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ECONOMETRIC ANALYSIS OF ONCOLOGY PATIENTS' HEALTH-RELATED QUALITY OF LIFE DETERMINANTS IN BULGARIA

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SUMMARY

Objectives: The present study investigates the determinants of oncology patients' Health-Related Quality of Life (HRQoL) in Bulgaria. Looking at some patients' characteristics, including control variables in the estimated model – demographics and the time from the disease onset, it studies the relevance of HRQoL diverse factors: some of them are related to the physical and psychological dimensions of the patients' illness experience, such as the levels of pain and anxiety/depression; some other concern more specifically the patients' therapeutic path, i.e., the feeling of participation in the therapy, their perceived uncertainty in illness (predictability and complexity), and the quality of the information received from the nurses and other medical personnel.

Methods: A questionnaire collecting information on HRQoL, uncertainty in illness and patients' experience with the hospital treatment has been administered to 306 oncology patients at four oncology centres in Bulgaria. Data has then been employed in the estimation of a Tobit model: the dependent variable selected has been the variation in the Visual Analogue Scale (VAS) score. The econometric model takes into account the characteristics of censoring in the dependent variable.

Results: Overall, the coefficients estimated, and the regression itself showed a good level of significance. Some dimensions of EuroQol-5D (EQ-5D) questionnaire – pain and anxiety/depression – have a significant impact on HRQoL, as well as some features of uncertainty in illness, as unpredictability and complexity. As expected, the longer the time elapsed from the diagnosis, the higher the reported HRQoL; the value of the information provided to the patients by the nurses as well as physicians is also relevant.

Conclusions: This study presents an analysis of the impact of uncertainty in illness, feeling of participation in the therapy, and communication with the hospital personnel on oncological patients' HRQoL, which increases the scanty evidence referring to the patient-centred care in the Bulgarian hospital setting. Further deepening might concern a wider sample, including data collected at other medical centres and/or in other geographical areas in Bulgaria as well as in other European countries.

Key words: oncology patients, Bulgaria, HRQoL, uncertainty in illness, Tobit model

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INTRODUCTION

Chronic, long-term illnesses and multi-morbidity greatly diminish patients' Health-Related Quality of Life (HRQoL), influencing not only the physiological but also psychological and emotional sphere (1). Hence, any approach to care for patients with chronic and long-term diseases should address the needs and requirements of the patients as a whole.

In such a perspective, focusing on the subjective wellbeing, the notion of HRQoL assumes a great relevance and becomes a major topic for researchers and social policy makers, who should develop programmes aimed at improving patients' health conditions together with their satisfaction (2). The HRQoL tools have the potential to identify specific and general health needs (3), moreover, measuring HRQoL provides outstanding insights towards approaches that may lead to improved quality of care.

The assessment of HRQoL becomes imperative for oncology patients, for which the illness state is often accompanied by changes in lifestyle that may be difficult to manage and whose personal health-related experiences and expectations are crucial factors for a qualitatively adequate assistance (4). Surveys on HRQoL in oncology and case reports have focused on the need to ensure quality, together with accountability and innovation in all cancer-related services (5). Such studies may help in drawing guidelines and protocols aimed at improving patients' assistance and support (6). Better assistance for oncology patients is among the priorities of health policy makers in all European countries (8).

The present study investigates the determinants of oncology patients' HRQoL in Bulgaria, focusing on the impact of diverse factors that characterize the patients' hospital experiences; it controls for demographic factors and the time of the cancer onset. Two crucial dimensions of the illness experience, the level of pain and anxiety/depression, are considered together with aspects specifically concerning the patients' experiences of hospitalization, namely, the feeling of participating in one's treatment path, the quality of the communication with nurses and other medical personnel, together with the unpredictability of the course of illness and the complexity of the therapeutic path. The relevance of the study can be appreciated when considering that the contributions related to patients' experiences and HRQoL are still limited in Bulgaria. In fact, this contribution aims at enlarging the scanty evidence on the illness-related experience of oncological patients in Bulgaria by adding another bit of knowledge to the evidence already offered by the authors in the previous study, by means of an ordered logit model on the determinants of oncology patients' satisfaction with their hospital treatment (7).

