THE PSYCHOLOGICAL IMPACT OF PAIN
ON ADOLESCENTS SUFFERING FROM
HIV/AIDS

BY

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the Masters Degree of Palliative Medicine at the University of
Cape Town South Africa

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DECLARATION

I, the undersigned hereby declare that the work contained in this thesis is my own original work and that I have not previously in its entirety or in part submitted it at any University for a degree.

Signed by candidate
Signature removed

Henry Seruyange
SUMMARY

Assessment plays a vital role in pain management and would be incomplete without establishing the psychological factors impacting on pain. These psychological factors in adolescents suffering from HIV/AIDS are mentioned in the literature but are not spelled out clearly.

This study, which established these factors, was conducted at The Mildmay Centre Uganda. The study combined both qualitative and quantitative methods and it involved eight HIV/AIDS adolescents who knew their HIV status. The adolescents were purposively sampled from a total of 87 adolescents who complained of pain during the period of four weeks. Eight subjects out of the 87 adolescents met the selection criteria and were therefore eligible for the study. The number was small because a large proportion did not know their sero-status, as the carers were unwilling to disclose to their children. In addition, a significant number were very sick with Karnofsky score equal to or less than 40% and therefore ineligible, and some refused to consent.

A doctor collected the initial data from the patients as well as from the patients’ files. The rest of the data was collected by the social worker via audio-recorded interviews. The initial results the doctor collected indicated that subjects had psychological factors, but could not reveal the depth of the problem. However these results did demonstrate that adolescents could conceptualise and understand pain. The data collected by the social worker was transcribed and analysed. The issues obtained from the adolescents were categorized and themes describing the psychological factors were formed.
The psychological factors from adolescents suffering from HIV/AIDS discovered by the study included: distress, disappointment, autonomic nervous system effects, withdrawal, upset, apprehension, misery, hopelessness, restlessness, exhaustion, separation, rejection and lack of empowerment. A combination of distress and rejection could act as a strong catalyst for suicide as two of the study subjects mentioned. After analysis it became clear that health workers, carers, community and school authorities play a big role in promoting these factors.

This observation formed the basis of recommendations at the end of the study. The recommendations included the need for a team approach to pain management that utilizes different cadres of health workers, carers at home, the community and school authorities. Another recommendation was to empower the adolescents themselves to be involved in the diagnosis, care and community sensitisation about pain management. It is also recommended that further research include a similar study on a bigger population in a rural setting, as this study examined eight adolescents that were all from a peri-urban setting. Lastly the Ministries of Health and Education should work hand-in-hand to make policies, which could assist doctors, communities, school authorities, and carers understand pain management better.
ACKNOWLEDGMENT

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ACRONYMS AND TERMS

Adolescent - Children between 12 and 18 years old
ACP - Aids Control Program
AIDS - Acquired Immunodeficiency Syndrome
ARV's - Antiretroviral drugs
AZT - Zidovudine, an agent used to treat HIV
CME - Continuing Medical Education
HIV - Human Immunodeficiency Virus
Karnofsky score - Analyses performance status and measures patients' activity of daily function and progress of the disease
Km - Kilometer
MOE - Ministry Of Education
MOH - Ministry Of Health
Neuropathic pain - Pain as a result of damage to or dysfunction of the nervous system
NSAIDS - Non-Steroidal Ant-inflammatory Drugs
Somatic pain - Pain produced by stimulation of specific peripheral receptors and conveyed by neurons dedicated to transmitting pain
STD - Sexually Transmitted Diseases
TASO - The Aids Support Organization
UNAIDS - Joint United Nations Programme on AIDS
VAS - Visual Analogue Scale
WHO - World Health Organization
CHAPTER ONE
INTRODUCTION

1.1 BACKGROUND

The research was carried out at The Mildmay Centre, located at Naziba Hill, Entebbe Road, about 12km from Kampala in Uganda. The centre is a specialist palliative day-care and training centre that caters for children and adults living with HIV/AIDS. Currently the centre has registered more than 10,000 patients and over 200 new patients are enrolled each month. There are 5,500 patients who are actively attending, over 2,200 of which are children. There are two main languages used at the centre, English and Luganda.

1.2 PROBLEM STATEMENT

The prevalence of pain in children suffering from HIV/AIDS is 20 - 50 % (Breitbart. et al, 1991). Pain in HIV/AIDS is mainly caused by opportunistic infections, which could be prevented by use of antiretroviral drugs (ARVs), but these drugs are not easily accessible because of the costs. The drugs used to control the opportunistic infections (OIs) are equally expensive. This means that pain remains an obstacle for many people who are living with HIV/AIDS in Uganda and other countries with limited resources.

Complete pain assessment has to be done in order to manage patients successfully. The assessment is incomplete if the psychological factors are not explored.
These psychological factors include anxiety, anger, fear, depression, boredom, insomnia, tiredness and social isolation. These factors can cause a lot of impact on pain in children. This is especially true in young people who are at an already difficult stage of life in countries with limited resources like Uganda.

Uganda had 1.7 million orphans by the end of 1999 (Malinga 2002). Not only is poverty a problem, but also many children in Uganda are orphaned. Dealing with the implications of HIV/AIDS - including pain - is especially complicated for these adolescents.

1.3 RATIONALE AND JUSTIFICATION FOR THE RESEARCH

Pain in children has been always underestimated or ignored (Schechter, Pain and pain control in children, http://www.ncbi.nlm.nih.gov 21/04/2005). Psychological factors are mentioned to be important in pain management but it is difficult to find specific research fully exploring this issue in adolescents (Gaughan et al 2002). In Uganda, there are two studies done on HIV/AIDS that addressed psychological factors and pain. One, by Ssemafumu (2001) addressed pain in adults above 18 years; another by Seggane and Kinyanda (2002) examined the psychological and social problems of HIV-Seropositive adolescents and their parents/guardians. In Ssemafumu’s study, psychological factors were mentioned to influence pain but feeling of the patient’s pain was not explored in-depth because the interest was in the prevalence of pain as a physical entity. The second study also failed to explore in any depth, the feeling of adolescents’ pain. If the psychological factors affecting adolescents in pain and attending The Mildmay Centre are brought out clearly by the study, then the holistic approach to pain will be strengthened.
The information gained from the research will be submitted for publication in the medical journals so that health care professional can benefit. Conferences discussing the research findings will be held targeting various palliative caregivers such as The AIDS Support Organization (TASO) and Hospice Uganda. Policymakers from the Ministry of Health will also be given this information, which might be useful when planning for palliative care in the country.
CHAPTER TWO

LITERATURE REVIEW

The literature search for this chapter was based on scientific journals, books and the Internet, UNAIDS, WHO and other reports found on google.com. The key words for the research are: "Pain", "Adolescent", "HIV/AIDS" and "Psychological factors".

This chapter presents literature on the statistics of HIV/AIDS in Uganda as well as global estimates. It also gives the prevalence of pain in children. There will be a brief mention of some of the painful conditions associated with HIV/AIDS in adults and children. Emphasis of pain assessment and the WHO analgesic ladder of pain management will also be mentioned.

Pain may be defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (International Association for Study of Pain 1986). It can be somatic, neuropathic, spiritual, social or emotional. Somatic pain is produced by stimulation of specific peripheral receptors and conveyed by neurons dedicated to transmitting pain. Neuropathic pain results from damage to or dysfunction of the nervous system (Back 1997).

HIV/AIDS has ravaged Uganda since the early 1980s. The global estimates of HIV/AIDS epidemic during 2003 were a total of 4.8 million people were newly infected with HIV, of which 4.2 million were adults and 0.63 million were children below the age of 15 years (UNAIDS/WHO, 2004).
As the disease has spread, so has our understanding of it and our ability to control it. As a result, the life expectancy of children with HIV/AIDS has increased. This has lead to an increase in quality of life outcome concern (Gaughan et al 2002). Gaughan et al acknowledge that there is limited research concerning pain in children with HIV/AIDS. By the end of December 2001 there were 1,050,555 people living with HIV/AIDS in Uganda (STD/ACP, 2002).

The prevalence of pain in HIV infected individual’s ranges from 40 to 60% (Breitbart. et al, 1991). And the prevalence of pain in children suffering from HIV/AIDS is 20 - 50 % (Breitbart. et al, 1991). It increases as the disease progresses and 50% of patients with AIDS reported pain and have an average of two or more types of pain simultaneously. The most common reported pain syndromes in the studies to date include painful peripheral sensory neuropathy, other types include pain due to extensive Kaposi’s Sarcoma, headache, pharyngeal and abdominal pain, arthralgias, as well as painful dermatological conditions (Breitbart, et al, 1988, Lebovits, et al, 1989, Schofferman, Brody, 1990, Singer, et al, 1993). HIV related peripheral neuropathy is often a painful condition and it affects up to 30% of people with AIDS (Cornblath, McArthur, 1988). It is characterized by a sensation of burning, numbness or anaesthesia in the affected extremity. Several antiviral drugs, such as Didanosine, Stavudine, Zalcitabine, chemotherapeutic agents used to treat Kaposi’s Sarcoma such as Vincristine, as well as other drugs like Phenytoin and Isoniazid, can also cause painful peripheral neuropathy. Reiter’s syndrome, reactive arthritis, and polymyositis are painful conditions reported in early HIV infection (Kaye, 1989). Other painful manifestations of HIV include arthritis such as painful articular syndrome, septic arthritis, and psoriatic arthritis and other
conditions such as vasculitis, Sjogren's syndrome, Zidovudine (AZT) myopathy, and dermomyositis (Espinoza et al., 1989). Conditions associated with chronic or intermittent pain include intestinal infections with mycobacterium avium intracellulare and cryptosporidium, hepatosplenomegaly, resulting in abdominal distention and pain, oral and oesophageal candidiasis, and severe spasticity associated with encephalopathy. Other HIV-related conditions that cause acute pain in children include meningitis and sinusitis, which results in severe headaches, otitis media, shingles, cellulitis and abscesses, severe candidal dermatitis and dental caries (Pain in Patients with HIV/AIDS, An Overview. http://www.hivpositive.com/f-Pain/LS7.6.html 29/12/2004).

The patient with HIV faces a lot of psychological distress, which is variable and can be influenced by social support, individual coping capacities, personality and medical factors (Pain in Patients with HIV/AIDS, An Overview. http://www.hivpositive.com/f-Pain/LS7.6.html 29/12/2004). The research report by Seggane and Kinyanda (2002) found distress as psychological effect and psychosis, depression, anxiety disorder, somatoform disorder, dementia, seizures, mania, suicide attempt and substance abuse as psychiatric effects. Children with HIV often come from multi-problem families, and these problems affect families' ability to deal with the disease and the pain it causes (Boland, Mahan-Rudolph, Evans, 1989).

According to WHO pain can have a devastating effect, both physically and psychologically on children with cancer and HIV/AIDS (WHO 1998). This is an issue we must deal with.
In order to have success in pain management, a holistic assessment of physical, psychological, spiritual, cultural and social aspects of the patient has to be done, as mentioned in pain control in children in Hospice Africa Uganda third edition 2002. Pain management should be individualized and should take into account the stage of the disease, concurrent medical conditions and characteristics of the pain of the HIV/AIDS patient. Effective management also requires ongoing reassessment of the pain and the effectiveness of treatment. 

The World Health Organization (WHO) ladder portrays a progression of the doses and the types of analgesic drugs for effective pain management (Pain in Patients with HIV/AIDS, Pain and Pain Management Modalities, http://www.hivpositive.com/f-PainHIV/Pain/LS1.4.html 29/12/2004). There are three major classes of drugs either used alone or in combination. These are the non-steroidal anti-inflammatory drugs (NSAIDS), opioid analgesics and adjuvant analgesics.


In most studies of pain, psychological factors are mentioned and recognized to affect perception of pain both in children and adults (Gaughan et al 2002). The psychological factors mentioned are anxiety, anger, fear, depression, boredom, insomnia, tiredness and social isolation. However, there is scanty research addressing psychological
factors in adolescents suffering from HIV/AIDS. This study explored this gap in the literature through empirical research.

2.1 AIM OF THE STUDY

The aim of the study is to identify the psychological factors in adolescents with HIV/AIDS presenting with pain at The Mildmay Centre.

