

# Original Article

## Quality of Life and Cancer

Nely Aparecida Guernelli Nucci, PhD;<sup>1</sup> Elizabeth Ranier Martins do Valle, PhD<sup>2</sup>

1 Psychologist – Center For Integral Assistance in Oncology of Dr. Mário Gatti County Hospital – Campinas-SP

2 Senior Professor at Psychology – Nursing School of University Of São Paulo – USP – Ribeirão Preto Campus

### Abstract

**Objective:** This study aims to evaluate the Quality of Life of patients with cancer. **Methods:** A Quality of Life evaluation instrument developed by The World Health Organization – WHOQOL-bref, was used. The investigation had as research subjects people distributed in two groups: one composed of 50 female and male adult patients engaged in treatment for different types of cancer in the Oncology Center of Hospital Municipal Dr. Mário Gatti, Campinas/SP, Brazil, and the other composed by 70 control-volunteers. **Results:** The groups did not present statistically significant differences regarding general psychological aspects, satisfaction with health and Quality of Life. In the final considerations, the study reaffirms the complexity, the subjective aspects and the magnitude of the concept of Quality of Life and recommends that one associates a qualitative evaluation for allowing subjective comprehension to occur.

**Key words:** Neoplasms; Quality of Life; Psychosocial Impact.

### Introduction

The last years has seen an increasing concern with what has been named “quality of life” and its scope in the most diverse dimensions. This concept has begun to be object of investigation and action, being studied for reasons based on human values, evidently multifarious in all its aspects.

Concerns about this question changes in history and, more recently, after World War II, western sociologists and economists had linked Quality of Life to the access to material goods (“welfare”) and to unlimited economic growth. Casas,<sup>1</sup> considers that the attempts to measure Quality of Life began basically in Economy with the concept of per capita income, within strict economic standards in the establishment of the belief of that the bigger a developing country growth the bigger the well-being of its inhabitants, evaluating well-being in terms of Gross National Product - GNP.

While Casas<sup>1</sup> attribute to Economy the first attempts in measuring Quality of Life, for Riaño<sup>2</sup> its origin is Medicine, coming from a

palliative function for treating chronic patients, including Psychology and Sociology, and extending the area of studies and research.

It is a general belief that Quality of Life is a multidimensional construct having contributions of several and different aspects or domains of life,<sup>3,4</sup> being thus more than a mere evaluation of health condition (that is, physical, psychological and social well-being) because it incorporates other life experiences, such as economic, occupational and domestic-familiar aspects.<sup>5</sup>

Having a disease affects no doubt the Quality of Life of individuals and must be the object of specific considerations. In the health area, the concept of Quality of Life must be

---

#### Correspondence

Nely Aparecida Guernelli Nucci

Rua José Augusto César, 301

Campinas, Brazil 13066-420

Fax 55 19 32135863

e-mail: nucci@terra.com.br

understood as an eminently subjective<sup>6,7</sup> factor whose evaluation must be done by patients and as a complex concept dependent of multiple factors and changeable situations in the course of time.<sup>8</sup> The impact of a specific disease seems to depend, thus, of innumerable factors, from which we can mention its chronic character, the threat or risk degree that awakens in the patient, as well as the limitations, losses and difficulties that it generates.

From the World Health Organization (WHO) definition of health (in 1946) as a condition of complete physical, mental and social well-being and not simple absence of disease, one perceives less emphasis on the biomedical dimension and a recognizance of the importance of the subjective, psychological component, of mental health as important factors in individual and group quality of life; these are essential aspects that cannot be omitted in planning health care in all levels.<sup>9</sup>

This subject is no doubt intrinsically important, but lately it is acquiring a greater relevance due to the argument that, besides its psychological and emotional dimension on patients and their relatives, it is very probable that "quality" of life has some effect in sick people's "quantity" of life. This means the way to face disease and the self-perception of well-being or malaise during the therapeutical process contributes, in a still unknown degree, to the disease's biological evolution and therefore, can be a real therapeutical co-factor susceptible to mobilization together with other types of treatment, seeking a common objective of biological improvement or cure.<sup>6,10</sup>

The disease subjective and social construction stems therefore from interactions and interpretations arriving from individual and specific experiences of each human being, narrowly linked to social and psychological aspects.

