

## Quality of Life of Adolescents Cancer Patients as Perceived by Patients, Nurses and Mothers

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### ABSTRACT

**Background:** Assessment of Quality of Life (QOL) is becoming an integral part of patient care and is considered an essential component in evaluating health care outcomes. In adolescents, the challenge of coping with cancer, the threatening diagnosis, its repeated treatment cycles and the need for frequent hospitalization that limits school attendance and other social activities is expected to have great impact on the quality of life of adolescents. With the relatively young age structure of Egyptian population and the increasing number of cancer survivors, understanding how adolescents with cancer feel and how disease and treatment affect QOL as perceived by patients, nurses and parents became an important challenge.

**Aim of work:** The aim of the present study was to assess the QOL of adolescents with cancer. The study also aimed at evaluation of the concordance of QOL as perceived by nurses and mothers on one hand and by patients on the other.

**Material & Methods:** A generic QOL inventory was adapted, translated into Arabic and subjected to validity and reliability. It was administered to 150 patients, 13-18 years old, in the National Cancer Institute, Cairo University, their mothers and nurses caring for them.

**Results:** The domains of positive concern as perceived by patients were symptoms distress and anxiety related to treatment, followed by body image and psychological wellbeing. The least was physical wellbeing.

**Conclusion:** Generally, there was a high concordance between nurses and patients and mothers and patients. Nurses tended to overestimate the importance of psychological wellbeing. They tended to underestimate cognitive abilities. Mothers tended to overestimate anxiety related to treatment and underestimate cognitive abilities.

**Key Words:** QOL - Adolescents - Perception - Nurses.

### INTRODUCTION

Oncology nursing requires special knowledge and can be difficult and demanding, because it

deals largely with seriously ill patients who have chronic illness and may be dying. In the younger age group of adolescence, understanding the physical, psychosocial and environmental parameters related to QOL and how to deal with mothers and other caregivers are essential components of nursing care of those patients.

Quality of life has been identified as an important nursing outcome variable that is influenced directly and indirectly by nursing care [11,13]. It is important during the initial assessment done by nurses, in both medical and surgical wards, to assess how adolescent patients cope with their stressful situations and observe their behavior for clues to readiness that largely affect their QOL [28]. This assessment of QOL provides an important outcome measure that complements physiological measures. Such information can help provide the basis for designing educational interventions to enhance the lives of children and adolescents with cancer [2].

QOL is generally a multidimensional concept encompassing several domains. These domains of quality of life have been identified and defined by different investigators and include physical, psychological, social and spiritual well-being [10]. In cancer, all these domains could be affected, especially for younger age groups and adolescents. Hinds [13] described QOL for adolescent cancer patients as a "subjective sense of well-being during the entire experience of cancer". This is a major concern in younger age groups whose self-image is often fragile. They may become depressed, withdrawing from friends and school and cutting themselves off from the social support of their peer group [16].

QOL can include both objective and subjective perspectives in its different domains [27]. Many tools have been developed to assess QOL of cancer patients. Most of these tools deal with adults and very few are designed for the younger age groups. Due to cultural differences, it was essential to develop a tool that suits our culture, eliminating confusing and embarrassing questions.

*Aim of work:*

The main objective of the present study was to assess the QOL of adolescents with cancer as perceived by patients, their mothers and nurses. The study also aimed at evaluation of the concordance of perception of QOL by nurses and mothers on one hand and by patients on the other hand. The final results could be used as a framework for culturally oriented care protocols.

## MATERIAL AND METHODS

*Setting and sample:* The study was conducted at the inpatient pediatric units of medical oncology department at the National cancer Institute, Cairo University. The study covered a sample of convenience of 150 patients, 13-18 years old, their mothers and 30 nurses involved in their care. All patients were receiving different forms of chemotherapy. Diagnoses were as follows: acute lymphoblastic leukemia (45%), osteosarcoma (35%), non-Hodgkin's lymphoma (15%) and others (5%).

*Study tool:* A generic form of QOL index-cancer version developed by Ferrans [9] was adapted and modified for the study. A group of experts in clinical and psychological domains evaluated validity of the tool. Reliability testing was done using Cronbach's alpha coefficient that measures the degree of reliability of the entire form. A coefficient of 0.85 was obtained indicating high reliability of the final version of the tool.

*The inventory included 7 categories of QOL concerns, namely:*

- 1- Physical wellbeing.
- 2- Symptoms distress.
- 3- Anxiety related to treatment.
- 4- Psychological wellbeing.
- 5- Social wellbeing
- 6- Cognitive abilities.
- 7- Body image.

These domains comprised different questions that could be answered as: always, occasional or never. Questionnaire was administered to patient, mother and nurses at the same time through the period from October to December 2002.

