

## METASTATIC BREAST CANCER CAREGIVER : NEEDS AND QUALITY OF LIFE EVALUATION

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### Abstract

Objectives of the study were: a) to analyze the quality of life in metastatic breast cancer caregiver and to monitor the trend during a and after the support; b) to divide caregivers in different profiles and risk categories; c) to analyze the predictor elements of major or minor physic, psychological and social well-being. 15 subjects were enrolled in this study (mean age 52 yo; DS  $\pm$  11); they underwent two questionnaires for the evaluation of caregiver's needs CNAT-C: Comprehensive Needs Assessment Tool for cancer Caregivers) and for the analysis of the quality of life (CQOLC: Caregiver Quality of Life Index-Cancer). The CNAT-C made out that the most frequent needs are physical and psychological health, to information and to the care staff. Female caregivers have more needs if compared to men in physical and psychological problems ( $p < 0,01$ ), social and familiar support ( $p < 0,05$ ), and spiritual help ( $p < 0,05$ ). There is a statistically significant correlation between the two scales. Data consent to personalize intervention and resources in patient-caregiver couple; the caregiver can be included in the metastatic breast cancer caregiver with the aim of optimize the quality of life.

**Key words:** breast cancer, caregiver, quality of life, needs, help

## Introduction

In most cases, caregiver and relatives are the first essential resource in patients suffering from metastatic breast cancer, in whom quality of treatment and the achievement of positive results depends on the ability of the caregiver [1]. However, the caregiver is exposed to physical, psychological, social, spiritual and practice issues that can influence the quality of life of the patient and of his family [2]. Caregiver can sick with cognitive impairment, anxiety, depression and other psychiatric disorders [3,4]. This person can also have difficulties in the workplace, due to the psychological impact of the disease not only in the patient, but also on his relatives that often suffering from a mental distress; it has been demonstrated a similar distress level in patients, caregiver and/or relatives in case of an oncological disease [5].

A caregiver can present relational difficulties due to the patient's cynism and to the therapeutical objectives [6]. A prospective cohort study highlighted the increased mortality risk of 63% in five years due to the psychopathological symptoms [7]. Purpose of the study were to a) analyze the quality of life of the caregiver and to follow up during and after the attendance; b) to divide caregivers in different profiles and risk categories and c) to analyze the predictor elements of major or minor physic, psychological and social well-being, in order to insert the caregiver role in a breast metastatic patients care.

## Methods

### Population

In this study were enrolled 15 subjects (6 M, 9 F9), mean age 52 yo, DS  $\pm$ 11; all included subjects gave written informed consent to participate to the study and to personal data processing.

*Inclusion criteria: relative of an oncologic patients with the role of main caregiver. Exclusion criteria: age < 21 yo; history of personal oncologic or psychiatric disease.*

### Evaluation instruments

Enrolled subjects underwent two questionnaires.

- CNAT-C (Comprehensive Needs Assessment Tool for cancer Caregivers), developed for a complete evaluation of caregiver needs of oncological patient caregivers. It is composed of 41 items divided in 7 groups: physical and psychological health (6 items); social/familiar support (5 items); health personnel (8 items); information (8 item); social and religious/spiritual support (2 items); health facilities (6 items); practical

support (6 items). Subjects may indicate their needs splitting them into "little, medium and very" [8]

- CQOLC (Caregiver Quality of Life Index-Cancer), an instrument used to evaluate the quality of life in relatives of oncologic patients. The scale includes four quality of life domains: physic, emotional, familiar and social functioning. CQOLC consists of 35 items with a score of 5 points (Likert scale): 10 items relating to the charge, 7 to disruptiveness, 7 to positive adaptation, 3 to financial concern and 8 items to additional factors (sleep disorders, satisfaction of sexual behaviour, mental fatigue, illness information, patient preservation and patient pain management [9].

## Results

The analysis of the questionnaire CNAT-C shows that the most frequent needs are related to physical and psychological health, to information and to personal care. In the area of physical and psychological needs, the most frequent are the worries about the patient (72%), anxiety (53%) and anger (52%). In the area of social and/or familiar support, caregivers need an "help to relax and for their personal lives" (56%) and an "help because of the excessive addiction of the patient" (49%). In the area of personal care (physician and nurses), caregiver need to easily and quickly meet the physician if necessary" (54%). Regarding to the needs of information, caregiver indicated "information on the patient care" (64%), on "alternatives and/or complementary treatment" (64%), on " the stress management due to the patient care" (57%) and " information about the disease and the progression" (56%).

Regarding to services and health facilities, the most frequent request were " an operator reference, that can support the caregiver during the assistance", that can be the landmark for the whole process of assistance (65%), a domiciliary nursing service (62%), instructions on facilities and hospitals" (57%) and "assistance and help for caregiver, like psychological counselling (55%). In the area of practical support, caregivers need "treatment near home" (44%), transport services (40%) and assisted treatment in a hospital or at home (39%). Women are more needs if compared with men in physical and psychological problems ( $p < 0,01$ ), social and familiar support ( $p < 0,05$ ) and spiritual support ( $p < 0,05$ ). The CQOL-C allows an evaluation on the quality of life to analyze the well-being of the caregiver; there is a linear correlation between the CQOL-C and the CNAT-C questionnaire, especially in the field of physical and psychological health ( $r$  di Pearson = ,566;  $p < 0,01$ )

and of the disruptiveness, especially in the field of physical and psychological health, in the social, familiar and spiritual support and practical needs (r di Pearson: from 0,251 to 0,465). The global quality of life scale correlates positively with the scale of needs in CNAT-C (r di Pearson comprise tra ,211 e ,476). Women represent the 63% of the total sample; there were some differences between male and female on the well-being in the caregiving. Women had a worsen quality of life if compared with men in the assistance ( $p < 0.01$ ), in the disruptiveness, and the their own quality of life ( $p < 0.05$ ). Regarding to the items of the quality of life questionnaire, there are some differences in the sleeping ( $p < 0.05$ ), mental fatigue ( $p < 0.01$ ) and the pain management ( $p < 0.01$ ).

### Discussion

Breast cancer represent the most frequent neoplastic disease in women; in absence of a valid and efficacy primary prevention, is essential the early diagnosis of asymptomatic woman [10], with a correct detection and differential diagnosis between benign and malignant disease [11,12] not only in women, but also in men [13,14], thanks to dedicated breast radiologists [15]. A late diagnosis often is associated to nodal involvement and metastatization [16] with a life expectancy reduction, recidive or the presence of almost all organs (lungs, liver, bone, skin and central nervous system). A valid support and a dedicated assistance could be a useful help in the disease progression. Questionnaires related to needs were administered to plan a psychological personalized help to the caregiver [17] and to define a caregiver-patient couple [18]. These information can facilitate and guide the assistance with time savings and improving the quality of the treatment.

The quality of life monitoring can provide information on well-being and on the disease progression, in order to have a true overview of the caregiver and can be used as a clinical indicator [19]; in some cases, a psychological support could be useful also if not required because of the low awareness of the psychological well-being and the needs of the caregiver [20] with a risk for himself and for the patient [21]. The monitoring of these conditions allows the evaluation of the caregiver status in terms of improvement or worsening in order to avoid depression status or mental distress [22] that can condition negatively on health condition of the patient [23]. Indeed, the evaluation of the needs and the quality of life not only in a breast metastatic patient [24-26], but also in the

caregiver, allows to define a couple to whom direct personalized intervention to optimize the outcome and to meet the needs of the patient and of the caregiver.

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