The present contribution adds to the existing literature by tackling for the first time the factors determining HRQoL, which are the basis for delivery of a patient-centred oncological care in Bulgaria (9). Patient-centeredness not only needs to endorse the patients' perspective but is the prerequisite of making the patients understand so they can take active part in the therapeutic choices; focusing on a patient centred communication reduces the uncertainty in illness and enhances patients' wellbeing (10).

The data used in this paper are drawn from the same survey used in the previously mentioned study (7). Nevertheless, as the aim of this work is an enquiry of the relation between factor contributing to patient-centred hospital care and the oncological patients' HRQL, the selection of the variables was different. We have, therefore, focused on the quality of the information provided to the patients by the nurses and other medical personnel, the patients' feeling of participating in the therapeutic path, their capability to predict the course of the illness and their possibility to rely on nurses.

MATERIALS AND METHODS

Institutional Setting

In Bulgaria, cancer incidence is slightly lower than in other countries in South-Eastern Europe, but the trends are similar. In 2020, there have been 36,451 new cancer cases registered in Bulgaria (11). The most common cancer in males was prostate cancer (24.3% of all cancer cases) while breast cancer was mostly prevalent in females (25.5% of all cases).

Cancer care in Bulgaria is concentrated in hospitals. Some of them are specialized in cancer treatment, whereas in other structures the medical oncology department is a division of a bigger hospital, together with many other specialties (7).

In Bulgaria, outpatient care concerning oncology is practically non-existent; in fact, all the diagnostics, procedures, infusions, etc., are being performed in the hospital setting and may require the patient's overnight stay. The oncology patients' long-term follow-up is also performed in the hospital.

Cancer patients in Bulgaria are assisted through clinical paths (that concern the phases of diagnosis, admission, acute care, surgery, recovery, etc., disposed in a specific sequence performed by the members of the medical team); and clinical procedures (that comprise medical examinations and the diagnostics arranged as a daily care). Inpatient care is financed from four sources: government budgets, municipal budgets, health insurance, and out-of-pocket expenditure.

Most of the people have adequate geographical access to care, although there are administrative barriers to the diagnostics and treatment of the patients, which are limited by either volume or budget.

There is a relatively good access to innovative treatments, such as chemotherapy, target therapy and immunotherapy. However, although the access to therapies is guaranteed to the patients, the scarcity of professional personnel involved in cancer care may condition the quality of the assistance provided to cancer patients in the whole country.

The number of specialists in medical oncology has grown in the recent years. It is estimated that, currently, there are more than 240 specialists in medical oncology taking care for all cancer patients in the country[1], while radiotherapists, medical physicists, nuclear medicine specialists are still in demand.

Questionnaire

The focus of our research has been directed to oncology patients, their HRQoL levels and their hospital experience. In general, quality of life is the perceived quality of an individual's daily life, i.e., the assessment of his/her wellbeing that includes every emotional, social and physical aspect; considering healthcare, HRQoL evaluates how the individual's wellbeing may be affected over time by a disease.

With these considerations in mind, the analysis tool employed is constituted by a questionnaire, arranged by the authors, and compounded of several parts (12). The questionnaire included some items from internationally validated scales, such as the EuroQol-5D (EQ-5D), the Visual Analogue Scale (VAS), the European Organization for Research and Treatment of Cancer In-Patient Satisfaction with Care Measure (EORTC), and the Mishel Uncertainty in Illness Scale (MUIS).

The EQ-5D questionnaire, implemented by the EuroQol group (13), is aimed at measuring HRQoL (14) looking at five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression; it also comprises a VAS section asking to mark health status on the day of the interview on a vertical scale with end points of 0 and 100. The bottom rate (0) corresponds to "the worst health you can imagine" and the highest rate (100) corresponds to "the best health you can imagine". A well-known limitation of the VAS is the so-called "end-of-scale bias": respondents are less likely to use the extreme ends of the scale for rating their health status. However, it is still useful and the simplest direct method for valuing HRQoL.

The EORTC (15) is a 32-item questionnaire assessing patients' appraisal of hospital doctors and nurses, as well as aspects of care organization and services. Among the dimensions investigated in the questionnaire are the assessment of comfort, cleanness, technical skills, etc., together with a comprehensive evaluation about the general level of quality of care.

