2	3	4

SOCIAL FUNCTIONING (<i>problems with...</i>)	Never	Almost Never	Sometimes	Often	Almost Always
1. Getting on with other children	0	1	2	3	4
2. Other kids not wanting to be his or her friend	0	1	2	3	4
3. Getting bullied by other children	0	1	2	3	4
4. Not able to do things that other children his or her age can do	0	1	2	3	4
5. Keeping up when playing with other children	0	1	2	3	4

SCHOOL FUNCTIONING (<i>problems with...</i>)	Never	Almost Never	Sometimes	Often	Almost Always
1. Paying attention in class					
2. Forgetting things					
3. Keeping up with school activities					
4. Having days off school because of not feeling well					
5. Having days off school to go to the doctor or hospital					

ID# _____
Date: _____

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Methodology of translation: They used the method described by Jim Varni in the PedsQL website and instructions he sent.

PARENT REPORT for CHILDREN (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the past **ONE** month by circling:

- 0 if it is **never** a problem
- 1 if it is **almost never** a problem
- 2 if it is **sometimes** a problem
- 3 if it is **often** a problem
- 4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

the past **ONE month**, how much of a **problem** has your child had with ...

PHYSICAL FUNCTIONING (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Walking down the road a little bit	0	1	2	3	4
Running	0	1	2	3	4
Participating in sports or running games	0	1	2	3	4
Lifting heavy things	0	1	2	3	4
Having a bath or shower by him or herself	0	1	2	3	4
Tidying up around the house	0	1	2	3	4
Having hurts or aches	0	1	2	3	4
Feeling very tired	0	1	2	3	4

EMOTIONAL FUNCTIONING (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Feeling afraid or scared	0	1	2	3	4
Feeling sad or unhappy	0	1	2	3	4
Feeling angry or cross	0	1	2	3	4
Trouble sleeping at night	0	1	2	3	4
Worrying about what will happen to him or her	0	1	2	3	4

SOCIAL FUNCTIONING (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Getting on with other children	0	1	2	3	4
Other kids not wanting to be his or her friend	0	1	2	3	4
Getting bullied by other children	0	1	2	3	4
Not able to do things that other children his or her age can do	0	1	2	3	4
Keeping up when playing with other children	0	1	2	3	4

SCHOOL FUNCTIONING (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
Paying attention in class	0	1	2	3	4
Forgetting things	0	1	2	3	4
Keeping up with schoolwork	0	1	2	3	4
Having days off school because of not feeling well	0	1	2	3	4
Having days off school to go to the doctor or hospital	0	1	2	3	4

ID#
Date:

PedsQLTM

Pediatric Quality of Life Inventory (UK)

Version 4.0

Comment: UK version sent by James Varni on CD – June 2002 and by C. Eiser

Translation team: Christine Eiser Ph.D.
Sheffield, England, email:
C.Eiser@sheffield.ac.uk

Methodology of translation: They used the method described by Jim Varni in the PedsQL website and instructions he sent.

PARENT REPORT for TEENAGERS (ages 13-18)

DIRECTIONS

On the following page is a list of things that might be a problem for **your teenager**. Please tell us **how much of a problem** each one has been for **your teenager** during the past **ONE month** by circling:

- 0 if it is **never** a problem
- 1 if it is **almost never** a problem
- 2 if it is **sometimes** a problem
- 3 if it is **often** a problem
- 4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

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—the past **ONE month**, how much of a **problem** has your teenager had with ...

PHYSICAL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Walking down the road a little bit	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports or running games	0	1	2	3	4
4. Lifting heavy things	0	1	2	3	4
5. Having a bath or shower by him or herself	0	1	2	3	4
6. Tidying up around the house	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Feeling very tired	0	1	2	3	4

EMOTIONAL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad or unhappy	0	1	2	3	4
3. Feeling angry or cross	0	1	2	3	4
4. Trouble sleeping at night	0	1	2	3	4
5. Worrying about what will happen to him or her	0	1	2	3	4

SOCIAL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Getting on with other teenagers	0	1	2	3	4
2. Other teenagers not wanting to be his or her friend	0	1	2	3	4
3. Getting bullied by other teenagers	0	1	2	3	4
4. Not able to do things that other teenagers his or her age can do	0	1	2	3	4
5. Keeping up with other teenagers during activities	0	1	2	3	4

SCHOOL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Paying attention in class	0	1	2	3	4
2. Forgetting things	0	1	2	3	4
3. Keeping up with schoolwork	0	1	2	3	4
4. Having days off school because of not feeling well	0	1	2	3	4
5. Having days off school to go to the doctor or hospital	0	1	2	3	4

PedsQL™

Pediatric Pain Questionnaire™

Parent of Young Child Form (5-7 years of age)

Name: _____

Date: _____ Record Number: _____

What words would you use to describe your child's pain or hurt?