2.2 OBJECTIVES

- To establish the psychological factors HIV/AIDS adolescents may experience in possible relation to the pain.
- To describe how the subjects conceptualise and understand the pain itself.
- To make recommendations for the management of psychological factors impacting pain.
Inclusion criteria:

Those included were adolescents between the ages of 12-18 years:

- Who had experienced pain and had their guardian/carer consented for the study.
- Whose sero-status had been disclosed to them and it was positive.
- Had experienced pain in the last six months.

Exclusion criteria:

Adolescents who had pain but who:

- Had not or their carers had not consented to participate in the study.
- Had a Karnofsky score equal to or less than 40% whereby including them in the study would be a burden. Karnofsky score analyses performance status and measures the patient's activity of daily function and the progress of the disease, see appendix 9.9. Karnofsky a score of 40% characterise the functionality of a patient and is defined as some one who is unable to care for him or her self; requires equivalent of institutional or hospital care; disease may be progressing rapidly (Osoba David and MacDonald Neil, Oxford Textbook of Palliative Medicine Second Edition).
- Had not been disclosed to and did not know their sero-status.
- Had no knowledge of English or Luganda.

During the course of four weeks, 1,334 HIV-positive children 18 years and below attended the Centre. Of these, 267 were adolescents and 87 of these adolescents complained of pain. Eight subjects out of the 87 adolescents met the above criteria and were therefore eligible for the study. The number was small because a large proportion did not know their sero-status, as the carers were unwilling to disclose to their children.
In addition, a significant number were very sick with Karnofsky score of 40% or less and therefore ineligible, and some refused to consent.

3.4 DATA COLLECTION

The nurse explained the nature of the study to the study subject and the guardian/parent. After the study subject and carer acknowledged that the nature of the study was understood, a consent form was signed by the subject if he or she was 18-years-old or by his or her carer if not. There were two consent forms, one written in English and one written in Luganda, see attached appendix 9.3 (Consent to participate in the study of psychological impact on pain) and a Luganda translation 9.4 (Okukkiriza okwetaba mukunoonyereza okukwata ku nengeri endowoozazo gyeziyinza okwekwanaganyamu n'obulumi bwofuna).

After consenting, the subjects were given the patient information sheet attached as appendix 9.1 (Patient information sheet) and the Luganda translation of patient information sheet 9.2 (Omulwadde bye yetaga okumanya ). They were then forwarded to the doctor who collected the demographic data (see appendix 9.5 Questionnaire to filled by the Doctor). The demographic data collected by the doctor from the file included: file number, date of birth, age, sex, carer (parent/guardian), state of parents whether alive or dead, education level, residence, district, date of knowing sero-status and WHO stage of the disease. This was followed by information on pain characteristics, diagnosis, treatment given and department to which the subjects were referred and the reason for referral (see appendix 9.6 Characteristics of pain to be filled by the Doctor). The Doctor identified the psychological factors and noted them in the file. These factors included:
anxiety, insomnia, depression, boredom, social isolation, anger, fear and tiredness (see appendix 9.6).

A social worker conducted the interview with subjects referred from the doctor, and the proceedings were audio-recorded as recommended by Clark (1997). The interview schedule used by the social worker to collect the information required, consisted of open-ended questions, as recommended by Payne (1997) (see appendix 9.7 Questions asked by the social work for audiotape recording and a Luganda translation, appendix 9.8 Ebyetaagisa okubuuza omulwadde nga bye kwanaganya no’bulumi Social worker bye yabuuzu omulwadde nebikwatibwa kulutambi). The questions used, were developed and based on identified psychological factors as defined by Gaughan et al (2002) and were related to pain. The interviews were conducted face-to-face in the subject’s first language, English or Luganda. Collecting information using this method has advantages in situations where literacy is low or where writing can be difficult or impossible, such as for patients suffering pain Payne (1997). Each subject was interviewed once for about 30 minutes. The subjects were interviewed in the absence of their carers, so as to avoid any influence from them. The information recorded on the audiotape was later on transcribed for analysis as is recommended by Clark (1997).

The doctor followed up the study subjects after two weeks to find out the outcome of pain and the psychological factors he found (see appendix 9.6). This follow-up was intended to check on the treatment given for pain and the short out come on the psychological factors found at the first time the subjects presented for the study. The interview schedule was piloted on 3 subjects before commencement of the actual study. The results of the pilot assisted the researcher to adjust the questionnaire and other tools
in the appendices to collect the data. Confidentiality was strictly observed throughout the study by using numbers to identify the subjects.

3.5 ANALYSIS

The researcher used a thematic analysis approach on the data collected as used by Gantley (1999). The process involved identifying the issues revealed in the data, which were later categorized. The data collected by the doctor, that is the demographic and pain characteristics, other painful events and effect of pain on life and commonly mentioned psychological factors, were organized in a tabular form (see chapter four tables 4.1, 4.2, 4.3, 4.4 and 4.5). In table 4.4 chapter 4, the frequency of the effect of pain on life was determined and then recorded. The information was recorded beginning with the youngest subject in each table except in table 4.4 whereby the most frequently mentioned feeling was started with. By doing this, the information obtained was easily examined and compared with each study subject.

After transcription of the recorded interviews, information collected in Luganda was translated into English and then the response to each question obtained from each subject was put in a table form. The questions asked by the social worker are in appendix 9.7 (Questions asked by the social work for audiotape recording) and appendix 9.8 (Ebyetaagisa okubuuza omulwadde nga bye kwanaganya no’bulumi Social worker bye yabuuza omulwadde nebikwatibwa kulutambi). Similar responses generated by study subjects were coded by numbers. Each numbered response was regarded as an issue. Issues conveying a similar meaning were grouped together to form categories (see chapter four table 4.6.1 Categories and Themes developed for psychological impact of
pain on adolescents with HIV/AIDS). Themes were developed from these categories to
describe the study subjects psychological factors identified. This method of data analysis
is similar to that of Gantley (1999), described in the Beginner’s Guide To Developing A
Thematic Analysis.

3.6 ETHICAL ISSUES

The study had to consider the ethical issues right from the beginning, as Stone
(2002) mentions. There was no invasive intervention or drug trial administered to the
study subjects and the study did not affect the normal management of the subjects. They
were attended to in the usual way The Mildmay Centre clinic handles patients. The
interviews were conducted in the study subject’s first language so that a rapport was
established and better self-expression was possible. Only study subjects who knew their
HIV status were selected to avoid stress, which could have arisen with such information.
The subjects and carers were informed of the aim of the research and informed consent
was obtained from only the study subjects and carers who understood the nature of the
research. It was stated clearly to the study subjects that they were free to withdraw from
the research at any time they wished without compromising their care. The researcher
was aware that the audiotape-recorded interviews could be stressful for the subjects so
sensitivity during the process of getting the information was emphasized to the research
assistant. Those found stressed by the process were to be referred to a counsellor. Before
commencement of the study written permission was obtained from The Mildmay Centre
administration and the scientific and ethical committee of the University of Cape Town
South Africa.
CHAPTER FOUR
RESULTS OF THE STUDY

4.0 INTRODUCTION

The results of the study on the psychological impact of pain on adolescents suffering from HIV/AIDS are presented here, in two sections. The first section includes five tables starting from page 16, and in these tables the demographic data, pain assessment, number of painful events, patients feeling, and the psychological factors are all depicted. All this information was collected by the doctor before the patient proceeded for audio-tape recorded interviews.

The categories and themes, which were deduced from the data collected by textual analysis of the study subjects’ interviews, were put in a table form starting from page 21. In this chapter, this table is followed by quotations from the study subjects in order to provide a more complete picture of the subjects’ feelings.

After two weeks the outcome of study subjects pain and commonly identified psychological factors related to experience with pain is summarised in a table 4.6.12.1 on page 34.
CONTINUATION OF THE RESULTS

TABLE 4. THE SOCIAL DEMOGRAPHIC CHARACTERISTICS OF ADOLESCENTS WITH HIV/AIDS
AT THE MILDMAY CENTRE IN YEAR 2004

<table>
<thead>
<tr>
<th>Patient</th>
<th>Age</th>
<th>Sex</th>
<th>State of parents</th>
<th>Carer</th>
<th>Education level</th>
<th>Residence</th>
<th>District</th>
<th>Date of sero-status</th>
<th>WHO Stage</th>
<th>Date of first attendance</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>13</td>
<td>M</td>
<td>One parent</td>
<td>Mother</td>
<td>Senior 1</td>
<td>Mulago</td>
<td>Kampala</td>
<td>1997</td>
<td>II</td>
<td>28-9-1999</td>
</tr>
<tr>
<td>Three</td>
<td>14</td>
<td>M</td>
<td>Orphan</td>
<td>Grandmother</td>
<td>Senior 2</td>
<td>Muyenga</td>
<td>Kampala</td>
<td>Not known</td>
<td>II</td>
<td>25-3-2003</td>
</tr>
<tr>
<td>Four</td>
<td>15</td>
<td>M</td>
<td>One parent</td>
<td>Grandmother</td>
<td>Senior 3</td>
<td>Makindye</td>
<td>Kampala</td>
<td>15-12-1998</td>
<td>III</td>
<td>15-12-1998</td>
</tr>
<tr>
<td>Five</td>
<td>15</td>
<td>F</td>
<td>Orphan</td>
<td>Uncle</td>
<td>Senior 3</td>
<td>Mutundwe</td>
<td>Kampala</td>
<td>27-9-2002</td>
<td>II</td>
<td>1999</td>
</tr>
<tr>
<td>Six</td>
<td>15</td>
<td>M</td>
<td>Orphan</td>
<td>Aunt</td>
<td>Senior 3</td>
<td>Abayita</td>
<td>Wakiso</td>
<td>1991</td>
<td>II</td>
<td>23-1-2001</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Ababiri</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seven</td>
<td>16</td>
<td>F</td>
<td>Orphan</td>
<td>Aunt</td>
<td>Primary 7</td>
<td>Kawala</td>
<td>Kampala</td>
<td>15-6-1992</td>
<td>II</td>
<td>25-1-2000</td>
</tr>
<tr>
<td>Eight</td>
<td>18</td>
<td>F</td>
<td>Orphan</td>
<td>Aunt</td>
<td>Tertiary</td>
<td>Bugolobi</td>
<td>Kampala</td>
<td>9-5-2000</td>
<td>II</td>
<td>9-5-2004</td>
</tr>
<tr>
<td>Patient</td>
<td>Location</td>
<td>Duration</td>
<td>Frequency</td>
<td>Time when Worse</td>
<td>Pain Score VAS</td>
<td>Radiation to:</td>
<td>Nature</td>
<td>Aggravated</td>
<td>Relieved</td>
<td></td>
</tr>
<tr>
<td>---------</td>
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<td>-----------------</td>
<td>-----------------</td>
<td>-----------------</td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>Chest pain</td>
<td>8 months</td>
<td>All time</td>
<td>Night</td>
<td>7</td>
<td>Back</td>
<td>Like dressing wound</td>
<td>Cough</td>
<td>Drugs, Sleep</td>
<td></td>
</tr>
<tr>
<td>Two</td>
<td>Left side headache</td>
<td>1 month</td>
<td>On &amp; off</td>
<td>Night</td>
<td>7</td>
<td>Doesn’t Radiate</td>
<td>Couldn’t Describe it</td>
<td>Nothing</td>
<td>Drugs</td>
<td></td>
</tr>
<tr>
<td>Three</td>
<td>Headache</td>
<td>3 days</td>
<td>On &amp; off</td>
<td>Day</td>
<td>5</td>
<td>Doesn’t Radiate</td>
<td>Like carrying something heavy</td>
<td>Activities</td>
<td>Drugs, Resting</td>
<td></td>
</tr>
<tr>
<td>Four</td>
<td>Chest pain</td>
<td>&gt;6 months</td>
<td>On &amp; off</td>
<td>Night</td>
<td>6</td>
<td>Doesn’t Spread</td>
<td>Burning</td>
<td>Cold weather, Cough</td>
<td>Drugs, Cold drinks</td>
<td></td>
</tr>
<tr>
<td>Five</td>
<td>Frontal headache</td>
<td>1 Week</td>
<td>On &amp; off</td>
<td>None</td>
<td>6</td>
<td>Doesn’t Radiate</td>
<td>Throbbing</td>
<td>Fits</td>
<td>Drugs, Rest (Sleep)</td>
<td></td>
</tr>
<tr>
<td>Six</td>
<td>Lower abdomen</td>
<td>&gt; A year</td>
<td>On &amp; off</td>
<td>Night</td>
<td>4</td>
<td>No</td>
<td>Dull/ Burning</td>
<td>Walking</td>
<td>Nothing</td>
<td></td>
</tr>
<tr>
<td>Seven</td>
<td>Left Shoulder</td>
<td>1 month</td>
<td>All time</td>
<td>Constant</td>
<td>6</td>
<td>Elbow</td>
<td>Like hit by hammer</td>
<td>Hit on shoulder</td>
<td>Drugs, Rest, Sleeping on Rt side</td>
<td></td>
</tr>
<tr>
<td>Eight</td>
<td>Para-umbilical</td>
<td>1 Year</td>
<td>All time</td>
<td>Constant</td>
<td>10</td>
<td>All over abdomen</td>
<td>Burning</td>
<td>Walking, Stretching, Passing- urine</td>
<td>Milk, Magnesium, Morphine</td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>Painful events</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>Abdominal pain, body aches, neuropathic pain, headache</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Two</td>
<td>Dysphagia, neuropathic pain, chest pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Three</td>
<td>Abdominal pain, neuropathic pain, ear pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Four</td>
<td>Abdominal pain, acute tonsillitis, headache</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Five</td>
<td>Neuropathic pain, abdominal pain, dental pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Six</td>
<td>Headache</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seven</td>
<td>Headache, abdominal pain, ear pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eight</td>
<td>Dysphagia, dental pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
TABLE 4.4 EFFECT OF PAIN ON LIFE OF EIGHT ADOLESCENTS WITH HIV/AIDS AT THE MILDMAY CENTER IN THE YEAR 2004