In our country, studies on Quality of Life of cancer patients are increasing in recent years, considering that cancer has a series of implications that will intervene with patients life, and recognizing a patient as a whole being that live in a particular social and political context, something that requires new methods in the evaluation and the work of health protection or recovery, methods that take into account the preservation of the quality of the patient life.

From Antiquity, cancer diagnosis has been

received with fear, anguish and desperation, involving the family as a whole and the friends, and consolidating social stigmata and preconceptions. Currently, in view of advanced therapeutical processes used for its treatment, cancer seems to be acquiring characteristics of a chronic illness and in many cases a curable one. Therefore, a greater concern emerges with the social dimension linked to the complete recovery of the health condition and the integration of the individual to the society.<sup>11</sup> Besides technical/clinical aspects in cancer diagnosis and treatment, what definitively puts it in the Public Health agenda is its social and economic impact. There is a high social cost, considering the suffering of individuals and their families, as well as the loss of years of life, which affects, consequently, their production.<sup>12</sup>

As happens in all serious disease, cancer brings to the fore, for the sick person and her family the possibility of imminent death, provoking deep alterations in their routine and lives. Besides, cancer meaning is very particular and personal, depending on varied factors that involve the moment in life when the patient comes to know the diagnostic, her past experiences, cultural prejudices and the information given by the media. The way the subject sees, interprets and lives this situation will determine her emotional reactions, the changes in her existential dynamics and beliefs, and all this could affect her Quality of Life.

In this context, the present study was developed aiming to evaluate Quality of Life of patients in cancer treatment in comparison with a Control Group.

## Material and Methods

The study used WHOQOL-BREF (The WHOQOL GROUP, 1998), a shortened version in Portuguese of the World Health Organization Quality of Life Assessment (WHOQOL-100), developed by the Division of Mental Health of the World Health Organization - WHO, in a multicentre and collaborative project validated in Brazil in the year 1998 by the Department of Psychiatry and Forensic Medicine of the Federal University of Rio Grande do Sul.<sup>13,14</sup>

The option for WHOQOL-BREF occurred due to the scarcity in our country of instruments validated specifically for evaluation of Quality of Life in cancer patients and was guided by four basic criteria:

1. Adequacy to the study objectives
2. Origin of the instrument: a scientific and multicentre study legitimated by the WHO
3. Version in Portuguese already developed and validated under scientific and ethical criteria meticulously respected<sup>15</sup>
4. Easiness of application: it requires little time for being answered and evaluated, is easily understood and present satisfactory psychometric characteristics.

The instrument comprises 26 questions divided in: general questions (2), physical domain (7), psychological domain (6), social relations domain (3) and environment domain (8).

The questions were formulated for a Likert-type answers scale, with three words between the extreme points of the intensity scales (not at all - extremely), capacity (not at all - completely), frequency (never - always) and evaluation (very unsatisfied - very satisfied; very bad - very good).

## Research Subjects

The sample was constituted by two groups:

Group 1 - Patients treating cancer: n = 50

Group 2 - Control Group: n = 70

The first group was constituted by adult, more than 18 years old, both male and female, in treatment of different cancer types in the Center for Integral Assistance in Oncology of the Dr. Mário Gatti County Hospital, in the city of Campinas/SP.

The 70 subjects of the Control Group had been chosen among inhabitants of Campinas/SP, in a region of similar socioeconomic level to the one presented by the patients who already had answered the questionnaire, being also similar in terms of age, sex, schooling and civil state, and the only exclusion criterion was having cancer. Both patients and Control Group subjects were invited to participate voluntarily of the research, and gave their informed consent by signing the Informed Consent.