*Statistical methods:* For the purpose of analysis, "always" and "occasional" responses were added together and the item was considered a domain of positive QOL concern. The frequency of positive concerns were calculated as percentages relative to the total number of responses in each of them. For each item, concordance between nurses' and mothers' perception could be either the same as that of the patient, over-estimated, or under-estimated by nurses and/or mothers as compared to patients.

Comparison of percentages was done using the chi-square test. The threshold of significance was fixed at the 5% level.

## RESULTS

The frequency of positive responses for main domains of QOL and selected items in each category is shown in Table (1) for patients, nurses and mothers. The patients' main concern was for symptoms distress (78%), followed by anxiety related to treatment (75%), body image (69%), whereas the least concern was for physical wellbeing. (34%).

Mothers' main concern was related to symptoms distress (90%), followed by anxiety related to treatment (81%). The least concern was for physical wellbeing (43%) and social wellbeing (47%).

As for nurses, their main concern was symptoms distress (99%), followed by anxiety related to treatment (90%). The least concern was for cognitive abilities (26%).

Tables (2,3) depict concordance between mothers', nurses' and patients' perception, as related to adolescents' perception. This is expressed as concordant, overestimated or underestimated by mothers/nurses.

Mothers tended to overestimate anxiety related to treatment (32%), social, physical and body image (30%, 29% and 28%, respectively) as an important QOL positive concern. They tended to underestimate cognitive abilities (29%).

Concordance was most obvious in relation to psychological well being.

Among nurses, concordance was highest in symptoms distress (56%), followed by body image and social well being (51 and 50%, respectively). It was least in cognitive abilities (16%). Nurses tended to overestimate all the domains except cognitive abilities that were underestimated in 74% of cases, differences were statistically significant;  $p = 5\%$ .

Table (1): Frequency of positive responses (%) for main categories of QOL as perceived by patients, nurses and mothers.

Category	Adolescents	Mothers	Nurses
Symptoms distress	78	90	99
Anxiety related to treatment	75	81	90
Body image	89	75	82
Psychological wellbeing	64	72	83
Cognitive abilities	56	54	26
Social wellbeing	51	47	59
Physical wellbeing	34	43	45

Table (2): Percent concordance between mothers' and patients' perception.

Category	Concordant	Overestimated	Underestimated
Psychological wellbeing	57	27	16
Anxiety related to treatment	53	32	15
Physical wellbeing	56	29	15
Symptoms distress	54	26	20
Body image	54	28	18
Social wellbeing	47	30	23
Cognitive abilities	51	20	29

Table (3): Percent concordance between nurses' and patients' perception.

Category	Concordant	Overestimated	Underestimated
Symptoms distress	56	26	18
Body image	51	27	22
Social wellbeing	50	27	23
Anxiety related to treatment	49	30	21
Psychological wellbeing	46	36	18
Physical wellbeing	48	30	22
Cognitive abilities	16	10	74

## DISCUSSION

Quality of life assessment includes dimensions related to physical/role functioning, emotional/psychological functioning, social functioning and somatic/physiological complaints. Ferrans [9] grouped these dimensions into five categories that focus on the patient's ability to live a normal life, happiness/satisfaction, achievement of personal goals, ability to lead a socially useful life and physical and/or mental capabilities. In the present study, seven domains were included in the inventory.

### Physical wellbeing:

The effect of physical wellbeing was only perceived by 34% of the patients. Leisure time exercise patterns may be related to psychosocial well-being in adolescents after cancer diagnosis [17]. In a study by Reinders-Messelink et al. [24], leukemic patients performed more poorly than the control group on both fine and gross motor skills.

### Symptoms distress and anxiety related to treatment:

Patients perceived side effects as their major concern (78%) followed by anxiety due to the disease, its treatment and other associated procedures (75%). These results are consistent with other studies [5,23] which stated that cancer diagnosis and treatment at this particularly vulnerable developmental stage can put the adolescent at high risk for physical and psychological handicaps and social and vocational problems. Woodgate [31] agreed that treatment of cancer with its lengthy duration is extremely stressful for adolescents. During treatment, adolescents feel tired. They have to face the physical changes caused by cancer treatment as hair loss, weight gain or loss and painful procedures that are stressful for teenagers and younger children.

### Psychological wellbeing:

Impact on psychological wellbeing was perceived by 64% of the patients. Youngsters with cancer have to cope with frequent hospitalizations. They often use denial as a coping technique. Ware [30] suggested that disease has its most immediate impact on personal functioning, then psychological distress/wellbeing. Sharan [25] found that 61% of adolescents evidenced emotional distress.

A number of studies suggest that youth who

are diagnosed with cancer are at increased risk for a variety of psychosocial adjustment problems including poor self-esteem and poor self-satisfaction [12].