<table>
<thead>
<tr>
<th>Effects of pain on life</th>
<th>Frequency (Number of adolescents who complained)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not able to go school &amp; Affects studies</td>
<td>4</td>
</tr>
<tr>
<td>Not able to walk &amp; do any activity</td>
<td>4</td>
</tr>
<tr>
<td>Not able to sleep</td>
<td>2</td>
</tr>
<tr>
<td>Sleep all time</td>
<td>2</td>
</tr>
<tr>
<td>Not able move shoulder</td>
<td>1</td>
</tr>
<tr>
<td>Admission to hospital</td>
<td>1</td>
</tr>
<tr>
<td>Double vision</td>
<td>1</td>
</tr>
<tr>
<td>Feeding in NG Tube</td>
<td>1</td>
</tr>
</tbody>
</table>
TABLE 4.5 THE COMMONLY IDENTIFIED PSYCHOLOGICAL FACTORS AND REFERRAL DONE FOR MANAGEMENT OF EIGHT ADOLESCENTS WITH HIV/AIDS AT PRESENTATION AT THE MILDMAY CENTRE IN THE YEAR 2004

<table>
<thead>
<tr>
<th>Patient</th>
<th>One</th>
<th>Two</th>
<th>Three</th>
<th>Four</th>
<th>Five</th>
<th>Six</th>
<th>Seven</th>
<th>Eight</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Psychological factor</td>
<td>Depression</td>
<td>Social isolation</td>
<td>Insomnia</td>
<td>Social isolation</td>
<td>Boredom</td>
<td>Social isolation</td>
</tr>
<tr>
<td>Referral</td>
<td></td>
<td>Occupational therapy</td>
<td>Spiritual care and Bereavement</td>
<td>Counselling</td>
<td>Counselling</td>
<td>Counselling</td>
<td>Counselling</td>
<td>Counselling</td>
</tr>
</tbody>
</table>
4.6 RESULTS FROM THE RECORDED INTERVIEWS ON THE PSYCHOLOGICAL IMPACT OF PAIN ON ADOLESCENTS WITH HIV/AIDS AT PRESENTATION.

The psychological factors and categories from which the themes were developed are shown in the table below. After the table some quotations from the study subjects are presented.

**TABLE 4.6.1 CATEGORIES AND THEMES DEVELOPED FOR PSYCHOLOGICAL IMPACT OF PAIN ON ADOLESCENTS WITH HIV/AIDS**

<table>
<thead>
<tr>
<th>PSYCHOLOGICAL FACTORS</th>
<th>CATEGORIES</th>
<th>THEMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Commonly identified psychological factors related to experience with pain</td>
<td>Categories developed from study subjects' different experiences of pain</td>
<td>Themes describing the psychological impact of pain on adolescents</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Feel: crying, unhappy, bad, uncomfortable, resting or sleeping, death</td>
<td>Distress</td>
</tr>
<tr>
<td></td>
<td>Pain may: fail to go, no one can take it away, HIV has no cure</td>
<td>Disappointment</td>
</tr>
<tr>
<td></td>
<td>Sweating and heart beat may or may not be present</td>
<td>Autonomic Nervous System Effects</td>
</tr>
</tbody>
</table>
Continuation of Table 4.6.1

<table>
<thead>
<tr>
<th><strong>PSYCHOLOGICAL FACTORS</strong></th>
<th><strong>CATEGORIES</strong></th>
<th><strong>THEMES</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Commonly identified psychological factors related to experience with pain</td>
<td>Categories developed from study subjects’ different experiences of pain</td>
<td>Themes describing the psychological impact of pain on adolescents</td>
</tr>
<tr>
<td>Missing or leaving school, failure to play and enjoy, failure to walk and do exercise, don’t want do anything or be disturbed</td>
<td>Withdrawal</td>
<td></td>
</tr>
<tr>
<td>People think adolescents are lying, they are not helped, and are forced to work</td>
<td>Upset</td>
<td></td>
</tr>
<tr>
<td>Fear of losing life or any part of the body like a leg or a hand, body image, skin rash</td>
<td>Apprehension</td>
<td></td>
</tr>
<tr>
<td>Can’t talk to friends, crying, lose interest reading and going to school, sleeping all time, useless to friends, don’t fit in society</td>
<td>Misery</td>
<td></td>
</tr>
<tr>
<td>Pain all time, can’t do anything, feel weak, no power, can’t help his/herself</td>
<td>Hopelessness</td>
<td></td>
</tr>
</tbody>
</table>
Continuation of Table 4.6.1

<table>
<thead>
<tr>
<th>PSYCHOLOGICAL FACTORS</th>
<th>CATEGORIES</th>
<th>THEMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Commonly identified psychological factors related to experience with pain</td>
<td>Categories developed from study subjects’ different experiences of pain</td>
<td>Themes describing the psychological impact of pain on adolescents</td>
</tr>
<tr>
<td>Insomnia</td>
<td>Over think, get dreams, sleep on and off</td>
<td>Restlessness</td>
</tr>
<tr>
<td>Tiredness</td>
<td>Work, walking and weak and sleeping all time</td>
<td>Exhaustion</td>
</tr>
<tr>
<td>Social isolation</td>
<td>Don’t want: stay alone, noise, disturbance and weakness, fear of being laughed at, friends don’t keep secrets, no fun</td>
<td>Separation</td>
</tr>
<tr>
<td></td>
<td>No: love, care, and problems not shared</td>
<td>Rejection</td>
</tr>
<tr>
<td>Other findings apart</td>
<td>If assisted and I could assist you too.</td>
<td>Empowerment</td>
</tr>
<tr>
<td>from the above psychological factors</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


4.6.2 Adolescents' definition of pain.

The responses given by the study subjects as to the definition of pain fall under the following major categories: like a wound, sickness, discomfort, unhappiness, and injury.

"Pain, pain is, it is kind of wound. It is wound that takes long to cure, especially for someone who is HIV positive..." (16-year-old female).

"Pain is when you feel that you are not happy... when some part of your body is not okay..." (14-year-old male).

"Pain comes in many ways, you may have pain you have got an injury..." (13-year-old male).

4.6.3 Anxiety

Adolescents' anxiety regarding pain was expressed by the following themes:

4.6.3.1 Distress

Many adolescents described that pain makes them feel like crying, being unhappy, feeling bad, uncomfortable, thinking of resting or sleeping and worrying about death; from these responses the theme of distress was developed. Apart from thinking that one is going to die, some think of committing suicide as a solution to the pain they are experiencing. Seven out of eight adolescents interviewed wished to die in order to avoid the suffering pain is causing to them. Two of them wished to commit suicide; one said she wanted to do so by taking an over dose of medicine.
“But if you are in pain you can’t do anything...it becomes overwhelming and you feel like resting” (18-year-old female).

“I think of two things, to die and avoid suffering, or get cured and stay well...” (14-year-old female).

“When I am in too much pain...get other problems like I might be tempted I feel like giving myself an overdose of medicine... so that I die and leave the world...” (15-year-old female).

4.6.3.2 Disappointment

Adolescents expressed disappointment because of a combination of having two incurable problems: HIV/AIDS and the pain that often comes along with the disease. They think pain may fail to go, no one can take away the pain and yet HIV/AIDS has no cure.

“You feel bad, you can’t tell when pain will go so that you can do what you would have liked to do” (15-year-old male).

“...I knew I was HIV positive and so I sank into depression and it was kind of big burden to my life.... may be I knew it very well there is no cure...” (16-year-old female).

4.6.3.3 Autonomic Nervous System Effects

The autonomic nervous system effects of sweating and heartbeat are not common problems, as majority of the adolescents did not or rarely experienced these effects when in pain. Two out of eight subjects mentioned that they never sweat when in pain. Four of
eight said that they rarely or sometimes sweat. As far as heartbeat is concerned, three out of eight subjects said that their heartbeat does not change when in pain. When pain comes, “I rarely do sweat” (18-year-old female).

“When pain comes sometimes I sweat, sometimes I don’t sweat” (13-year-old male).

“Ya when I am in pain my heart beats faster, and I become thinking most and when I think most my heart start pumping at high level” (13-year-old male).

Does your heart pump a lot when you are in pain? “No” (15-year-old male).

“Sometimes it pumps, other times not, it stays as usual... i am worried of pain, that is why the heart pumps faster” (14-year-old female).

4.6.3.4 Withdrawal

Four out of eight adolescents expressed their concern that pain can result in missing or leaving school. Pain could not allow three out of eight adolescents to play, enjoy, walk and do exercise. Some did not want to do anything or be disturbed at all when they are in pain.

“The other worries are may be stopping studying, because of pain... instead of concentrating on your studies, definitely you won’t listen to the teacher” (16-year-old female).

“I do loose my studies because I like going to school very much and when I am in pain, I am so worried because I do miss studies... Else... I always do...like being in groups... I want to be groups playing...but when I am in pain I am in my own place not enjoying... ” (14-year-old male).
“...when you are sick...you can’t walk, can’t do any exercise to make your body strong” (18-year-old female).

4.6.4 Anger

Adolescent’s anger regarding pain was expressed by the following themes:

4.6.4.1 Upset

Adolescents get upset when in pain because others often think they are lying and they can fail to be helped and even are forced to work when in pain. Three out of eight adolescents said people think that they are lying, while six of them were not helped. Five out of eight adolescents were upset because they were forced to work.

“I also feel annoyed when I am in pain and fail to get somebody maybe to stay close to me and may be give me some counselling and help me in some things, like giving me medicine take care of me...” (15-year-old male).

“...when they hear somebody saying that you are sick, they laugh, and say it is not true” (18-year-old female).

“...well I am in pain but say...you must go and fetch water, then after fetching water you will talk of your pain” (14-year-old male).

“...write funny things on my report that I dodge classes what they don’t know that I have HIV” (15-year-old female).
4.6.5 Fear

Adolescent's fear regarding pain was expressed by the following theme:

4.6.5.1 Apprehension

Adolescents were apprehensive because they expressed fear of losing life or any part of the body. Four out the eight subjects expressed fear to lose life, while four out of eight expressed fear to lose any body parts.

"So you might be having pain when they have knocked you and they say, we are going to cut off your leg because it is not going to walk again...that the leg is already expired..." (13-year-old male).