Gathered data was analyzed statistically by

means of SPSS Syntax - WHOQOL-bref Questionnaire, according to the instructions for application and evaluation of the instrument supplied by Whoqol Center in Brazil.

The answers were tabulated and we applied the statistical tests t Test - for the continuous variables, and Chi-square for the categorical variables. The significance level established was 0.05.

The instrument internal consistency was evaluated with Cronbach confidence coefficient, with satisfactory values in the total (26 questions): Control Group - 0.8956; Patients Group - 0.8295 and Total 2 Groups - 0.8764.

## Results and Discussion

The groups (patients and control) did not present significant statistical differences, as Table 1 shows.

As regards time for completing the questionnaire, a statistically significant difference is perceived: patients used an average 23 minutes and the Group Control 15 minutes.

A possible inference is that patients had answered the questionnaire in the treatment period, in ambulatory environments, many times using wait intervals for some procedure, and that can have facilitated the unconcern with time used or else patients used the questionnaire as a way to contact their own selves and for thinking about existential questions. Other possible reasons are little anxiety regarding their work routines, for most patients were receiving social security benefits or were already retired.

Control Group subjects were in their work routine and this could explain their concern with time expended to answer the questionnaire.

Patient and Control Groups members' ages are in Table 2.

Both groups have low socioeconomic status, with incomes varying from less than 1 to 6 minimum wages. This data was considered important, facilitating the comparison between the groups, even so it was not in the Respondent Information Form of the standard instrument.

## Questions

Although the questionnaire presented

Table 1 - Description (mean  $\pm$  standard deviation or %) of patients and control studied

Characteristics		Patients (N=50)	Controls (N=70)	p
Age (Years)		52.9 ( $\pm$ 13.8)	50.3 ( $\pm$ 12.1)	0.268
Sex	Male	38%	29%	0.277
	Female	62%	71%	
Schooling				0.792
	< 1st Degree - Partial	72%	67%	
	1st Degree - Complete	14%	19%	
	$\geq$ Degree - Partial	14%	14%	
Civil State				0.850
	Single	10%	7%	
	Married	74%	77%	
	Divorced/Widow(Er)	16%	16%	
Questionnaire Administration				0.616
	Self-Administered	22%	23%	
	Assisted By Researcher	16%	10%	
	Administered By Researcher	62%	67%	
Time For Completing (Minutes)*		23,5 ( $\pm$ 13.0)	15,2 (+5.3)	<0.001

Table 2 – Research subjects ages (frequency and %) – patients and controls

Age	N	%
<19 years	1	0.8
20 A 29 years	9	7.5
30 A 39 years	8	6.7
40 A 49 years	30	25.0
50 A 59 years	37	30.8
60 A 69 years	27	22.5
70 years or more	8	6.7
Total	120	100.0

questions that demanded closed answers, subjects (Patient and Control Groups) made verbal commentaries or reflections that the instrument is not able to deal with.

These verbal manifestations, understood and considered as “thinking aloud”, without interventions nor questionings, were only written down and, even so not taken into account in statistical analysis, had been considered in the results discussion, favoring a broader scope for understanding subjects. These considerations are placed after the statistical result for each question.

## General questions

### 1) How would you rate your Quality of Life?

(Figure 1)

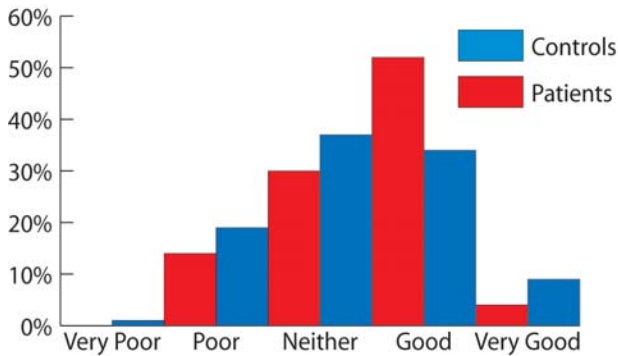
Many times, it was necessary to explain the term “Quality of Life”. Interviewed patients and Control Group subjects alike asked about the meaning of the term. Following Application Manual instructions, the clarifications were based on the definition of the World Health Organization – WHO, used in the instrument elaboration. This occurred with at least 50% of subjects and seems to show the little contact, or little familiarity of subjects with the term, as well as with the concept of Quality of Life, allowing hypotheses about the interference of socioeconomic status, schooling, age, among other factors that, not being in the scope of the questionnaire, were not evaluated.