1. Please rate how much pain you think your child is having at the present time by placing a mark somewhere on the line.



Not hurting
No discomfort
No pain



Hurting a whole lot
Very uncomfortable
Severe Pain

2. Please rate how severe the worst pain your child had in the past week (7 days) by placing a mark somewhere on the line.

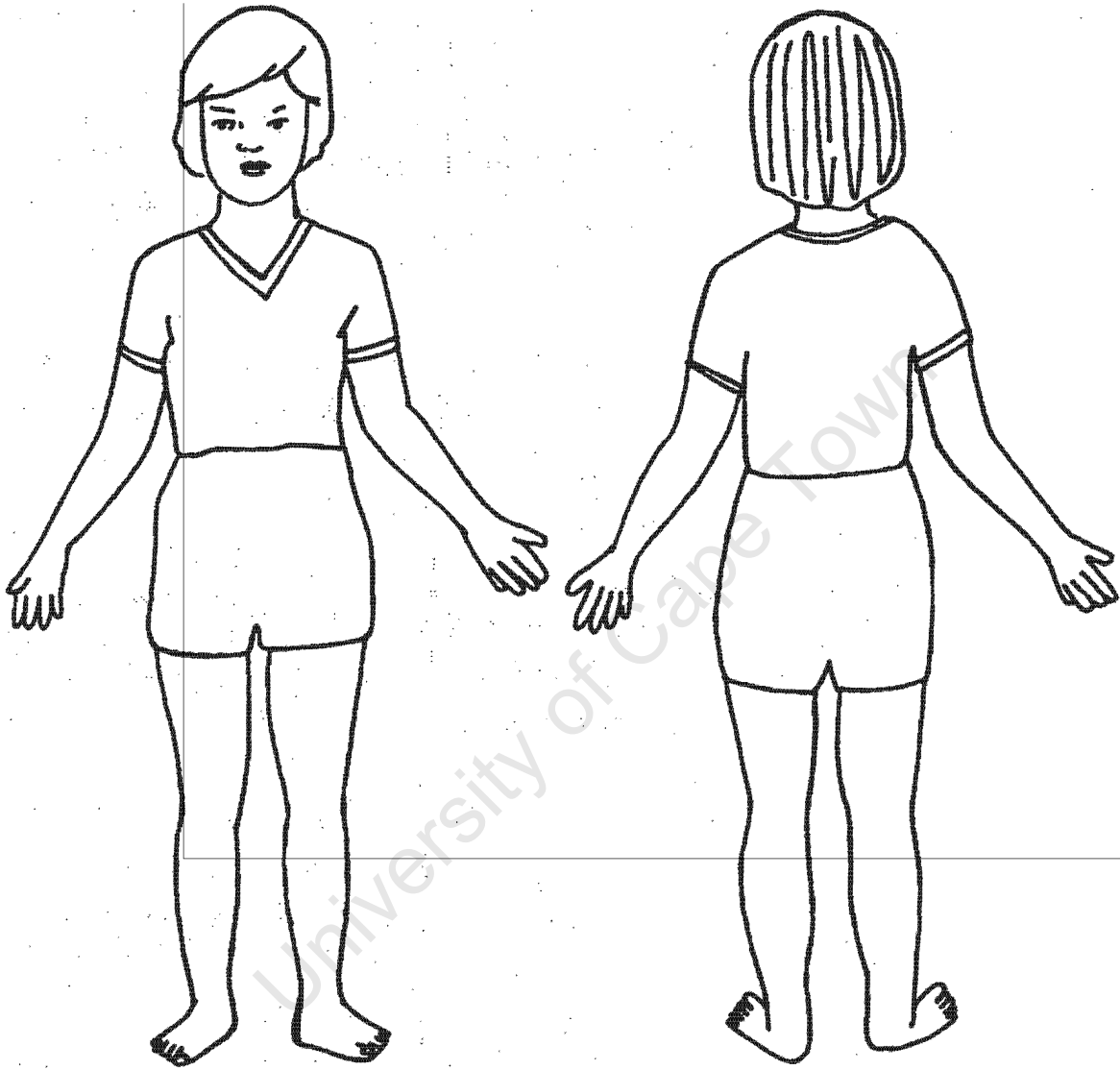


Not hurting
No discomfort
No pain



Hurting a whole lot
Very uncomfortable
Severe Pain

Please mark an **X** on the **exact** place where you think your child is having pain now. If there is more than one painful place, mark them '1', '2', '3', etc., starting with the most painful place as '1'.