"... the fear pain brings to my mind is that, I fear... i fear...dying though death is for everybody." "...my friends...some feel they want to take me to the bathroom and show which I don't want to do because they ask me what happened to your skin so...I fear" (15-year-old female).

4.6.6 Depression

Adolescent's depression regarding pain was expressed by the following theme:

4.6.6.1 Misery

Almost all adolescents expressed misery, as they felt unable to talk to friends and found themselves like crying all the time. Another source of misery pain can bring in adolescents is losing interest in reading and going to school. They will find themselves sleeping all the time, hence became estranged from friends and society.
“...you may lose interest or in reading books...when I don’t read books and first of all I will not pass because I am in pain... When people are infected with the virus, HIV virus may think that that is the end of the world...which is not true” (16-year-old female).

“When I am sick and very weak, when I am very weak I feel I am useless...” (14-year-old female).

“You feel unhappy or useless...” Because you will be sleeping all the time, alone with nobody around you, nobody to talk to” “Whenever pain comes, when you can't do what you would like to do, and stay in pain all the time...” (15-year-old male).

4.6.7. Boredom

Adolescent’s boredom regarding pain was expressed by the following theme:

4.6.7.1 Hopelessness

All subjects expressed hopelessness, as pain can make them feel weak and they can struggle to help themselves or do anything active.

“...it might be a little pain i do not take care of it and afterwards it end in becoming bigger and bigger” (14-year-old male).

“...you might be in pain when you can’t, ...you might want to have something when that one who is giving you treatment is not around or has gone to get...or you want to go for a short call but you lose power, ...you can’t help yourself and what you do you find even when you have urinated on the bed..” (15-year-old male).
4.6.8 Insomnia

Adolescent's insomnia regarding pain was expressed by the following theme:

4.6.8.1 Restlessness

All subjects felt restlessness because pain was leading to worrying, dreams, and trouble sleeping.

"I keep awake because there are some people.... somebody tells you are feeling pain when he or she sleeps in the morning they will tell you now the person is dead..." (15-year-old female).

"Pain, dreams and thoughts, can all prevent me from sleeping..." "...tell him (brother) what I have dreamt and got scared,..." (14-year-old female).

"When pain comes you ...you might even not do what... get asleep." "When pain goes off slowly ...you get some sleep like for two minutes, and again it comes back, you wake up for some other five minutes....so you find the whole night, you have slept for just six minutes" (13-year-old male).

4.6.9 Tiredness

Adolescent's tiredness regarding pain was expressed by the following theme:

4.6.9.1 Exhaustion

Four out of eight adolescents get exhausted because of pain. Exhaustion results in sleeping all the time, as mentioned by two out of the eight adolescents. Three out of eight adolescents reported that they are exhausted because of working or walking when experiencing pain.
“...you might feel in pain,...you could have no power to do what...to play, instead of playing you could be thinking about treatment.” (13-year-old male).

“Work, when am in pain I have a little pain and am doing some work, that work makes me tired just a little...in a little time because am feeling pain” (15-year-old male).

“Because of sleeping all time, you can’t sit with others, this makes your body tired” (15-year-old male).

4.6.10 Social isolation

Adolescent’s social isolation regarding pain was expressed by the following themes:

4.6.10.1 Separation

The subjects reported that while they usually would not like to stay alone, they often end up separated from others for various reasons related to their pain. Four out of eight adolescents separate from others when in pain because of noise and a desire to avoid being disturbed. Two of them separate from others for fear of being ridiculed. Weakness was one of the reasons why almost all adolescents in pain decide to separate from others. One adolescent avoids friends because peers do not keep secrets and they fear many finding out about their pain.

“I like staying with people and talking to people... there are some people in society who don’t bare others ...some people will laugh at you” (16-year-old female).

“You don’t want anybody to make noise, to be bothered...if you are alone no body will be saying you have AIDS or you are in pain.... sometimes you get wrong friends who can’t keep your secret and they go on telling everybody” (18-year-female orphan).
"...don't want fun...you want to be alone your own life because of pain" (14-year-old male).

"...sometimes you feel weak and you decide to stay there, sitting..." (14-year-old female).

4.6.10.2 Rejection

When adolescents in pain are not shown love and care they feel rejected, as three out eight subjects pointed out. Two out eight feel rejected if their problem is not shared with others.

"...whenever you don't show love to a child, the child over thinks,... but if you show love a child forget all about other things... and avoid to regretting why he or she was produced" (15-year-old female).

"I would like to guide my fell people that when you are in pain ... try to share your problem with your elder person near you, your teacher or counsellor or a doctor any one you can see faster " (14-year-old male).

4.6.11 Other findings in relation to pain

The following theme was developed from other findings adolescents had in relation to pain:

4.6.11.1 Empowerment

Two out of eight adolescents had no other things to say in relation to pain. One suggested that empowering him could lead him to assist other people.

"...if we have something we are missing, you assist us, even us you might find that we assist you " (13-year-old male).

The doctor who saw and gave treatment to the study subjects followed them up two weeks later to check on the treatment given and the short outcome of the psychological factors. However the subject who reported a pain score of 10 and was put on morphine came before the two weeks to assess his pain and again later with the other study subjects. The results are summarised and presented in the table below.
TABLE 4.6.12.1 THE OUTCOME OF PAIN AND COMMONLY IDENTIFIED PSYCHOLOGICAL FACTORS FOUND BY THE DOCTOR ON FOLLOW-UP OF EIGHT ADOLESCENTS WITH HIV/AIDS AT THE MILDMAY CENTRE IN THE YEAR 2004

<table>
<thead>
<tr>
<th>Patients</th>
<th>One</th>
<th>Two</th>
<th>Three</th>
<th>Four</th>
<th>Five</th>
<th>Six</th>
<th>Seven</th>
<th>Eight</th>
</tr>
</thead>
<tbody>
<tr>
<td>Out come of</td>
<td>Openness, calmness</td>
<td>Positive attitude</td>
<td>Being accepted in home</td>
<td>Depression went down</td>
<td>Was able to cope with another family</td>
<td>Improved</td>
<td>Got better</td>
<td>Improved</td>
</tr>
<tr>
<td>commonly identified psychological factor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain on VAS</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>
CHAPTER FIVE

DISCUSSION OF THE STUDY RESULTS

5.0 INTRODUCTION

In this discussion there is a brief comment about the results presented in tables, that is, the social demographic characteristics, the pain characteristics, the effect of pain on life and psychological factors found on the first encounter with the doctor. This is followed by the adolescents' description of the way they understand pain. Thereafter a discussion of the themes developed from the information given by the study subject follows. It is important to note that some themes cut across several psychological factors. The outcome of pain and commonly mentioned psychological factors will be discussed. This discussion will not be detailed because the study was not focused on measuring pain and the details of psychological factors recoded by the doctor was not available.

5.1 THE SOCIAL DEMOGRAPHIC CHARACTERISTICS OF ADOLESCENTS WITH HIV/AIDS

The study subjects were adolescents between 13 years and 18 years of age, and while the study did not intended to balance the gender, there were 4 males and 4 females. As the number of adolescents living with HIV/AIDS continues to increase (American Academy of Pediatrics, http://www.aap.org/policy/re9827.html 14/02/2003)- probably due to improved management of OIs and use of ARVs- the risk of transmission of HIV to uninfected adolescents is likely to increase. The number of adolescents with psychological factors impacting on pain subsequently will increase as well. It will be
problematic if the psychological factors in adolescents increase without their depth being fully understood. This increase will lead to an increased demand for people with good knowledge of pain management in this age group. In turn there will be increased demand in training health workers to meet the demand, which will put a big burden to majority of African countries, which have limited resources. Training could benefit health workers if the psychological impact of pain on adolescents are well-understood and carefully explained in such trainings. These factors have been brought out clearly by the research and are mentioned in the subsequent discussion.

Of the adolescents involved in the study, six were orphans who had lost both parents, while two others had lost one parent. Most of them had carers like aunts, uncles and grandmothers while one was staying with a sister and another with a mother. In the absence of ARVs and access to drugs for management of OIs by the time HIV/AIDS children become adolescents, they would have lost their parents and end up being cared for by relatives. The psychological distress depends on many factors, social support being one of them, as mentioned in the Overview of Pain in patients with HIV/AIDS, http://www.hivpositive.com/f-Pain/LS7.6.html 29/12/2004. The social outcome of these children depends on the way they are handled, so the themes describing the psychological impact of pain in this research could have been a result of this.

It is known that adolescent girl orphans normally take over the woman's role of doing the domestic work, which would make her psychological burden greater (Malinga 2002). In this study the four male and the four female study subjects were lucky because they all had carers and were not the heads of the families. Subjects who survived as
caretakers in childhood households would probably have been encountered if the study was done on a larger sample as this is common in Uganda.

If the relatives repressed or denied these children grief when they lost their parents - as is common for adults to think that children do not grief or their grief is shorter and mild (Breige 1996) - then the psychological problems these adolescents are going through might result in psychiatric illnesses.

It is important to note that adolescents could have many of these problems even in the absence of pain and HIV/AIDS. This is especially true for orphaned adolescents. A combination of adolescence and orphanhood might have influenced the results of the study. The result of being orphaned by the time HIV/AIDS children become adolescents needs to be studied further. In addition, a quantitative research with a larger sample might be necessary to ascertain whether this is true. This situation is likely to be different in countries with access to ARVs, because lives of parents of such children would be prolonged and the children would also have access to treatment. Once they have access to treatment then their immunity will be boosted and the chance of contracting OIs reduced. Further study would be needed to make thorough recommendations for other countries.

The majority of the study subjects were attending school. The highest level of education was tertiary institution, while the lowest of the subjects was primary seven. One subject’s education status is unknown, she was staying with a sister who was probably not in position to pay school fees. Lack of education is one of the commonly recognised problems faced by orphans, however in this study almost all subjects were going to school. All were staying in Kampala district, except stayed in Wakiso district. Both districts are in urban areas and this might also have influenced the research results.
All the subjects knew their sero-status and were all in WHO stage II of the disease except one who was in stage III. One subject was told about her HIV status late compared to the others. This is not a surprise because a lot of children are not told their status. The information gathered from the following website, http://aapolicy.aappublications.org/cgi/content/full/pediatrics;103/1/64 30/9/2005, indicates that between 25 percent and 90 percent of school-age children with HIV/AIDS have not been told they infected. It took her a long time to know because disclosure of HIV status in children is difficult. In most cases the carer and the child are not ready to handle the news. It is the level of maturity of an individual child that affects his or her ability to handle the news and adults face many problems that also affect their ability to deal with the disease and the pain it causes (Boland, Mahan-Rudolph, Evans, 1989). Knowledge of their status by the time of the study was very useful in the research context of data collection because it eliminated emotional upsets. It is mentioned in the American Academy of Pediatrics (http://www.aap.org/policy/re9827.html 14/02/2003), that children who knows their HIV status have a higher self-esteem than infected children who are unaware of their status. All had attended The Mildmay Centre for more than a year, and hence were in a familiar environment, which could also have enhanced their confidence in communication during the recorded interviews.

The intervention strategies proposed later in this report would require, as a prerequisite, the determination of the level of support carers are providing the adolescents. If problems are identified with either the quality or form of support, carers need to be given the necessary assistance. The coping capacities, personality and medical
factors also need to given attention, as is mentioned in the Overview of Pain in patients with HIV/AIDS (http://www.hivpositive.com/f-Pain/LS7.6.html 29/12/2004).

5.2 PAIN CHARACTERISTICS OF ADOLESCENTS WITH HIV/AIDS

Before a detailed interview was carried out, the research assistant assessed the study subject's understanding of the characteristics of pain. It was established that all the study subjects could localize the site of their pain, and that they could talk about the duration and frequency of the pain. The majority had the pain on and off, but a few had it all the time. Their pain was described as burning, throbbing and like a wound. They also mentioned that the pain could be worsened by activities and relieved by drugs. These results increased the author's confidence in carrying out the research because the study subjects had a good knowledge of their own pain.

The Visual Analogy Scale (VAS) was used to measure the study subject's pain. The scale ranges from 0 up to 10, point 0 means no pain and 10 is pain as bad as you can imagine (Ingham J and Portenoy R Oxford Textbook of Palliative Medicine Second Edition). The severity of pain measurement is very important because it helps to follow the course of pain and to assess the effect of treatment.