So me written commentaries done when subjects answered this question:

*“Good... I think it’s good... It’s difficult, isn’t it? Not so good, but what use saying it’s bad? No use... only attracts more bad things... I think it’s good like God wants... write that it’s good.” (contr. 46)*

*“Neither bad nor good; it’s as it goes... What am I going to answer... Good. I think it’s good.... write it” (contr. 17)*

*“I don’t know... quality... everything is so bad... pain, malaise, nausea, little money... but I have my*



**Figure 1** – General evaluation of quality of life – (no statistically significant difference: 0.328)

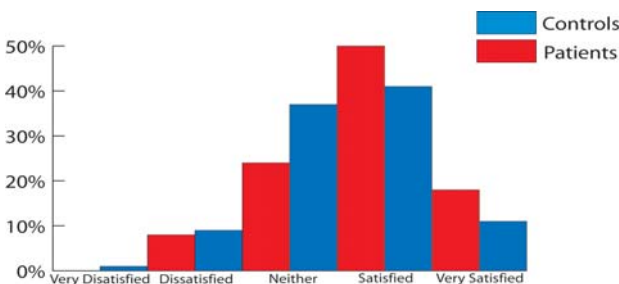
children, my woman... many people have nothing... what use to complain? Very good, good ... you can write it... (pat. 11)

“Looks like everything is so complicated... the illness, the lack of money, the problem of my pregnant daughter... but life is good. It is always good... I have faith it’s going to improve... you can write good” (pat. 38)

In these occurrences, the researcher allowed a time to think or even review the reply, but subjects kept in all cases the first option.

**2) How satisfied are you with your health?** (significance: 0.451) (Figure 2)

It must be taken into consideration that, although not having a serious illness as cancer, some subjects of the Control Group had brought information on other health problems (osteoporosis, migraine, allergy, menopause, eye problems, voice problems, hypertireoidism,



**Figure 2** – Evaluation of satisfaction with health condition

hypertension, ) with subjective significations and very particular attributions of interference in their life routine.

Patients, by their turn, could have answered taking into account their perception or even a medical evaluation about a better health condition

at the moment of answering the questionnaire.

We could perceive, although the instrument does not provide elements for understanding meanings in a broader dimension, that the discourse permeating closed answers sometimes revealed negation or ambivalence:

“I am very satisfied with my health. It’s all good, I am excellent. You can write satisfied” (pac.07)

“I think all is good... at times we have pain... in the column, in the head... no surprise, for everything is so difficult... write that I am satisfied... no gain in complaining... write satisfied (contr. 13)

Other times, in the Patient Group, satisfaction seemed based on the perception of being well-taken care of, that the treatment was successful.

“I am very satisfied. I’m feeling very better. I find that the drugs are working.”

As regards the four dimensions, it was possible to observe that there were statistically significant differences in the physical, social relations and environment domains, which seem to refer to more objective data, with more concrete interferences in a disease-treatment situation. Concerning the psychological domain, no statistically significant differences were observed (Table 3).

**Physical domain**

In the physical domain, as expected, the questions that had presented greater discrepancy between the groups, from a descriptive point of view, were the ones related to a greater necessity of medical assistance, energy loss, sleep difficulties etc. for patients with cancer.

In this domain, patients and participants of the Control Group present a similar positioning regarding questions about impediments brought by physical pain, locomotion, motivation for routine activities and to work.

Patients seem to surpass the limitations brought by the disease, and we could possibly hypothesize that they can be re-signifying their life and temporality, in an attempt to keep their identity and social roles.