Front

Back

PedsQLTM

Pediatric Pain QuestionnaireTM

Parent of Child Form (8-12 years of age)

Name: _____

Date: _____ Record Number: _____

What words would you use to describe your child's pain or hurt?

1. Please rate how much pain you think your child is having **at the present time** by placing a mark somewhere on the line.



Not hurting
No discomfort
No pain

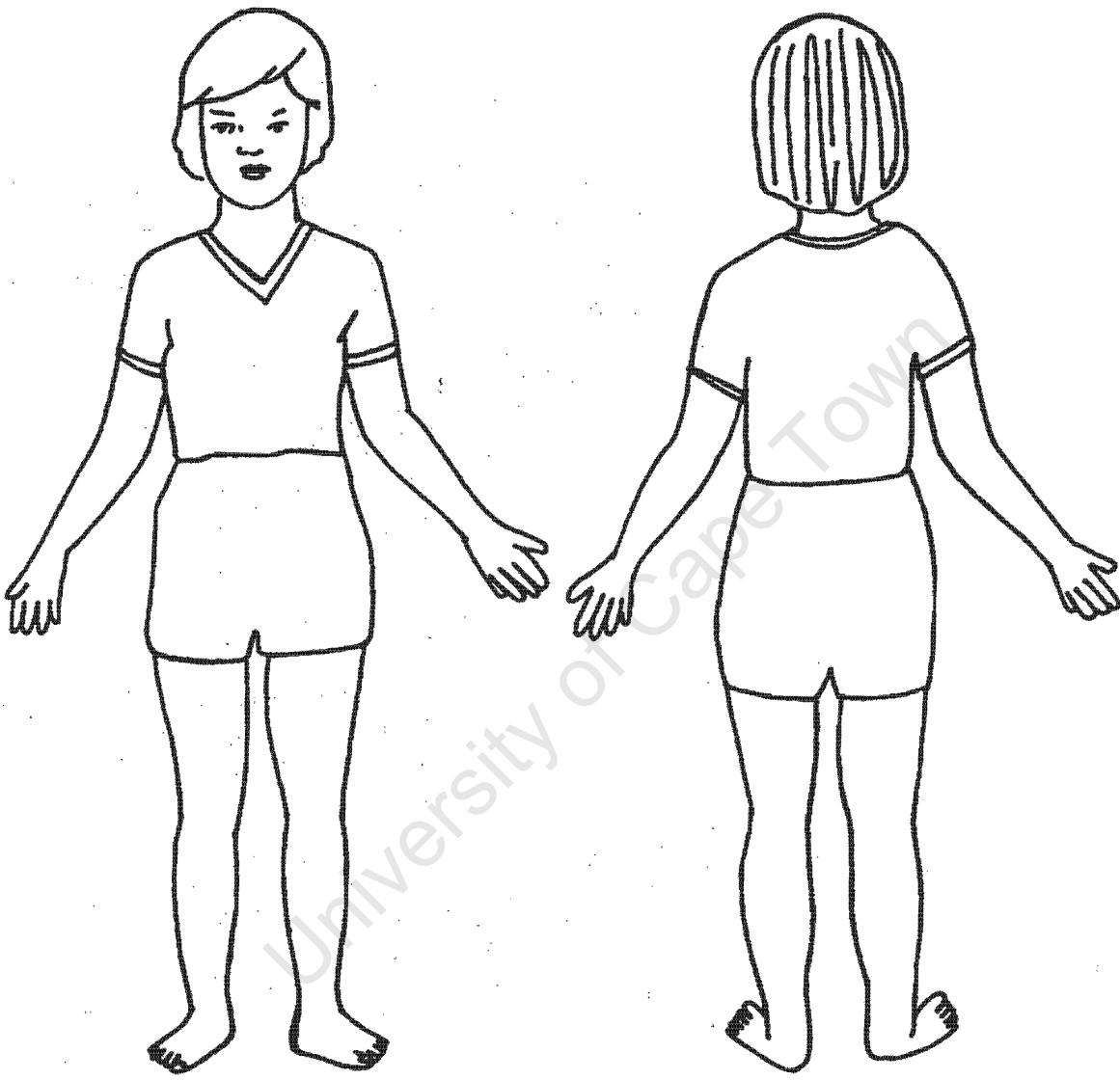


Hurting a whole lot
Very uncomfortable
Severe Pain

2. Please rate how severe the **worst pain** you think your child had **in the past week** (7 days) by placing a mark somewhere on the line.