After explaining the study subjects how to use the VAS, they were requested to measure the severity of their pain by selecting the number which best describes their pain. The study subject's rated their pain and it ranged from 4 to 10 on the VAS. There was one subject who measured his pain to be at 10 meaning that his pain was as bad as you could imagine. Majority had moderate pain between 5 and 7 on the VAS. The study subject's pain was treated according to the cause and using the WHO analgesic ladder

Those with a score of 4 were given paracetamol, a Non-steroidal Anti Inflammatory Drug (NSAID) step one drug and those with scores between 5 and 7 were given diclofenac, a NSAID, plus codeine a weak opioid step 2 drugs. The one who had a score of 10 was given morphine solution a step 3 drug. This patient was the one given a short appointment in order to assess the effectiveness of the drug.

All study subjects had experienced pain for some time, were very articulate about their pain and were able to express a vivid description of pain. The author became more confident because the questionnaire used in audio-tape recording required a subject who could conceptualize his/her feeling about pain. The level of education might have contributed to the effective way these subjects articulated their pain. Probably the situation would have been different if the study was done in a rural area with subjects that had lower levels of education. However this is a clear demonstration that children experience pain and deserve proper attention and management of their pain. The level of understanding demonstrated by the adolescents should be utilized in the pain assessment in order to offer proper pain management. This level of understanding is also mentioned in Palliative Care and Symptom Management, Pain and Children (http://www.cansearch.org 21/04/2005) specifically that teens can be quite responsible and descriptive about their pain.
5.3 OTHER PAINFUL EVENTS SUFFERED BY EIGHT ADOLESCENTS WITH HIV/AIDS AS NOTED FROM THE FILES AT THE MILDMAY CENTRE IN YEAR 2004

All the adolescents had at least three or more painful events, as shown in table 4.3. The prevalence of pain in HIV/AIDS ranges from 40% to 60% in adults and from 20% to 50% in children (Breitbart et al, 1991). Out of those in pain 80% will report one or more painful symptoms over the period of 6 months (http://www.hivpositive.com/f-Pain/LS7.6.html, 29/12/2004). The results from this study are in agreement with the literature because all the adolescents who had pain reported at least three or more painful events. Cornblath and McArthur (1988), mentioned HIV related peripheral neuropathy is a painful condition and it affects up to 30% of people with AIDS. Shingles or Herpes Zoster is one the recognized HIV-related conditions which cause pain as mentioned in the overview of pain in HIV/AIDS (http://www.hivpositive.com/f-Pain/LS7.6.html, 29/12/2004). In this study, four out of eight adolescents had ever suffered from Neuropathic pain due to Herpes Zoster. Herpes Zoster is one of the OIs, which can affect HIV patients at an early stage, and all the study subjects were in stage II except one who was in stage III. Other common painful events noted were, abdominal pain, shoulder joint pain and headache. These painful events are among the most commonly reported pain syndromes (Breitbart, et al, 1988, Lebovits, et al, 1989, Schofferman, Brody, 1990, Singer, et al. 1993). In majority of the subjects the abdominal pain and headache were due to malaria, which is also very common in Uganda in both HIV positive and negative patients. In some patients dental, chest and throat infection were the cause of pain. All

5.4 EFFECT OF PAIN ON LIFE ON ADOLESCENTS WITH HIV/AIDS

When adolescents were asked about the effect of pain on their lives, the answers given indicated that they had some problems that needed to be explored in depth. The problems that were quickly apparent included sleep disturbance, inability to walk, attend school or to do any activity. The most commonly mentioned effect on their lives, with a frequency of four, was the inability to go to school and carry out activity. The second most common effect was sleep disturbance, which had a frequency of two. This is in line with the WHO report of 1998 on children with cancer and HIV/AIDS, which mentioned that pain has devastating physical and psychological effects. These effects came out more clearly from the recorded interviews where further discussions of these effects are dealt with in detail in section 5.6.

A holistic assessment of physical, psychological, spiritual, cultural and social aspects of the patient needs to be done- as mentioned in pain control in children in Hospice Africa Uganda third edition 2002- if patients suffering from pain are to be relieved of their problems. The effects of this suffering were made more clear in the recorded interviews. Further discussions of these effects are dealt with in detail in section 5.6.
5.5 THE PSYCHOLOGICAL FACTORS FOUND AT PRESENTATION

In the study subjects’ files, the doctor found the psychological factors mentioned in table 4.5. The psychological factors captured were insomnia, social isolation, anxiety, depression and boredom. This is in line with the current literature (Pain in patients with HIV/AIDS, Pain and pain management Modalities, http://www.hivpositive.com/f-PainHIV/Pain/LS1_4.html 29/12/2004), which states that psychological factors affect pain management. Unfortunately the details of these commonly mentioned psychological factors were unavailable. This is one of the reasons why this research was conducted; when one looks at these factors as they are mentioned in the literature one cannot tell exactly what is included in them and as a result no effective intervention can be worked out.

The subjects were referred for: counselling, spiritual care and occupational therapy to address the psychological factors. After compiling all the data it become apparent that the intervention from counselling, spiritual and occupational departments, where these subjects were referred, would have been much better if details of the psychological factors were found out. A further study to quantify the effectiveness of these interventions would be valuable.

5.6 THE RECORDED INTERVIEWS ON PSYCHOLOGICAL IMPACT OF PAIN ON ADOLESCENTS WITH HIV/AIDS

5.6.1 Adolescents definition of pain

The study subjects described pain as: a wound, sickness, one being uncomfortable, not being happy, being in agony and a feeling you get when injured.
Their understanding of pain is almost similar to the way International Association for Study of Pain (1986) describes it. In this study pain is defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Distress was the theme developed from the study subjects’ descriptions of pain.

Adolescents are in a transitional period between childhood and adulthood and it is during this period when many changes take place in their bodies. These changes are physical, intellectual, emotional and social as mentioned by Fisher (1987). When these changes are taking place for normal development of an adolescent, pain negatively impact on them. As a result pain can be a real frustration to this age group if they fail to walk, carry out activities and go to school, where they expect to equip themselves with the knowledge. That is the reason why it is important to carry out a holistic assessment as mentioned in Hospice Africa Uganda third edition 2002, in order to find and address all the above problems.

5.6.2 Distress

Distress is one of the themes developed under anxiety because pain makes adolescents feel like crying, being unhappy, feeling bad, uncomfortable, thinking of resting or sleeping and worry about death. Some of this information was captured in the first encounter the study subjects had with the doctor and then in the recorded interview details of psychological impact of pain came out more clearly.

One factor that was mentioned by two adolescents was thinking of committing suicide by taking an overdose of medication. However when the social worker inquired
whether the study subjects were still thinking of committing suicide, the response was no because they had continued coming to the Centre and were counselled. The social worker had to find out whether those thoughts are still present so that necessary action could be taken. It was stated clearly right before the commencement of the research that if subjects were found stressed appropriate action were to be taken. The reason given for committing suicide was that pain could make life meaningless and death would be a solution to escape this suffering. This is alarming because HIV/AIDS patients are prescribed many drugs and most likely few doctors and carers have ever thought that adolescents get such strange feelings. A similar situation could occur in patients facing severe pain in other life threatening illnesses. In Musisi and Kinyanda’s research report of 2002, suicide attempts was one of the psychiatric findings in adolescents with HIV in general, but this research has shown pain specifically can cause adolescents to think about suicide. Apart from pain, these suicide tendencies could be the result of poor bereavement suffered by these children when they were young as Breige (1996 in Helping children to grieve) quoted Jewett (1982).

Musisi and Kiyanda (2002) used a SRQ-25 tool which involves a yes or no response to a set of standard questions; however in this research, questions aimed to prompt the study subjects to conceptualise, in their own language, the way they feel when in pain. This study found that an adolescent’s mind can be much occupied by thoughts of death. One 15-year-old female was so concerned about her death and that of her sister as mentioned in Chapter four section 4.6.3.1. Death was not new to these adolescents because all study subjects were orphans; they had lost one or both parents. Since the prevalence of pain in HIV/AIDS ranges between 40 to 60% (Breitbart W.et al, 1991)
some parents of these children- if not all- are likely to have died in pain. This could be one of the reasons why these children's minds are so preoccupied with death when in pain; they probably conclude that they are going to face the same fate their parents faced. The study looked at eight subjects who are part of the 11% of Uganda's HIV/AIDS orphans (UNAIDS/WHO, 2002). These subjects attend busy clinics where most health workers do not investigate and cannot imagine what goes on in the minds of such patients. It is very likely that the health workers do not consider that death is one of the thoughts they hold; however it is, as seven out eight subjects mentioned so.

Some physical factors cut across other psychological factors; an example is the strange feeling of crying. It is found in the way adolescents understand pain and also in causes of anxiety. Pain makes them cry, as mentioned in chapter 4, because they are not happy, they can't display their talents anywhere. Crying could be a response to the physical hurting, but in this study it was indicted to be a result of distress because it was not the first time they were getting pain. Sometimes they would have wished to walk around, but pain won't allow them and they end up lying down in distress.

If health workers- especially doctors- were required to take detailed history and be prepared to listen and probe adolescents who present pain, all these factors surrounding the theme of distress would clearly be brought to light. Once a proper assessment is done and all these factors are captured, then appropriate intervention can be applied and suffering will be alleviated.
5.6.3 Disappointment

Disappointment is another theme developed under anxiety. When adolescents in pain are faced with the uncertainty of pain clearing or getting something to clear the pain, they often feel disappointed. Though during anxiety one will be agitated, adolescents expressed disappointment as a sign of giving up, they felt nothing could relieve their pain. Adolescents often have much they wish to do and are disappointed when pain prevents them from doing so. It is clear that pain can effect stages similar to those one might experience when grieving, namely anger because of pain, bargaining for pain to go, depression if pain fails to go and acceptance when pain becomes chronic. It is only denial found in grieving which do both not share, and also treatment plans in both cases are different.

For these adolescents, disappointment is aggravated by the knowledge that HIV/AIDS has no cure. Having persistent pain and HIV/AIDS leads to a combination of two incurable conditions, as mentioned in Chapter four section 4.6.3.2, and can be a source of big disappointment in their lives. This is a realistic impression because pain control in children is reported to be poor due to myths surrounding pain perception in children. One of the myths, which specifically apply to this age group, is addiction to opioids (Pain and Children, http://www.cansearch.org 21/04/ 2005).

The study examined few subjects but it demonstrated that pain is still under treated in children. Health workers must take detailed history if they have to get at some of these psychological factors. Good knowledge of pain control in adolescents is also essential in order to alleviate the disappointment and distress associated with pain.
5.6.4 Autonomic Nervous System Effects

The autonomic nervous system effect was developed from anxiety. Sweating and fast heartbeat, were not consistent expression when adolescents were in pain. The majority of study subjects did not or rarely experienced these effects, as mentioned in section 4.6.3.3 in Chapter four, yet they are classified under psychological factors related to pain. The autonomic effects were not or rarely experienced probably because most study subject were not having acute pain.

5.6.5 Withdrawal

Withdrawal is the last theme under anxiety and was developed from the following categories: missing or leaving school, failure to play and enjoy, not wanting to do anything or to be disturbed. Adolescents are often conflicted of what they want. An example is when they may wish to be alone and on the other hand they also want to be of the group (Fisher 1987). The research has shown that when in pain, adolescents exhibit a version of this. They want to stay with friends so that they can play and be happy. However, when in pain they are forced to withdraw from society at the expense of all what they would have liked to do in a group.

Missing or leaving school because of pain is a very difficult issue for adolescents. They are aware that their future lies in education, so when pain interferes with school programs they find themselves withdrawn. Besides worrying about their future, they also miss chances of competition. Adolescents love to take part and shine in active sports (Fisher, 1987). Once in pain they will be disrupted from this activity. They also expressed that pain will lead to unfair competition because they are given similar exams to those
who do not miss school. As a result, they end up performing poorly as mentioned in Chapter four section 4.6.3.4. One tried to force himself to go to school but because of lack of concentration due to pain he ended up stopping going.