**Psychological domain**

Both patients and Control Group participants gave answers that, inside the Psychological Domain as a whole, presented no



Table 3 – Median ( $\pm$  standard deviation) of domains in a comparison of patients and controls

Domain	Patients (n=50)	Controls (n=70)	p
Physical	13.9 ( $\pm$ 1.9)	13.0 ( $\pm$ 1.5)	0.003
Psychologic	13.6 ( $\pm$ 2.3)	13.2 ( $\pm$ 1.8)	0.261
Social Relations	15.5 ( $\pm$ 3.0)	14.2 ( $\pm$ 3.1)	0.023
Environment	14.5 ( $\pm$ 2.7)	13.7 ( $\pm$ 3.0)	<0.001

statistically significant differences, allowing the conclusion that feelings, emotions, and sufferings happen in all the human life dimensions. The disease is not the only cause of pain and suffering. Day-by-day life challenges seem to be a permanent process of searching for a dynamic balance of all factors that make human life and that will determine the degree of a healthful attitude for each one of us.

### Social Relations Domain

Discrepancies occurred in the questions about personal relations and to the satisfaction with the support received from friends. Patients with cancer seem to be more satisfied with social and familiar relations, and friendships in the evaluation of the support received, in the necessity of perceiving themselves as relational beings. The decrease of personal resources and the restrictions on external conditions in the life of this being affected by the disease seem themselves changed into encouragement for discovering of possibilities of a better self-understanding, developing and extending not only this self-understanding but also the understanding of other people and the world.

Without statistically significant differences, there appear in this domain the answers related to the question of satisfaction in sexual life.

### Environment Domain

Discrepancies appeared in the questions linked to security in daily life, and security felt in daily life is related to financial questions and violence. Patients said to be more supported and protected by society than did controls.

Statistically significant differences were also noticed in the questions about the evaluation of the physical environment, the availability of the necessary information in daily life, opportunities of leisure, satisfaction with housing, access to health services, satisfaction with

transport, and satisfaction was greater on the part of patients than on the Control Group.

The high rate of satisfaction found in the answers of patients regarding access to health services can be related to the fact that they are already systematically inserted in these services, having faced the initial difficulties for this insertion. Concerning satisfaction with transport, it is important to remark that a great many patients in oncology treatment gets specialized transport, through ambulances of the City hall or other comparable support. The percentage of satisfaction with transport is thus greater than in the Control Group. The member of this latter complain for not receiving any type of aid or improvement in terms of transport. The interviewed live in the city periphery, with the obvious difficulties of collective transport in the great cities (price of the ticket, discomfort, non-observance of schedules).

In this Domain - Environment – no statistically significant differences was found in the answers relative to the evaluation of financial conditions for satisfaction of necessities. The two groups referred to economic/financial difficulties and restrictions, what was expected, because all belong to the same social class. The highest percentages disclose that, in the two groups, the majority of the respondents does not have enough money to satisfy its necessities.

## Conclusion

We suggest to associate to the questionnaire some qualitative evaluation, since the dimension of subjective attribution of meanings is not considered in more objective instruments.

The instrument favored an approach to the concept Quality of Life, with the perception of its subjective scope. To the participants it seems to have offered an opportunity for reflection on

their own life, satisfactions, necessities and sense of existence.

In the whole, participants of the two groups reacted favorably to the questionnaire and the participation.

*"It helps to think about life. It was fantastic"* (control)

*"I liked it! The questions are part of life. It reflects what happens the people."* (patient)

As they are treating cancer, a disease that still brings stigmata and preconceptions, it would be expected that patients show a negative vision of their Quality of Life, in comparison to the Control Group, but this was not observed. Comparing these groups, the study ratified the complexity, broadness and subjectivity of the concept Quality of Life and the innumerable factors that it covers. Quality of Life is not restricted to be healthy, but depends, essentially, of the expectations each human being has, the way the world feels for them and the way they relate to it.