The MUIS has often been used for oncology patients (16); among the last applications there are some contributions aimed at assessing the uncertainty associated with the course and treatment of the disease (17–18). Diverse subsequent re-elaborations of MUIS have led to a 4-factor structure encompassing 32 items and

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[1] According to the registry of Bulgarian Medical Association there are 242 specialists in medical oncology (data of 2021): https://blsbg.eu/bg/medics/search

4 dimensions related to different facets of uncertainty (ambiguity, complexity, inconsistency, and unpredictability) that may condition patients' daily life and psychological wellbeing. In particular, complexity considers "the cues about the treatment and the system of care that are multiple, intricate and varied"; unpredictability is instead related to "the lack of contingency between illness and treatment cues and illness outcome" (19).

Estimation Strategy

The dependent variable was obtained by a linear transformation[2] of the difference in the VAS scores reported (the VAS score at the time of disease onset and the VAS score at the moment of the questionnaire administration), that records the subject's perceptions of their own current overall health and monitors changes with time. The higher the value of the dependent variable the smaller the perceived deterioration in HRQoL.

In order to investigate the relation between patients' perceived HRQoL and some possible determinants of it, related to the therapeutic path experienced, a Tobit approach was selected (20) and the following hypotheses were considered:

H1 – some dimensions of EQ-5D as pain or anxiety/depression have a significant impact on HRQoL;

H2 – HRQoL relies on some features of uncertainty in illness, measured through the MUIS, such as unpredictability and complexity;

H3 – the relevance of the information conveyed to oncology patients on HRQoL is different according to the source of the same information (physicians or nurses) and this circumstance makes it necessary to strengthen this health professionals' communication skills;

H4 – HRQoL is positively related to the feeling of participation in the therapeutic path.

Here, the choice for the Tobit model is justified by the circumstance that the variation in the VAS score had a lower limit of 0 and an upper limit of 100, so that data are censored, as required by the Tobit model.

The specification of the model is:

$$Y_i = \begin{cases} y_i^* \text{ if } y_i^* > 0 \\ 0 \text{ if } y_i^* \leq 0 \end{cases} \qquad (1)$$

The underlying idea is that the HRQoL, scored through the VAS, depends on subjective items as age and gender and the time elapsed from the disease onset, which are treated as controls; it also depends on two major dimensions of the wellbeing possibly jeopardized by the illness experience such as the level of pain and anxiety/depression (H1) and it is by no-means affected by the hospitalization experience characterized by feeling of participating; the perceived quality of the information received, uncertainty in illness (H2–H4).

The Tobit model has been used in similar studies directed at investigating HRQoL together with uncertainty in illness, e.g., the study by Giammanco and Gitto (21).

Observed Sample

Data and information for the present study have been collected at four oncology centres (Serdika Medical Centre in Sofia, Nadejda Medical Centre in Varna, University Hospital Tsaritza Yoanna – ISUL in Sofia, Central Onco Hospital in Sofia). These centres assist about 5,000 patients every year.

A total of 400 patients were consecutively approached, 306 of whom accepted to be interviewed during their hospital stay. The average response rate was 76.5%, with slight differences among oncology centres. The Serdika Medical Centre response rate was 78%; the Nadejda Medical Centre response rate was 74%; the ISUL response rate was 77%; and the Central Onco Hospital response rate was 73%.

The objective of the study was clearly explained by the physicians. All patients agreed to be interviewed and answered the questions posed by the interviewers (psychologists or physicians who received a brief training to standardize the administration of the questionnaires).

RESULTS

Some information and descriptive statistics are summarized in Table 1.

Patients were, on average, 66 years old, 47% were females, 71% were married or lived with someone. On average, individuals have been diagnosed for 11 months (range from 2 to 30 months), 55% followed a pharmacological treatment with chemotherapy, and 73% presented other comorbidities.

The VAS score that described patients' health status before the disease onset was of 82 over 100; instead, the VAS score acknowledged at the time of the interview was around 43. Patients did not declare an improvement in their health conditions comparing to the previous year, 22.5% affirmed the health status had remained the same, while 77.2% said it had worsened.

The uncertainty due to the health status was measured through the administration of the MUIS questionnaire. We looked at the correlations between the dependent variable (VAS score) and the answers given to the MUIS: the items with the highest significance levels were selected to be included in the econometric analysis. They were the items No. 24 ("I can generally predict the course of my illness") that concerns the dimension of unpredictability; No. 26 ("I'm certain they will not find anything else wrong with me") regarded unpredictability as well. Instead, the third item considered No. 30 ("I can depend on the nurses to be there when I need them") was related to the dimension of complexity.