Awareness of their sero-status can be a cause for the withdrawal from the society because they think everybody looking at them will be saying that they are HIV positive. However this will be contradictory to the American Academy of Pediatrics (1999) report, which says that children who know their status have a higher self-esteem, than those who are unaware of their status. If they decide to withdraw, the author would look at it as self-discrimination because the withdrawal would be due to the adolescent’s feeling, not a reaction from the community. Stigma is a big problem in communities, but this research has shown that adolescents’ state of mind rather than his or her perceived prejudice within the community can also lead to withdrawal from the community.

Adolescents reported that they don’t want to do anything or to be disturbed when in pain. Pain leads to them to withdraw from society in order to avoid being asked to do work which would increase their pain. Adolescents could be forced to work either because their carers do not know that they are in pain or because the family’s circumstance is such that, even when the carer is aware of the adolescent’s pain, the adolescent still must do his or her part to support the family. As Malinga (2002), reported uncles and aunties may also fall sick and become unavailable. Then the responsibility of work can fall on other people like women, young girls, grandmothers or the orphans themselves.

The community, school authorities and relatives or carer of adolescents need to understand the situation and render the necessary support. Pain and psychological distress
as a result of pain is a responsibility of everybody. It is only when this is realized, that 
adolescents will have the opportunity to lead a reasonable life and minimize their 
discomfort.

5.6.6 Upset

Upset was a theme developed under anger because when adolescents are in pain 
people often think they are lying, and they fail to be helped and are forced to work. 
People with HIV/AIDS- especially in advanced stages- tend to be weak. If a child is born 
with HIV, by the time he or she survives to adolescents he or she will be in advanced 
stages of the disease, as the study demonstrated that seven out of the eight study subjects 
were in stage II see table 4.1. In the literature review in chapter two section 2.1 it is 
mentioned by Breitbart et al (1991) that the prevalence of pain increases as the disease 
progresses. Therefore it would be wrong to assume that adolescents with HIV/AIDS 
would be lying that they are in pain and to force them to work or fetch water, as 
mentioned in Chapter four section 4.6.4.1. Since even some health workers can fail to 
recognize pain, the author does not blame the carer who forces these adolescents to go 
and do some work when they are in pain. It is not only carers who thinks that adolescents 
are lying: even teachers have the same thinking, as demonstrated in Chapter four section 
4.6.4.1 by a 15-year-old male. This is the last thing this group would have expected from 
a teacher, whom they believe to know everything, but who may fail to understand that 
they are sick and in pain.

There is also disbelief by fellow students who don’t take these adolescents serious 
and will just laugh about their being sick, as mentioned by a 18-year-old in Chapter four
section 4.6.4.1 It is upsetting to the adolescents if they fail to get the help they deserve when in pain. They get annoyed if nobody helps them. Under normal circumstances adolescents are considered very difficult to understand and any difficulties in communication are likely to be exaggerated when they are sick.

Health workers must play their part in pain management at the same time the community needs to be sensitised as far pain and psychological impact of pain is concerned. Teachers and other people in the community need to rule out both physical and psychological suffering adolescents are going through before they concluded that adolescents are lying to them.

5.6.7 Apprehension

This study revealed that adolescents are apprehensive because of fear, which results from thoughts of losing life or any part of the body. Adolescents who are orphans are faced with multiple loses: loss of parents, loss of sisters and friends and loss of their own lives. On top of those numerous losses, pain poses a threat of losing some body parts; because they think if the pain persists a doctor may decided to cut off the patient’s limb. Apart from being apprehensive because of death and loss of body parts, some were apprehensive because of their body image. Adolescents naturally are self-conscious and over-sensitive about their physical appearance, as Fisher (1987) wrote. Some skin conditions that result from HIV/AIDS are disfiguring and others are painful. A change in appearance therefore can be a source of psychological concern, though in the study it was mentioned by one subject. If one shuns away from bathing then the skin condition is likely to worsen, and hence the apprehension is going to increase.
Health care workers need to give support and allay adolescents’ apprehension of losing body parts. Skin conditions should be managed well and difficult cases should be referred to a dermatologist. However some skin conditions can respond only to ARVs, which are still not available to many patients in resource limited settings.

5.6.8 Misery

Misery was one of the themes, which was expressed as depression. As the author mentioned above, adolescents worry that their pain may stop them from going to school; on the other hand it also may lead to loss of interest in going to school. In the first instance they want to go school but cannot, and in the second they don’t want to due to the increasing effects of pain; the normally confusing years of adolescence are made even more difficult.

During this period of adolescence, much is expected to be taking place—interaction with others exchanging ideas, gaining new knowledge by reading and going to school. Pain can cause misery because it can deny adolescents all these activities. Fisher (1987) said that adolescents love to partake and shine in active sports, but they also like to shine in academics, as demonstrated by the above 16-year-old in Chapter four section 4.6.6.1.

Failure to interact with others and to gain more knowledge from school, can lead to yet another misery where adolescents could end up sleeping all the time. A 15-year-old male mentioned that pain makes him unhappy and also useless because he sleeps all the time. Once this problem is recognized, an occupational therapist must become part of the team so that adolescents are helped to carry-out energy conserving activities and are
able to remain with friends. Where facilities could allow, adolescents should be encouraged to participate in in-door games, which do not require a lot of physical energy.

5.6.9 Hopelessness

Hopelessness is a theme developed under boredom and it disturbs adolescents when they are in pain. When some of the adolescents are in pain they become weak and fail to help themselves. Unlike when they are withdrawn and just don't want to do anything, they find themselves hopeless when they would like to do something and fail. As mentioned by Fisher (1987) adolescents are over-sensitive, and, for example, urinating on the bed would lead to a feeling of hopelessness. This is one of the results of being hopeless mentioned by one of the study subject.

Getting detailed information from patients about how they are feeling is very helpful to the health workers, family members and friends with such patients because they could take appropriate measures to avoid problems leading to this psychological factor.

5.6.10 Restlessness

Restlessness was a theme developed under insomnia, because when adolescents are in pain they often think of the worst, get nightmares and end up with disturbed sleep. This is especially likely to happen when they are misinformed, as a 15-year-old female mentioned that she was told that somebody went to sleep when he was in pain and was found dead the following morning. Explanation of how death occurred is very important as Breige (1996) said. He said that it is not helpful to say that the dead person is asleep as
children would be afraid to sleep in case they never wake up again. This is almost similar to the information given to one of the study subject that one patient was found dead when he slept while in pain. Unless such the presence of incorrect beliefs is discovered and corrected information is shared with the patient- and counselling given if necessary- these types of false beliefs will cause unnecessary restlessness in that patient.

Communication is very important because wrong information can lead to many disturbances; poor sleep being one of them. Adolescents understand that death is permanent but they have great difficult accepting and talking about it (Breige 1996). The majority of the study subjects are orphans, who might still be in a process of bereavement, as such they need to be given appropriate information about death. Children should always be told the truth and be facilitated to grieve so that they will be helped to cope with their problems and bereavement to prevent future psychiatric illnesses (Breige 1996).

Dreams and thoughts are some of the sources of restlessness for these adolescents. Poor pain control can result in partial pain relief. Once there is no pain one can sleep, but when it returns then one wakes up and starts wondering to what to do. Health care workers should anticipate this and pain control should be given around the clock to avoid pain which could come at night and interrupt sleep. To make matters worse, often the wrong information is given to children, as mentioned above. It is important to note that pain has two conflicting psychological factors, one is misery which leads to sleeping all the time as mentioned above and two is restlessness whereby there will be sleeping on and off. The health worker should try to find which of these factors are affecting patients because each requires a very different management approach.
It is mentioned in the literature that there are non-pharmacological approaches such as relaxation and imagery, distraction and reframing, psychotherapy and structured support, hypnosis among many others, that can be used in pain management (Beck 1991, Fawzy, et al, 1990, Graffam, Johnson, 1987, McCaffery, Beebe, 1989, 1992, Spiegel, Bloom, 1983, 1989, Munro, Mount, 1978). If one can carefully select from the above-mentioned approaches, the restlessness mentioned by the study subjects can be avoided.

5.6.11 Exhaustion

Exhaustion is a theme developed under tiredness, and it comes as a result of adolescents having too much thought, sleeping all the time, involved in some work and walking, even though they are weak. A combination of many of the psychological factors mentioned above can result in exhaustion.

When an adolescent sick with HIV/AIDS tries to work, he or she may become exhausted, as a 15-year-old male explained in Chapter four section 4.6.9.1 that working while in pain leads to getting very tired. It has been mentioned above that sleep disturbance can lead to restlessness, but at the same time if one sleeps all the time he or she might get exhausted. Lack of exercise could lead to this factor and it is therefore important to have an occupational therapist who can educate patients to carry out energy conserving exercises.

Health workers need to educate the carers about the psychological factors found and advise them to believe and understand what the adolescents tell them in order to avoid exhaustion as a result of too much work.
5.6.12 Separation

Separation is a theme developed under isolation. It has been mentioned above that adolescents can be conflicted under normal circumstances but pain can also be the cause. Fisher (1987) said conflict can lie in the spasmodic need to be alone, and on the other hand, adolescents want to be part of the group. It has been mentioned above that adolescents in this sample wish not be alone because they would like to talk with others, learn and compete. But on the other hand they may prefer to be alone in order to avoid noise, disturbance, fear of being laughed at, weakness and disloyalty by some people.

HIV positive adolescents who are orphans suffer from double separation- one due to lose of their parents and a second due to pain. Decisions to separate themselves from others are mentioned in the Chapter four section 4.6.10.1. One reason, which was mentioned by three subjects out of eight, was noise. Pain leads adolescents to separate from others because they prefer to avoid noise. An 18-year-old female prefers to separate from others because of stigma due to HIV/AIDS. The subjects did not mention stigma due to HIV. This may be due to small sample size or because the study selected only children who knew their status.

In the American Academy of Pediatrics (1999). it is mentioned that health care professionals and families are concerned about the difficulty children have keeping a "secret" and limiting the disclosure to selected persons. The research has shown that children try to keep their secret by separating themselves from those they think would not be able to keep quite about their illness.
They are sensitive, and being laughed at is one of the reasons why they separate from others. Adolescents would like having fun with others but pain does not allow this to happen, as mentioned in chapter four section 4.6.10.1.

Communities and carers need to be informed that separation is a big source of stress in adolescents. They should be advised to avoid these identified psychological factors so that adolescents could have peace and stay with people.

5.6.13 Rejection

Rejection is another theme developed under social isolation because of pain. Adolescents feel rejected when they are not shown love, care, or when no one want to share with them their problems and nobody is present for assistance. Fisher (1987) said adolescents love intensely and hate intensely. If someone shows them love they could also love that person intensely.

They often feel rejected when not shown love, as a 15-year-old female mentioned in Chapter four section 4.6.10.2 that if a child is shown love she would forget all about other problems and will avoid regretting having been born. McGlone (1986) said rejection is a source of terror and a catalyst for suicide. The present researcher thinks rejection and distress can act as a strong catalyst for suicide, as one of the adolescent mentioned in Chapter four section 4.6.3.1, that pain makes her think of committing suicide.

Sharing is part of love and sharing a problem with somebody leads to comfort because out of love one will expect to be helped. A 14-year-old male appealed to his fellow patient that they should seek help from a counsellor, a teacher, a doctor or
somebody older. This is very important because the multidisciplinary team should include these people mentioned by the 14-year-old male. The team also needs to be equipped with knowledge about pain because adolescents have confidence in them. Health workers should show love to patients when they come for treatment and the same message should be passed to the community and the carers in order to respond to their need for sharing and comfort.

5.6.14. Empowerment

Empowerment was the theme developed from other feelings about which adolescent wanted to talk. One adolescent of 13 years demonstrated that he could play an active role in his own diagnosis and care. This means that if well understood and empowered, they could assist others in their environment. Adolescents could also aid professionals in this task by providing full information and enabling empathy with their condition. This could be a demonstration of their transit from childhood to adulthood as mentioned earlier.

