

Quality of Life Varies with Pain during Treatment in Adolescents with Cancer

Maria Calissendorff-Selder, MD, Gustaf Ljungman, MD, PhD

Department of Women's and Children's Health, Children's University Hospital, Sweden

ABSTRACT

Pain is one of the most feared problems for adolescents with cancer. Pain produces stress with negative physiological and psychological effects. Therefore, effective pain management during cancer treatment may influence the outcome. This study investigates variations in pain and quality of life during treatment in adolescents with cancer, and whether there is a co-variation between the two.

In a prospective longitudinal questionnaire investigation, quality of life in eight adolescents with cancer was assessed with the psychological general well-being index (PGWB) and compared with the patients' experiences of pain according to repeated structured interviews.

Pain troubled the adolescents most in the beginning and in the end of the treatment period, but troubled them less in-between. During treatment, quality of life was low in the beginning, higher in the middle and lower in the end. Pain co-varied inversely with quality of life and the adolescents thus seemed to have higher quality of life when pain-relieved. This finding emphasizes the importance of pain management in children and adolescents with cancer.

INTRODUCTION

Pain in children is often underestimated and therefore inadequately treated (1–5). This is also true for children with cancer (6–11). Pain in children with cancer can

often be reduced to one or more of four basic categories: treatment-related (e.g. pain as side-effects of chemotherapy and radiation), procedure-related (e.g. pain due to lumbar puncture, bone marrow aspiration or postoperative pain), cancer-related (e.g. pain due to infiltration of tumor in various organs or tissues) and pain of other origin (12). Treatment- and procedure-related pain have previously been shown to be greater problems than cancer pain, and thus most pain experienced by children may be regarded as iatrogenic (10,11). Pain is the most feared problem for children on treatment for cancer (13), and therefore deserves attention and further investigation. Pain produces stress with negative physiological (1,2,14) and psychological (15) effects. Therefore, effective pain management during cancer treatment may influence the outcome.

Children with cancer experience variations in pain during treatment (16). Pain seems to be a greater problem at diagnosis, and towards the end of treatment, than in-between. Reasons for this are that pediatric malignancies often respond rapidly to treatment (12), that the pain experience may be reduced with the increased security and confidence that comes with time, and that this latter effect weans off towards the end when the patients' medical visits become less frequent (16). Clinical observations suggest that the children's sense of subjective well-being or distress varies with pain. Pain management, where pharmacological and/or psychological approaches may be used depending on the individual child's coping strategies, reduces pain and concurrently distress, which might improve quality of life. Quality of life is also affected by other factors such as security and confidence.

Our hypothesis was that there is an inverse correlation between the experience of pain and quality of life. To our knowledge, this has previously not been studied in adolescents with malignant diseases. The aims of the investigation thus were to study variations in pain and quality of life in adolescents with cancer during treatment, and whether there is a co-variation between the two.

PATIENTS AND METHODS

This study is part of a project, where children and adolescents with malignant diseases admitted, during one year, to the Unit for Pediatric Hematology and Oncology at the Children's University Hospital in Uppsala (a tertiary referral center for pediatric oncology) were invited to join a prospective longitudinal questionnaire investigation about pain, pain management, and quality of life. Questionnaires were presented orally to ensure that they were correctly apprehended.

Inclusion criteria were: 1) age between 13 and 18 years, 2) treatment period from one month after diagnosis to three months post treatment, 3) understanding of Swedish sufficient to make the interview possible, 4) not terminally ill and 5) more than one interview possible. Children below 13 years of age were excluded because the questionnaire for quality of life was not validated for this age group.

Eight adolescents were included in this study, five of which were interviewed twice and three, three times. We did not interview during the first month, because

the situation for the families is usually psychologically very complex at this time.

Structured interviews based on a previously used questionnaire (11,16) were performed to investigate the patient's experience of pain. For assessment of quality of life, a questionnaire with 22 questions, the psychological general well-being index (PGWB) (17), was used.

Two experienced nurses familiar with problems of pediatric oncology performed the structured interviews under standardized conditions. Interviewers were associated with the pediatric oncology ward, but were not primarily medically responsible for the adolescents they interviewed to avoid biases.

The PGWB index was used to measure the affective or emotional states of the adolescents, which corresponds to a sense of subjective well-being or distress. The index consists of six subscales that can be put together to construct an overall index, which is sensitive to an individual's psychological general well-being. The subscales are: anxiety (5 questions), depressed mood (3 questions), positive well-being (4 questions), self-control (3 questions), general health (3 questions) and vitality (4 questions). For each item there are six response options that are scored on a scale from 0 to 5, according to the frequency of the affective experience. A value of 0 is given for the most negative option, and 5 for the most positive option. The score range for the PGWB index is thus 0 to 110 - the higher the score, the better the quality of life - whereas the range for the subscales is from 0 to 15, 20, or 25. From the 22 items 6 subscale scores without overlapping items and 1 overall PGWB index score can be derived.