Please mark an X on the **exact** place where you think your child is having pain now. If there is more than one painful place, mark them '1', '2', '3', etc., starting with the most painful place as '1'.



Front

Back

PedsQLTM

Pediatric Pain QuestionnaireTM

Parent of Teen Form (13-18 years of age)

Name: _____

Date: _____ Record Number: _____

What words would you use to describe your teen's pain or hurt?

1. Please rate how much pain you think your teen is having **at the present time** by placing a mark somewhere on the line.



Not hurting
No discomfort
No pain

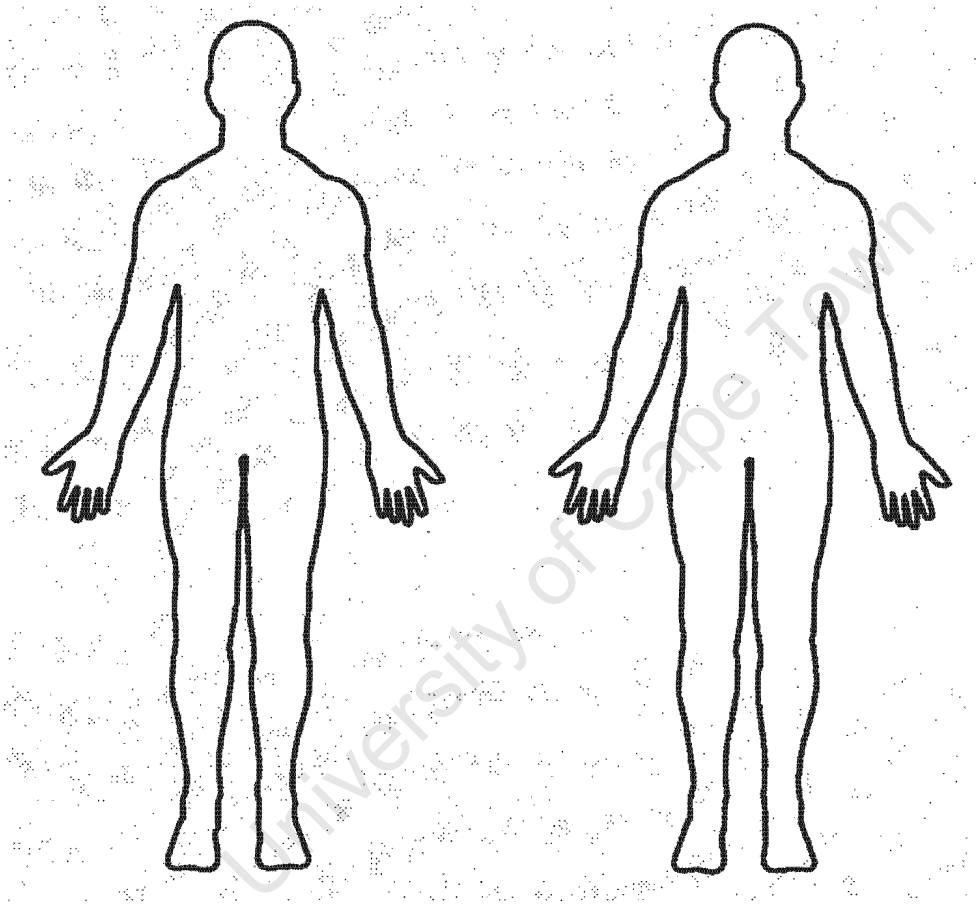


Hurting a whole lot
Very uncomfortable
Severe Pain

2. Please rate how severe the **worst pain** you think your teen had **in the past week (7 days)** by placing a mark somewhere on the line.



Please mark an **X** on the **exact** place where you think your teen is having pain now. If there is more than one painful place, mark them '1', '2', '3', etc., starting with the most painful place as '1'.



Appendix C

Patient information and consent

Patient information

Dear parent/caregiver

HIV and AIDS affect people in many different ways. Not only can this disease make your body feel sick, but it can also change the way you feel or your ability to do everyday things. We call this "quality of life". If as health care workers we can find out how HIV affects children's lives we will be able to treat them better.

The PedsQL™ questionnaire asks you questions about how your child feels and what you think about his/her health. It is not a test, and there are **no right or wrong answers**. It takes about 5 minutes to complete. It contains questions about your child's physical, emotional, social, and school functioning **in the past one month**.

Please be sure to read the instructions carefully and choose the response that is the closest to how you truly feel and not what you think I want you to say. We are interested in your **individual** perspectives. However, feel free to discuss the questionnaire with your child **after** you have completed it and returned it to me. If you have any questions, please let me know.