5.7 THE OUT COME OF PAIN AND COMMONLY IDENTIFIED PSYCHOLOGICAL FACTORS ON FOLLOW-UP

5.7.1 OUT COME OF PAIN

After the doctor’s management of pain following the WHO analgesic ladder and treatment of the identifiable causes, all study subject’s came back with tremendous improvement. The course of pain and the effectiveness of the treatment were assessed using the VAS. Five out of the eight study subjects pain had disappeared and the
remaining three had more than 50% improvement as evidenced by reduction from 6 to 3, 4 to 1 and 6 to 2 on the VAS respectively. This good outcome can be attributed to the fact the study subject selected were not very sick because those who were very sick with karnofsky score of 40% or less were excluded from the study and the doctors at the center are well trained in pain management. Those who still had pain, the doctor modified their treatments and were given another appointment. Physicians are supposed to select the most appropriate pharmacological and non-pharmacological interventions for pain management (McGrath P, Oxford Textbook of Palliative Medicine Second Edition). The doctor who treated the study subjects followed and monitored the efficiency of the interventions. However those whose pain had disappeared were followed in the usual way the center follows up patients.

5.7.2 SHORT OUT COME OF COMMONLY IDENTIFIED PSYCHOLOGICAL FACTORS

The following psychological factors, social isolation, insomnia and anxiety were identified in six of the subjects. They were referred for counseling and on follow-up, the doctor found that they all had some improvement. One of the remaining two subjects was referred for occupational therapy because he reported boredom and was also found to have improved. The last one had a problem of depression as result of loss of a family member. She was referred for spiritual and bereavement care, which resulted in some improvement. Unlike in follow-up of pain where 63% of the study subject reported to have no pain, all subjects reported improvement not disappearance of the psychological factors.
When these findings are compared with the research results, there is a need to look deeper into the psychological problems impacting on pain in adolescents. If a large study is done and confirms the research findings, then another angle needs to be taken when looking at the psychological factors in adolescents for better pain management (Pain in patients with HIV/AIDS, Pain and pain management Modalities, http://www.hivpositive.com/f-PainHIV/Pain/LS1.4.html 29/12/2004).
CHAPTER SIX

CONCLUSIONS

Adolescents have many significant psychological factors that impact on their pain experience and it is important to address these factors if clinicians wish to assist those experiencing pain optimally. In most studies of pain, psychological factors are mentioned and recognized to affect perception of pain both in children and adults (Gaughan et al 2002). The common psychological factors mentioned are anxiety, anger, fear, depression, boredom, insomnia, tiredness and social isolation. However, there is scanty research addressing psychological factors in adolescents suffering from HIV/AIDS. This study explored this gap in the literature through empirical research.

The research was able to demonstrate that the conceptualisation of pain by HIV-positive adolescents in Uganda was similar to that mentioned by the International Association for Study of Pain (1986). They were able to talk about their pain; a fact that gave the author confidence to understand how psychological factors were impacting on their pain. The results from brief interviews by the doctor with study subjects indicated that they had some psychological factors that were not well elaborated in previous research. However these factors came out clearly from the recorded interviews conducted by the social worker. This was a clear indication that the routine interaction of the patients with the doctors hints at the psychological factors but lacks deep understanding of what is going on. That is also why on follow up after the doctor taking an appropriate measure to address the psychological factors he found, the study subjects report to have improved but not complete disappearance of the problems.
The author was able to determine the psychological impact of pain on adolescents suffering from HIV/AIDS. Previously defined psychological factors impacting pain were recognized in the subjects and the following, more telling themes were developed: distress, disappointment, autonomic nervous system effects, withdrawal, upset, apprehension, misery, hopelessness, restlessness, exhaustion, separation, rejection and empowerment. Under the themes of restlessness and disappointment, it became clear that these children have a problem of lack of proper bereavement counselling that could also impact their pain. A combination of distress and rejection could act as a strong catalyst for suicide as two of the study subjects mentioned. The research was exploratory and revealed themes reflecting psychological impact of pain on adolescents suffering from HIV/AIDS which can be investigated in a larger study.

As the literature mentioned, the life expectancy of children with HIV/AIDS has increased with increased quality of care (Gaughan et al 2002). These psychological effects found are likely to remain a real challenge to the quality of life of adolescents in the absence of ARVs. There is also an increased risk of transmission among people in this the age group because of increased life expectancy. Due to increased life expectancy, adolescents are likely to progress to advanced stages of HIV/AIDS, which is associated with increased incidence of pain (Breitbart et al, 1991). In this study, seven subjects were in stage II and one in stage III - that means their disease is progressing, hence their incidence of pain is also on the rise.

The majority of the study subjects were orphans, a reality that could have influenced the results. Orphans face many problems, pain being one of them, even if they are not HIV positive. However the situation could change if ARVs were easily available
because parents would survive longer to look after their children, and HIV positive adolescents will have less or no painful events because their immunity would be improved.

If a full assessment of pain, which includes physical and psychological factors, is properly done then patients suffering from pain can be well managed. Without the full assessment, health workers and other carers are not in a position to fully provide for these adolescents. I believe that the majority, if not all, of the psychological factors found in this study are due to poor pain control. Until pain control in both adults and children is improved the quality of life of people suffering from pain will continue to be poor.

The health workers, carers, community and the school authorities play a big role in influencing these factors. The health workers not only fail to recognize these factors but also fail to control pain using appropriate drugs, despite clearly written WHO guidelines for pain control. The carers and community fail to believe that these adolescents are in pain and instead they think that they are lying. At times the adolescents are given strenuous work to do because these adults think they are lying. School authorities also fail to understand what these adolescents are going through, and, as a result, they think that they are dodging classes.

In order to manage these psychological factors well, a multidisciplinary team approach has to be applied. The team should consist of health professionals, carers, school authorities and the community.

Training of health professionals in pain management is very important if pain relief is to be achieved. Community and school authorities need training programs, which could enhance their pain awareness so that they could also participate in pain
management. Details of the training suggestion in the field of HIV/AIDS that could assist all the people concerned will be discussed in the following section of recommendations.
CHAPTER SEVEN

RECOMMENDATIONS

This research has addressed the gaps in knowledge that exists in our understanding of the psychological impact of pain in adolescents suffering from HIV/AIDS. Many factors have been identified that impact on pain. The recommendations below should be considered because they could result in better management of pain especially in the face of lack of a cure for the HIV virus and limited availability of ARV drugs in Uganda and other places.

7.1 THE FOLLOWING ARE THE RECOMMENDATIONS FOR FURTHER RESEARCH:

1. The research examined adolescents who were staying in urban area and, it is not possible to determine if similar results could be obtained in a rural setting. Therefore the author recommends a study on a bigger sample size, both in rural and urban setting with adolescents who are orphans and non-orphans.

2. The author recommends doing a retrospective study on records of adolescents who committed suicide in the past to determine whether there was a related history of pain and HIV/AIDS. If any relationship is found, it would be an imperative for an immediate action plan to provide interventions for high risk HIV/AIDS patients. After noting such serious issues, health workers would be advised to work with carers to make a close observation of all the drugs given to the patients especially adolescents to safe guard against possible suicides. Such
patients would be referred to a counsellor to deal with some of the other feelings described by the study subjects.

3. When patients' files were examined, it was noted that patients were referred for psychosocial and spiritual counselling and occupational therapy. The author recommends that research to quantify the effect of these interventions be conducted.

4. A study on how adolescents handle bereavement in Uganda is crucial and recommended. While this research focused on psychological factors, the issue of bereavement came up as one aspect of adolescents' life currently not well addressed. Children should always be told the truth and facilitated to grieve so that they will be helped to cope with their problems and bereavement to prevent future psychiatric illnesses (Breige 1996). It is difficult to tell whether carers and health workers in Uganda have the knowledge of facilitating children go through the process of grieving, that is why the author is recommending to conduct a research addressing this problem in Uganda.

7.2 THE FOLLOWING ARE RECOMMENDATIONS FOR PRACTICE:

1. A simple and standard tool should be developed to capture psychological factors in adolescents suffering from HIV/AIDS. If such a tool was developed and circulated to health workers, then assessment of psychological factors could easily be done. Before such a tool is developed, health care workers need to be reminded to be more vigilant when assessing adolescents suffering from HIV/AIDS.
2. To increase doctors' knowledge of pain control, the author recommends that before one graduates as a medical doctor special lectures on pain management be provided, and at the end of studies an examination on pain management be given to all medical students. For those who are already in the medical field, the policymakers of MOH have to set seminars which should be requirements of CME to cover pain management every year.

3. The author recommends that psychological issues require a multi-disciplinary team approach. The team should consist of: community volunteers or workers, health workers, the carer and the school administration. The health workers should determine the psychological factors and apply appropriate treatment, including counselling. They should also take the task of explaining to the carer what will be going on and empower them with the necessary knowledge to assist the adolescents. When at home, the carer should collaborate with the school authorities to send reasonable class work materials to the adolescent. The health workers and school authorities need to be given seminars addressing general issues about HIV/AIDS and facts about pain. Schools already teach about first aid, pain and the psychological issues- which could arise from schools- should also be taught.

4. Policymakers in MOH and MOE should work hand-in-hand to develop a simple educative package to distribute to schools in order to disseminate knowledge about pain in people with HIV/AIDS. Since there has been a great deal of HIV awareness, especially as far as transmission and prevention is concerned in schools, it is high time to address the issues of pain in HIV/AIDS in schools.
5. The author recommends that carers of adolescents with HIV/AIDS be offered sensitisation seminars about pain. The health centres can organize these seminars quarterly at their facilities. MOH could design radio programs- that would be aired at night when majority of people at their homes- for the communities. The best time would be after the news. Television programs would be most effective but televisions are not easily accessible. Mobile films would be another alternative, and they could be organized by MOH.

6. Another recommendation is that health workers develop a program to empower adolescents to play an active role in the diagnosis and care of their own pain. Once empowered they could play an important role in schools, homes and community to pass on the message and at the same time get the assistance they would require.
8. REFERENCES


16. Gantley M A. Beginner’s Guide to Developing a Thematic Analysis An Introduction to Qualitative Methods for Health professionals, Royal College of General Practitioners 1999 p14-20:


42. Stone Patrick. To determine the choice of the research methodology. Issues in research 2002; 265.


9. APPENDICES

9.1 PATIENT INFORMATION SHEET

The name of the person going to carry out this study is Dr. Seruyange Henry. The study is trying to look at factors, which might influence the way you perceive pain.

The interviews will be conducted in your first language, that is to say the language you understand very well.

Before you participate in this study, you will be required to sign a consent form, which will also be in your first language.

Your participation in the study will be entirely voluntary and if you refuse to participate or withdraw from participation at any time, there will be no prejudice to the quality of your subsequent clinical management and care.
9.2 OMULWADDE BYE YETAGA OKUMANYA

(Luganda translation of patients information sheet)

Omuntu agenda okukola okunoonyereza kuno bamuyita musawo Seruyange Henry.

Okunoonyereza kuno kugezaako okuntunuulira kumbeerazo ezabulijo bwe ziyinza
okukyusa engeri gyo wulilamu obulumi.

Ebinakubuuzibwa bija kubera mululimi iwo lwotegelera ddala obulungi.

Naye nga tonatandika kwetaba mukunoonyereza kuno, kikwetagisa okumala okussa
ekinkumu oba omukono kulupapula luno okukakasa nti okkiriza okwetaba
mukunoonyereza kuno.

Olupapula luno naIwo lugya kuba mululimi lwotegeera obulungi.

Okusalawo okwetaba mukunooyereza kuno kwakyeagalire era oli waddembe okugaana
okukwetabamu, oba okukuvaamu ekiseera kyonna woyagalira.

Tojja kunenyebwa ng’osazeewo okugaana okwetaba mukunoonyereza kuno,oba
ng’okuvudemu, era obujjanjabi bwofuna tebuja kutataganyizibwa, bujja kugenda
mumaaso nga bulijjo.
9.3 CONSENT TO PARTICIPATE IN THE STUDY OF PSYCHOLOGICAL IMPACT ON PAIN.

The study requires your permission to participate in the study of psychological impact on pain at Mildmay Centre. It will be conducted when you have come to the centre to seek medical assistance and you must have pain experience for more than six months. The study will look at your feelings as far as pain is concerned and your age has to be between twelve (12) and eighteen (18) years old.