Informed consent was obtained from patients and parents and the local research ethics committee approved the study.

For statistics, Kendall's tau_b was used for non-parametric correlations. P values of <.05 were considered significant. Linear regression analysis with ANOVA was used to test associations between variables. All statistical analyses and graphical presentations were performed using SPSS 10.0 (SPSS Inc. Chicago IL.)

RESULTS

For demographic and interview data see Table 1.

Quality of life measured with the PGWB index was about 70 in the beginning of the treatment period, when intensive pain was more frequent than later (Figure 1). In the end of the treatment period the mean PGWB index was slightly lower than the value in the beginning, and intensive pain was again more frequent. In the middle of the treatment period, PGWB index reached its highest values and intensive pain was less common. The inverse correlation (correlation coefficient = .403) between pain and quality of life was significant ($p=.018$).

When the mean PGWB subscales are presented individually (Figure 2), they are lower in the beginning of treatment, and except for general health only, there is a peak at four months. The next peak is at nine months, when all of the subscales

Table 1. Demographic and interview data

	Gender	Diagnosis	Age (yrs) at diagnosis	1st Interview*	2nd Interview*	3rd Interview*
1	M	Lymphoma	16.4	1	12	
2	F	Ewing sarcoma PNET	17.7	4	8	
3	F	Osteosarcoma	18.3	12	21	22
4	M	Nasopharynx cancer	15.6	2	8	
5	M	Acute lymphoblastic leukemia	13.3	5	12	
6	F	Hodgkin's lymphoma	14.9	2	8	
7	M	Acute lymphoblastic leukemia	14.1	2	5	8
8	M	Rhabdomyosarcoma	17.3	2	5	9

*Months after diagnosis.

reach their highest, or nearly highest, values. After nine months, subscales decline and in the end of treatment, subscales differ. Anxiety, depressed mood and self-control tend to increase slightly, while positive well-being is unchanged, and general health and vitality decrease considerably in the end of treatment.

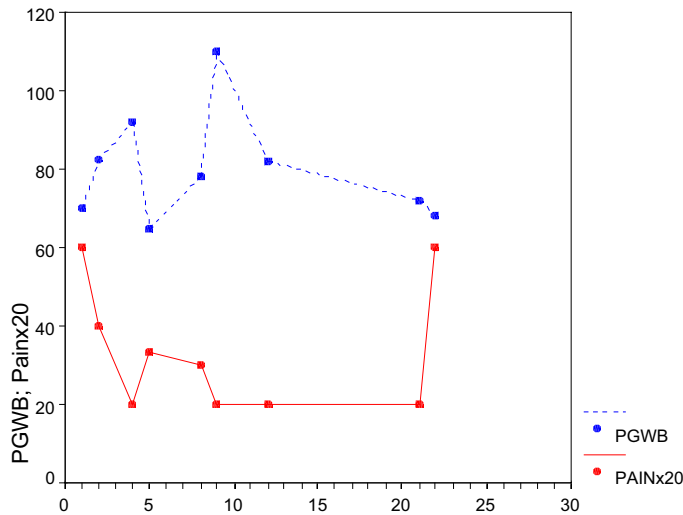


Figure 1. Mean PGWB index and mean pain x 20. PGWB = psychological general well-being. Pain value is multiplied by 20 to adjust it to the values of PGWB.

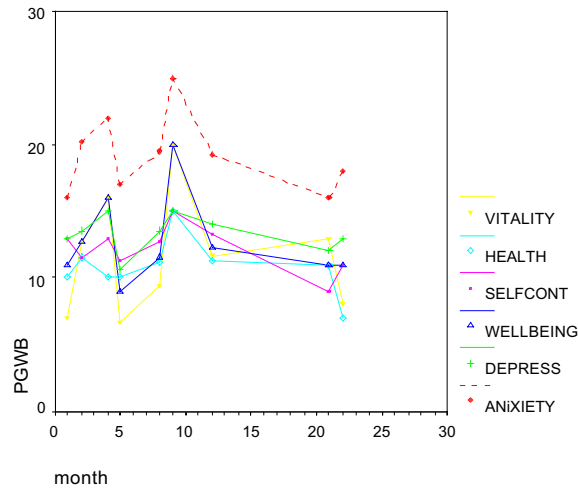


Figure 2. Mean PGWB subscales. PGWB = psychological general well-being. The subscales are: anxiety, depressed mood, positive well-being, self-control, general health, and vitality.