#### *Social wellbeing:*

Almost half of the study patients were socially adjusted. Ware [30] and Banner [1] stated that social functioning is not affected immediately by disease. They agreed that relationships with family, siblings and schoolmates comprise the primary social sphere of the adolescent with cancer. Although the family is usually the principal source of support, it may also be a major source of anxiety.

#### *Cognitive abilities:*

About 56% of the sample had problems with cognitive abilities. This agrees with the study of Eiser [8] who revealed that adolescents experience difficulties in concentrating and understanding simple instructions. As a result, reading and math performance are often two grade-levels below expectation [4]. Adolescents with cancer have been found to be at risk for school adjustment difficulties for a number of reasons including increased absenteeism [3,22]. Research on long-term effects has shown that some forms of cancer treatment result in difficulties in cognitive functioning, poor academic achievement and learning disabilities. According to Hockenberry-Eaton et al. [14], adolescents who miss more school time perceive more cancer stressors and have a lower adjustment rating.

#### *Body image:*

Impact of body image change on QOL was perceived by 69% of patients. Dudas [7] approved that alteration in body image occurs when changes in appearance, function, or control result in a conflict between the image that has been established over time and the current reality. Negative adjustment is much more likely when significant physical changes result from the disease or treatment. Due to appearance changes with an often fragile self-image, the task of self-acceptance might be threatened as well [16&26].

#### *Mothers and nurses perceptions:*

Ranking of importance of QOL by mothers was almost the same as that of patients. However, mothers tended to lay more importance for almost all domains except cognitive abilities and social wellbeing that were perceived to have the same

importance by patients and mothers. The same was observed for nurses' perception except for cognitive abilities that were considered a major concern by 26% of nurses only.

Concordance between mothers and patients varied between 57% for psychological wellbeing and 47% for social wellbeing. Overestimation of different domains varied between 32% for anxiety related to treatment and 20% for cognitive abilities. Mothers underestimation of the importance of different domains varied between 29% for cognitive abilities and 15% for both anxiety related to treatment and physical wellbeing.

Concordance between nurses and patients varied between 56% for symptoms distress and 16% for cognitive abilities. Overestimation of different domains by nurses varied between 36% for psychological wellbeing and 10% for cognitive abilities. Nurses' underestimation of the importance of different domains varied between 74% for cognitive abilities and 18% for both symptoms distress and psychological well being.

These findings raise many questions regarding the relation between patients', families' and nurses' perception of QOL. Manne et al. [20] indicated that ratings made by the adolescents, parents and nurses reflect different perspectives. Nurses' ratings are based upon overt distress; parents' ratings reflect their subjective perception of the child's sufferings, while adolescents' self-reporting is influenced by their social, cultural and psychological background. Donnelly [6] mentioned that parents who are raising adolescents are commonly more connected to cultural habits and traditions. Vance [29] studied the relationship between child-parent reported-QOL and found poor to moderate concordance between child and parent reports.

The oncology nurse should have guidelines for assessing cultural beliefs that might influence the family's coping style following a cancer diagnosis. High concordance should be achieved between patients', parents' and nurses' ratings of QOL [29]. The nurse could provide assistance by assessing the family situation at home [15,32]. It might be helpful if parents notify a teacher or counselor in school about the adjustments going on at home. Their observations of changes in the child's behavior or school performance may be indicators of the child's coping ability.

In a study by King et al. [18], it was observed that nurses usually perceive patients to have a poorer QOL than what is actually reported by patients. Lindley and Hirsch [19] assessed oncology nurses' attitudes, perceptions and knowledge of QOL of patients with cancer. Authors concluded that nurses value QOL as an outcome measure, but lack knowledge and time regarding its measurability by reliable tools. These studies stressed the importance of having a reliable tool, adequate knowledge and sufficient time to correctly measure QOL and to develop intervention to that help patients and families determine what makes QOL better for their patients. Nurses need to teach mothers how to care for the child and should provide psychosocial support to the family. Nurses need to identify factors that will mediate a positive adjustment and outcome [21]. Nursing care should be coordinated to meet patient's physical and psychological needs while involving the family when appropriate [28].

#### Conclusion:

There was a high concordance between nurses and patients and mothers and patients. Nevertheless, nurses tended to overestimate the importance of psychological wellbeing and to underestimate cognitive abilities. Nurses should be trained on how to evaluate quality of life of youngsters with cancer as a part of the nursing care process. They should realize patients' and parents' concerns to be able to guide them in their coping process. Perception of QOL by mothers and nurses should be as close as possible to patients' perception. Adequate tools should be available and sufficient time for assessment and intervention should be provided. Involvement of a school teacher or counselor might be also helpful.

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