You are not forced to participate and all the medical care the centre provides to you will not be affected by your refusal or acceptance to participate. What will be required from you is to answer some question about your feeling as far as pain is concerned. The permission the study is seeking from you is to freely talk about your pain experience. In order not to forget your own words an audio recording of the interview will be done. You are free to pull out of the study and none of the services the center provides to you will be affected. On the information sheet your identity will be protected and your name will not appear anywhere and it will not be mentioned in the analysis and in the final report. A number but not your name is going to be assigned on the information sheet.

The researcher will require permission from older children and carer who will consent on behalf the children below the age of 18 years. If the carer and the child are not interested in the study the services rendered to them will not be compromised by their refusal to participate. The carer and the child will be free to pull out the study at any time when they feel to do so.

The study might distress you and if you feel so do not hastate to let the researcher know. If you are found to be distressed, arrangements could be done to relieve your stress.
You are free to know all the information gathered in this study. You may not gain
directly by participating in the study but the information you will provide may add more
knowledge to the existing one or may increase confidence to the existing knowledge.
Once this is attained then other people having similar problem in different parts of the
world will benefit from the information you will have given.
Before you agree to participate in this study you must understand all the information
given on this consent form. If there is anything not clearly understood you are free to ask
any body.
Have you understood the nature of this study and you or your child agrees to participate
in this study? (1=Yes; 2=No)
Participant’s name (print) ____________________________
Signature __________________________________________ Date: ____________
Researcher’s name _________________________________
Signature __________________________________________ Date: ____________
9.4 OKUKKIRIZA OKWETABA MUKUNOONYEREZA OKUKWATA KU N'OBULUMI BWOFUNA.

(Luganda translation of the consent form)

Kyetagisa okufuna olukusa okuva gy’oli mukusoma kuno. Okusoma kujja kubelawo bwonooba nga ozze okufuna obujanjabi kudwaliro lya Mildmay, era kijja kukwetagisa okuba ngo’linako kubumayirivu obw’obulumi obutakka wansi wa mwyizi mukaaga. Okusoma kujja kwesigama kubulumi era essira lya kutekebwa kubaana abali wakati we myaka kumi nebiri(12) ne ekumi nomunaana (18).


Anonyereza ajja kwetaaga okufuna olukusa okuva ew’omwana alina emyaka 18 era n’okuva ew’omujjajabi ew’omwana akka wansi we myaka eygo.Omwana oba omujjajabi waddebe okugaana bwaba nga tayagadde era okugaana tekujja kunya.
kubujjanjabi bwe mufuna. Kikkatirizibwa nti omwana n’omujjanjabi baddembe okuva mukunoonyereza kuno wonna webaagalira.

Okunoonyereza kuno kuyinza okuletera okunakuwala ennyo era tolonzalonza kubuliira omunoonyereza. Enteekateka ejja kubaawo eri buli muntu anesanga nga ali numbera eyo.

Ddembe lyo okumanya ebivudde mukunoonyereza kuno. Oyinza obutaganyulwa mukunoonyereza kuno naye ebinavaamu bijja kwongera kw’ebyo ebimanyidwa oba bijja kukakasa ebiwandiike. Bwe wanabaawo ekizulidwa abantu wano ne mumawanga amalala munsi yonna, bayinza okuganyulwa olwebyo by’onooba oyogedde.

Nga tonetaba mukunoonyereza kuno olina okukakasa nti ebyo ebyogedwako waggulu obitegedde bulungi. Bw’oba ngo’lina kyobuusabuusa oli waddembe okubuuza okutuusa ngo’tegedde.

Okakasa nti ebikwata mukunoonyereza kuno obitegedde, era gwe oba omwana wo okkiriza okwetaba mukunoonyereza kuno?

(1=yee 2=nedda)

Erinya lyo (wandlika munyukuta ennene)

Ssaako omukono/ekinkumu Ennaku

z’omwezi/omwaka

Omunoonyereza

Omukono Ennaku z’omwezi/omwaka
9.5 QUESTIONNAIRE (TO BE FILLED BY DOCTOR)

(Fill in spaces)

Date:..............................................

File number:......................................

Age:................................................................

Sex:................................................................

Tick one:

Both parents are alive..................

One parent alive.....................

Total orphan.........................

Indicate relation to carer:....................

Do you go to school?

Tick Yes or No:

Yes................

No............... 

Level of education:..............................

Residence:...........................................

District:............................................... 

Date of knowing sero-status:.................. 

WHO stage:...........................................

Date of first attendance at Mildmay Center:............................................
9.6 CHARACTERISTICS OF PAIN (TO BE FILLED BY DOCTOR)

(Fill the appropriate answer/s in the space/s)

1. Location of pain: ..............................................................

2. How long has it been there? ..............................................

3. Is it there all the time or does it come and go? ...................

4. Is it worse at any particular time of the day or night? .........

5. How severe is it? (Use the severity scale below to mark the response)

Severity:

Numerical Scale.

<table>
<thead>
<tr>
<th>No pain</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>Severe pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10</td>
</tr>
</tbody>
</table>

Or Visual Analogue Scale

No pain .......................................................... Worst pain (pain you cannot imagine)

6. How much does it affect your life?  1. ................................

2..........................................................

3..........................................................

4..........................................................

(Continue if more than 4) ...........................................

..........................................................

7. Does it spread anywhere? Yes... No... (Tick one)

If yes describe where ............................................

.........................................................
8. What exactly is it like?

9. What makes it worse?
   1. ........................................................
   2. ........................................................
   3. ........................................................
   4. ........................................................
   (Continue if more than 4). ...........................................

10. What makes it better?
    1. ......................................................
    2. ......................................................
    3. ......................................................
    4. ......................................................
    (Continue if more than 4) ...........................................

NB Note from the file any other types of pain the study subject has ever experienced.

   1. ......................................................
   2. ......................................................
   3. ......................................................
   4. ......................................................
   (Continue if more than 4) ...........................................
Diagnosis: ...........................................................................................................

Treatment given this and previous visit/s

<table>
<thead>
<tr>
<th>Type of pain</th>
<th>Drugs</th>
<th>Frequency</th>
<th>Other remedies</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
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<tr>
<td>2.</td>
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<tr>
<td>3.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
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</table>

Referrals: (Note from the file any referral and reason/s)

<table>
<thead>
<tr>
<th>Department:</th>
<th>Reason/s</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physiotherapy</td>
<td></td>
</tr>
<tr>
<td>Occupation therapy</td>
<td></td>
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<tr>
<td>Counseling</td>
<td></td>
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<tr>
<td>Social worker</td>
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<tr>
<td>Spiritual care</td>
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<tr>
<td>Nutrition</td>
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<tr>
<td>Laboratory</td>
<td></td>
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<tr>
<td>Hospital</td>
<td></td>
</tr>
</tbody>
</table>

FOLLOW UP VISIT:

(NOTE THE OUTCOME FROM THE FILE)

Date: ...............................................

Numerical Scale.

0  1  2  3  4  5  6  7  8  9  10
<table>
<thead>
<tr>
<th>Type of pain</th>
<th>Scale</th>
</tr>
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<tbody>
<tr>
<td>1.</td>
<td></td>
</tr>
<tr>
<td>2.</td>
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<td>3.</td>
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<td>4.</td>
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</table>

<table>
<thead>
<tr>
<th>Referred to</th>
<th>Reason/s</th>
<th>Outcome of Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physiotherapy</td>
<td></td>
<td></td>
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<tr>
<td>Occupation therapy</td>
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<tr>
<td>Counseling</td>
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<td>Social worker</td>
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<td>Spiritual care</td>
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<td>Hospital</td>
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<tr>
<td>Type of pain</td>
<td>Scale</td>
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<td>4.</td>
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<tr>
<th>Referred to:</th>
<th>Reason/s</th>
<th>Outcome of Intervention</th>
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<td>Hospital</td>
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9.7 QUESTIONS ASKED BY THE SOCIAL WORK FOR AUDIOTAPE RECORDING.

1. Pain: What is pain? Can you describe what you exactly feel?

   What do you understand about pain?

2. Anxiety. If you get pain what abnormal and overwhelming sense of feeling do you get? What do you think about when pain comes? Do you sweat when pain comes? Does your heart beat faster when you are in pain? What worries come to your mind when in pain? What kind of threat do you get when you are in pain?

   Do you get any reason for panicking?

3. Anger. When do you feel annoyed when you are in pain? What do you feel like doing when you are annoyed? Is there anything which makes you annoyed when you are in pain? Do you think there is any body that makes you annoyed when you are in pain?

4. Fear. What fear does pain bring to your mind? Do you get fear of losing anything because of pain? Any example that you can give? (Example of fear includes losing life, any part of the body, a friend, a brother, a parent, school and anything the patient may mention.)

5. Depression. How does pain make you unhappy, lose moral and interest, feel that you worthless or useless?

6. Boredom. When do you feel empty or lazy when you are in pain?

7. Insomnia. What keeps you awake when you are in pain? For how long do you remain awake?
8. Tiredness. What makes you feel tired when you are in pain?

9. Social isolation. Why do you like to stay alone when you are in pain? Why don’t you want to play, visit a friend, go to school, or have fun with others when you are in pain?

10. Any others. What else do you want to share with regarding pain?

Comment:
This information was administered in the patient’s own language. The patient’s participation in the study was entirely voluntary and was free to refuse to participate or to withdraw from participation at any time, there was no prejudice to the quality of they subsequent clinical management and care.
9.8 EBYETAAGISA OKUBUUZA OMULWADDE NGA BYE KWANAGANYA NO’BULUMI SOCIAL WORKER BYE YABUUZA OMULWADDE NEBIKWATIBWA KULUTAMBI.

(Luganda translation of questions asked by the social worker)


5. Okwenyamila. Obulumi bukumalako butya essanyu oba okuwulira nti tolina mugaso?

6. Obuteyagala. Ddi lwowulira ngo’li munnaku olwo’bulumi?

7. Okubulwa otulo. Kiki ekikugaana- okwebaka ngo’limubulumi? Oyinza kumala bbanga ki ngo’tulo tugaanye okujja?
8. Obukoowu. Kiki ekikuleetera okuwulira obukoowu ngo’limubulumi?

9. Okweyawula kubanno? Lwaki oyagala okubeera wekka ngo’limubulumi? Lwaki toyagala kuzanya oba kukyaaliira mikwaano gyo, oba okugenda kussomero oba okwesanyusaamu nabantu abalala bwoba ngo’limubulumi?

10. Ebirala. Kiki ekirala kyewandiyagade okumbulira kubikwatagana kubyo’bulumi?

Comment:
This information will be administered in the patient’s own language. Participation in the study will be entirely voluntary and if you refuse to participate or withdraw from participation at any time, there will be no prejudice to the quality of your subsequent clinical management and care.
15 April 2004

REC REF: 127/2004

Dr E Gwyther
Public Health & Family Medicine

Dear Dr Gwyther

PSYCHOLOGICAL IMPACT OF PAIN ON ADOLESCENTS SUFFERING FROM HIV/AIDS AT MILDMAY CENTRE, KAMPALA, UGANDA

Thank you for submitting your study to the Research Ethics Committee for reviewal.

It is a pleasure to inform you that the Research Ethics Committee has formally approved the above mentioned study.

Please quote the above Rec. reference number in all correspondence

Yours sincerely

PROF T ZABOW
CHAIRPERSON
8th April 2004

Dr Henry Seruyange
The Mildmay Centre
PO Box 24985
Kampala
Uganda

Dear Dr Seruyange

Re Masters Research Proposal

Thank you for the copy of the research proposal for your Masters looking at the Psychological impact of pain in adolescents suffering from HIV/AIDS. The Directors have discussed your proposal and we are happy for you to go ahead with the study. Prior to commencing please could you clarify the following:

• You have given a timeline re number of days please could you give this to us with the dates on so we know exactly when you will be doing what
• You have not made it clear with regards to the funding of your research – unless we have a letter from you asking us to help with the funding we will assume that you are funding the research

Throughout the course of your study it is important for you to keep the Directors updated with regards to your progress. It is also important for you to remember that apart from your written report for your Masters Course, no abstracts or papers may be submitted on this research without prior approval of the Directors.

We would like to take this opportunity to wish you all the best with your research. If you have any further questions please do contact us.

Yours sincerely

Julia Downing

Director, Mildmay International Study Centre, on behalf of the Directors