Human beings always have expectations, always want something better for themselves and it seems that the patient facing a serious disease modifies her world view, re-signifying interpersonal emotions, relationships, the self-image, and re-valuing conflicts and concerns, as well as her existential dynamics, also revealing a greater acceptance of the physical environment and housing conditions.

WHOQOL-BREF brought information and the positioning of the participant groups on the satisfaction with transport, housing, leisure, sexuality, among others, which are important factors for a general evaluation of the social conditions of respondents. Thus, these data can allow for an excellent understanding of the importance of support and actions directed to health assistance.

We all know the conditions of our country's public health in our country are not ideal ones. After all, scientific and technological advances are not enough. There is basically a need for, beyond universal access to them, the attention to interaction, the construction of confidence relationships and solidarity between patients and health professionals, sick people and their families.

In virtue of the sped up process of technological development in Medicine, it seems that the singularity of patients, their beliefs, emotions and values go to the background, and

"the disease" becomes the central object of recognized scientific knowledge and the most important element in the assistance process. This latter needs in view of all this, to be urgently humanized.

The reflections on humanized assistance includes the patients insertion in a complex personal, familiar and social context; the understanding of the personal, social and emotional necessities patients have; an adequate communication among patients, their families and the health team; the necessities of those who take care of and those who are taken care of.

This reflection can create opportunities for seeking the generative dimension of basic values that structure human existence and give sense to life, to care, to interpersonal relations.

## References

- Casas F. El Concepto de calidad de vida en la intervención Social en el ambito de la infancia. Proceedings of III Jornadas de Psicología de la Intervención Social. Colégio Oficial de Psicólogos. Instituto Nacional de Servicios Sociales; Madrid, Espanha;1991.
- Riño DG. Calidad de Vida. Aproximación Histórico-Conceptual. Bol Psicología 1991;30:55-94.
- Aaronson NK. Methodologic issues in assessing the quality of life in cancer patients. Cancer 1191;67:844-50.
- Gotay CC, Moore TD. Assessing quality of life in head and neck cancer. Qual Life Res 1992;1:5-17.
- Fraser SCA. Quality of life measurement in surgical practice. Brit J Surg 1993;80:163-9.
- Bayés R. Psicología Oncológica. 2ª ed., Barcelona, Martinez Roca, 1991, 191p.
- Font A. Valoración de la Calidad de Vida en Pacientes de Cáncer. Bellaterra, Barcelona: Universidad Autónoma de Barcelona, 1988.
- Barreto P, Pascual A. La calidad de vida en el enfermo oncológico. In: Buendía, J. Psicología Clínica y Salud: Desarrollos Actuales. Murcia: Universidad de Murcia, 1991, p. 67-76.
- World Health Organization. Constitution of the World Health Organization. Basic Documents. WHO. Geneva, 1946.
- Ader R, Felten DL, Cohen N. Psychoneuroimmunology. 2a ed.; San Diego. Academic, 1991.
- Valle ERM. Vivências da família da criança com câncer. In: Carvalho, M. M. L. (org.). Introdução à Psiconcologia, Campinas, SP, Ed. Psy, 1994, p. 219-242.
- Brasil, Ministério da Saúde. Secretaria Nacional de Assistência à Saúde. Instituto Nacional de Câncer. Coordenadoria de Programas de Controle do Câncer – Pro-Onco. Registro de Câncer: Princípios e Métodos. Rio de Janeiro: Pro-Onco. www.inca.gov.br. Acesso em 2003.
- The Whoqol-Group. Development of the World Health Organization WHOQOL-BREF Quality of Life Assessment. Psychol Med 1998;28:551-8.
- Fleck MPA, Leal OF, Louzada S, Xavier M, Chachamovich E, Santos L, Pinzon V. Desenvolvimento da versão em português do instrumento de avaliação de qualidade de vida da Organização Mundial de Saúde (WHOQOL-100) 1999. Rev Bras Psiq 1999;21:19-28.
- Fleck MPA. Aplicação da versão em português do instrumento WHOQOL-bref. Rev Saúde Públ 2000;34:178-83.