In linear regression analysis, variation in pain score predicted 21 % of the variation in the total PGWB index. In the PGWB subscales the corresponding figures were: general health 27.6 %, positive well-being 17.4 %, vitality 14.9%, anxiety 14.2 %, depressed mood 6%, and self-control 3.3%.

According to the first interview, two adolescents experienced pain before diagnosis very often, three sometimes, and three seldom or never.

In the beginning of the treatment, the adolescents were asked how often they had experienced intensive pain during the three months preceding the interview. Three adolescents had experienced intensive pain sometimes, and five had never experienced intensive pain. This pain was caused by cancer, treatment, and procedures or of other origin. When the adolescents were asked the same question later during treatment, pain had decreased for the three adolescents with intensive pain and had not increased for those with less pain, except for one.

DISCUSSION

We found that pain troubled the adolescents most in the beginning and in the end of the treatment period, but less in-between. This is in accord with a previous study demonstrating that pain is a major problem for children with cancer and that it varies during the treatment period (16). During treatment, quality of life was low in the beginning, higher in the middle and lower in the end. Pain co-varied inversely with quality of life and the adolescents thus seemed to have better quality of life when pain-relieved. This seems reasonable given that pain has negative physiological

(1,2,14) and psychological (15) effects on children.

The main limitation of this prospective longitudinal investigation is that it was performed on only eight adolescents and therefore should be regarded as a pilot study. In such a small study group, each individual's answers considerably affect the results and power is not high, implying that the results must be interpreted with caution. Nevertheless, in spite of the few patients, the inverse correlation between pain and quality of life was significant. Another aspect is that this material of eight patients comprises seven different diagnoses. However, there are many similarities between different treatment protocols where the general trend during the last decades has been more aggressive, multimodal, high-intensity, long-term therapy regimen (12).

During the middle period of treatment the patients seemed less bothered by pain than in the beginning and in the end. The major reason for better pain control and higher quality of life during the middle period of treatment is probably not a change in pain management, but a real decrease in pain thus improving quality of life. This is in agreement with clinical observations, which also suggest that the children's sense of subjective well-being or distress vary with pain. During this middle period, the adolescents experienced higher quality of life than in the beginning and in the end. This is also in accord with another study implying that quality of life in adolescents with cancer was higher during treatment than after (18).

The PGWB index means have been 76 to 84 for community samples (17) and 46 to 50 for mental health patients at intake and in treatment (19) for populations in the ages 14 to 74 years in the USA. The adolescents in our study had a PGWB index mean of about 70 in the beginning of treatment and in the end; the times when they experienced more intense pain. This is lower than PGWB mean values for the community sample mentioned above. During periods when the adolescents experienced less intense pain, the PGWB index mean was considerably higher, 90 to 110, which indicates that the adolescents, when pain relieved, experienced higher quality of life.

Quality of life issues have been much discussed during the last few years, and new measures have been developed. The ideal measure still does not exist, but today there are measures that have been developed especially for children and adolescents with cancer (20,21,22,23). At the time of the study, however, there were no such specific measures that had been validated and translated into Swedish. The PGWB index was chosen because it was considered the best choice at the time. It remains to be clarified whether the adolescents are so well pain-relieved that they experience higher quality of life, if they feel less pain because their quality of life is higher, or if other factors are important. Factors that could affect pain as well as quality of life are security and confidence and a feeling of being seen and respected as an individual. The clinical impression is that security and confidence generally increase during treatment, but often decrease again in the end of treatment because of less frequent contacts with the oncological team.

It is most important to reduce pain and distress as much as possible because of their

negative physiological (1,2,14) and psychological (15) influences during cancer treatment. It is also important that the adolescents undergoing cancer-treatment get pain-relief to achieve higher quality of life.

Most of the PGWB subscales vary according to the mean index, but the subscale for general health differs at four months when it returns to the same value as at one month after diagnosis, whereas the other subscales increase. In the end, the considerable decline in general health and vitality, which deviates from the other subscales, could cause the decreased quality of life. The decline in these two subscales might be explained by the long period of illness and treatment that the adolescents have endured.

In conclusion, pain and quality of life varied during treatment of adolescents with cancer. Pain co-varied inversely with quality of life and the adolescents thus seemed to have higher quality of life when pain-relieved. This has to be further confirmed in larger studies, but the results agree with findings in adult cancer populations (24,25). This finding emphasizes the importance of pain management in children and adolescents with cancer.

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Corresponding author: Gustaf Ljungman
 Department of Women's and Children's Health
 Children's University Hospital
 SE-751 85 Uppsala, Sweden
 Phone: +46-18-6115586
 Fax: +46-18-500949
 gustaf.ljungman@kbh.uu.se