All the information in the questionnaire is confidential (private) and only people involved in the study will have access to it. At no time will it be made public alongside your or your child's identity (name). Any answers that you give will not change the way your child is treated at the clinic. You do not have to take part in the study to receive treatment at the clinic.

Consent:

I understand what this study is about and have had all my questions about the study answered. I have been given a copy of the information sheet and the consent form and understand the contents. I understand that taking part in this study is my choice and that if I decide not to, it will not cause any problems with the treatments of my child at this clinic. I may decide to stop taking part in the study at any time.

I understand that all information from this study is strictly confidential and only people involved in the study will have access to it.

I would like to complete the PedsQL questionnaire.

Caregiver/Parent signature:

Caregiver/Parent Name:

Date:

Witness signature and full name:

Date:

Name and signature of person who obtained consent:

Date:

University of Cape Town

Appendix D

Patient data

Study number:

Demographic details:

Name of child: _____

Gender: M/F

Date of Birth: _____

Hospital number: _____

Name of parent/caregiver: _____

Relationship to child:
Parent/Grandparent/ Foster parent/ Other _____

Date of interview: _____

Medical details:

Age of Diagnosis of HIV: _____

Length of Time attending the Harriet Shezi Clinic: _____

CDC Category:
N/A/B/C

CD4 count: _____

Current Medical Problem List: _____

Appendix E

ACT CHARTER FOR CHILDREN WITH LIFE-THREATENING OR TERMINAL CONDITIONS AND THEIR FAMILIES

- 1) Every child shall be treated with dignity and respect, and shall be afforded privacy whatever the child's physical or intellectual ability.
- 2) Parent shall be acknowledged as the primary carers, and shall be centrally involved as partners in all care and decisions involving their child.
- 3) Every child shall be given the opportunity to participate in decisions affecting his or her care, according to age and understanding.
- 4) Every family shall be given the opportunity of a consultation with a paediatric specialist who has particular knowledge of the child's condition.
- 5) Information shall be provided for the parents, and for the child and the siblings, according to age and understanding. The needs of other relatives shall also be addressed.
- 6) An honest and open approach shall be the basis of all communication, which shall be sensitive and appropriate to age and understanding.
- 7) The family home shall remain the centre of caring whenever possible. All other care shall be provided by paediatric trained staff in a child-centred environment.
- 8) Every child shall have access to education. Efforts shall be made to enable the child to engage in other childhood activities.
- 9) Every family shall be entitled to a named key worker who will enable the family to build up and maintain an appropriate support system.
- 10) Every family shall have flexible respite care in their own home or in a home-from-home setting for the whole family, with appropriate paediatric nursing and medical support.
- 11) Every family shall have access to paediatric nursing support in the home, when required.
- 12) Every family shall have access to expert, sensitive advice procuring practical aids and financial support.
- 13) Every family shall have access to domestic help at times of stress at home.
- 14) Bereavement support shall be offered to the whole family and shall be available for as long as required.

List of changes/corrections made to the dissertation

As per recommendation of the reviewers the following changes have been made:

1) Methodology:

"The comparison of PedsQL scores.... should be added here --- A comment was added to section 3.6.

"Higher score should read lower score" --- the interpretation of the scores was taken directly from the recommendations by the author of the PEDSQL questionnaire. A higher score does in fact indicate a higher HRQOL i.e. a score of 80% denotes good QOL compared to a score of 20%, which is regarded as poor.

2) Results:

Comparison with literature section added under section 4.3.2

"Pain results ranked according to age" – As the sample has a wide age range in a small sample a easier way to compare the results is perhaps to analyze the data according to the subgroups established by the 3 different questionnaires. This analysis seems to indicate lower scores for all categories in the younger age group. Of course, the compounding effect of clinical category can not be assessed. These results may also be biased by the small sample size.

Age group	Mean	Psychosocial	Physical
5-7 years	64.37	68.22	56.85
8-12 years	72.59	75.00	68.08
13 years +	69.57	73.3	62.50

"Perception of pain in different age groups" --- I agree this is a very important evaluation. I feel however that this would be more suitable to study using the direct questioning of the child, rather than the parent proxy evaluation.

3) Discussion:

"Comparison with literature results should not be presented in the discussion" --- The results and figures have been moved to section 4.3.2. in the results section. Only the comments on the results have been retained in the discussion.

"Numbering should be omitted" --- Uniform numbering has been used throughout the dissertation to clearly demarcate different sections. The separate discussions on the 2 aims of the study namely assessing HRQOL and assessing pain are easily locatable using the current numbering. I feel that the numbering adds to the clarity of the different aspects addressed during the discussion and would prefer the keep the current formatting.