

EVALUATION OF THE QUALITY OF LIFE IN PATIENTS WITH GENETIC DIAGNOSIS OF LYNCH SYNDROME: RESULTS FROM A RESEARCH STUDY AT THE FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI – MILANO

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Introduction

Quality of life (QoL) is defined by the WHO as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns [1]. Specifically, it assesses the general well-being of the individual from physical, psychological, emotional, social, and spiritual perspective. In the recent years QoL in cancer patients has attracted growing interest for monitoring treatment effect and the burden of the disease. From this point of view Lynch Syndrome (LS) represents one of the most intriguing cancer-related scenario to define a methodological workflow for QoL assessment. LS is in fact an autosomal dominant inherited disease associated with an increased risk to develop colorectal or gynaecological cancer, as well as in other sites (e.g., ureter, renal pelvis, stomach, small intestine, brain and skin).

Aim

The main purpose of this research was to investigate the QoL in LS patients registered and prospectively monitored at the Unit of Hereditary Digestive Tract Tumors of the Fondazione IRCCS Istituto Nazionale dei Tumori of Milan (INT). Given the burden of the increased risk to develop cancer during the lifetime, the study also aimed to explore the dimension of cancer worries.

Method

QoL was investigated with the Short Form 36 (SF-36) questionnaire [2] and concern about cancer with the Cancer Worry Scale Revised for Genetic Counseling (CWS-GC) questionnaire [3] adapted for LS. The online LimeSurvey tool (LimeSurvey GmbH, Hamburg, Germany. <http://www.limesurvey.org>) hosted on the INT servers were used to anonymously all the collected data. Each participant received an e-mail contained a brief explanation of the study together with instructions and the link to the online questionnaires. Regarding the SF-36 questionnaire, questions were coded and transformed in eight positively health scale indices and then grouped to generate the scores using the U.S. general population coefficients. Subsequently, the relationship between these scores (8 items and 2 standardized indices) and the main characteristics of the participants (such as gender, age groups, and previous cancer occurrence) was assessed.

Results

238 participants out of the 321 were enrolled (response rate of 74%). Among the latter, 15 were ruled out because the two questionnaires were not fully completed. The cohort of patients consists of 128 women (57.40%) and 94 men (42.15%); one patient did not provide this information. The age ranged from 19 to 78 years, (the median age was 51 years). Most participants at the time of questionnaires completion were married (50.67%) with children (59.19%). As regards to the SF-36 questionnaire, the physical component index (PCS) scored 51.16, slightly higher than the mental component index (MCS) 43.88. Regarding the

modified CWS-GC, 60% of the patients had already developed cancer, mainly-localized in the colon (67.16%). Moreover, more than 90% of patients understood the result of the genetic test for LS and reported they were satisfied with the information they received from clinicians about the disease, although most subjects declared that they are *'quite'* concerned about upcoming medical examinations. Patients without a history of cancer achieved better scores in the physical and social dimensions. Younger patients (< 50 years old) better scored in the physical dimension while patients older than 45 years had higher scores in the mental dimension. Men achieved better scores on the mental dimension. Regarding cancer worries questionnaire, women were more concerned than men, as well as young patients (< 50 years old) were more worried about the possibility of developing cancer for the first time; similarly, more adult patients (> 45 years old) were worried about the possibility of developing a new cancer related to LS.

Conclusions

Cancer history, age and gender impact on the QoL perception of patients. Specifically, female and older patients with a previous cancer history showed a lower mental, physical and social well-being score when compared to the counterpart. Besides, they showed a significantly greater concern about cancer. In accordance with these results, we can consider the use of two questionnaires (SF-36 and CWS-CG) as a good tool to investigate QoL in LS patients. This same tool could also be applied to other cancer patients.

References.

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