Among the answers given to the EQ-5D, the items concerning "pain" and "anxiety/depression" were considered in the present analysis, as the highest scores reported were related to these items.

The rationale that led to the selection of the items from the EORTC questionnaire was the aim to focus on the perceived quality of the information provided by physicians and nurses.

Nurses play a major role in improving patient's outcomes: it has been seen in some studies that patients feel more comfortable when nurses encourage them to open up about their level of pain and discomfort (22). On the other hand, physicians represent the key figure in the healthcare process, certainly, their competence

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[2] The great majority of patients recorded a worsening of their HRQoL, hence the linear transformation was performed in order to obtain positive values of the dependent variable.

Table 1. *Descriptive statistics*

Variable	Mean	SD	Min	Max
Age	66.38	9.23	41	88
Gender (female = 1, male = 0)	0.467	0.500	0	1
Married	0.711	0.454	0	1
Education: graduate	0.561	0.497	0	1
Distance from oncology centre (km)	42.719	72.526	0	380
Time from diagnosis (months)	10.581	6.183	2	30
Comorbidities	0.729	0.445	0	1
Pharmacological treatment (yes = 1, no = 0)	0.552	0.498	0	1
Judgment on health status today: excellent	0.020	0.139	0	1
Judgment on health status today: very good	0.059	0.235	0	1
Judgment on health status today: good	0.176	0.382	0	1
Judgment on health status today: acceptable	0.298	0.458	0	1
Judgment on health status today: poor	0.414	0.493	0	1
Same health status as one year ago (yes/no)	0.225	0.418	0	1
Worse health status than one year ago (yes/no)	0.772	0.420	0	1
Health status before the diagnosis	81.79	16.99	30	100
VAS score	42.575	17.628	0	90
Pain (EuroQol)	1.674	0.895	1	4
Anxiety/depression (EuroQol)	2.738	1.253	1	5
Feeling of participation	66.095	28.707	25	100
Physicians' information provision	79.725	11.510	58.33	100
Nurses' information provision	86.805	8.897	58.33	100
MUIS 24: I can generally predict the course of my illness (unpredictability).	3.513	1.014	1	5
MUIS 26: I'm certain they will not find anything else wrong with me (unpredictability)	2.477	1.226	1	4
MUIS 30: I can depend on the nurses to be there when I need them (complexity)	1.720	0.738	1	4

is desirable and decisive in the overall evaluation of the patient about the service received and in improving HRQoL.

Patients might expect to receive information characterized by a greater degree of technical specificity by the physicians, while nurses are expected to talk with a more colloquial language and to provide patients with the information pertinent to the performance of daily activities. In the sample, patients rated 79.72 the physicians' information and 86.8 the information provided by the nurses

Table 2. *Tobit model results*

Dependent variable: variation in VAS score	Coefficient (std. errors)	95% confidence interval	
Age	0.051 (0.096)	−0.139	0.241
Gender	3.801** (1.751)	0.354	7.248
Time from disease onset	0.667*** (0.141)	0.390	0.945
Pain	−1.788* (1.037)	−3.831	0.254
Anxiety/depression	−3.455*** (0.724)	−4.879	−2.030
Feeling of participation	0.055* (0.029)	−0.003	0.114
Physicians' information provision	0.121* (0.076)	−0.029	0.271
Nurses' information provision	0.277*** (0.096)	0.087	0.466
MUIS 24: I can generally predict the course of my illness (unpredictability).	2.218** (1.157)	−0.058	4.496
MUIS 26: I'm certain they will not find anything else wrong with me (unpredictability)	1.817*** (0.697)	0.445	3.189
MUIS 30: I can depend on the nurses to be there when I need them (complexity)	2.958** (1.554)	−0.191	0.602
Constant	−12.621 (14.259)	−40.697	15.455

Number of observation (uncensored) = 277; LR χ^2 = 131.48; $p < 0.001$; Log-likelihood = −1117.934; pseudo R^2 = 0.055; σ = 13.693 (std. error = 0.582)
Significance levels of 0.05, 0.01 and 0.001 are indicated by *, **, and *** respectively.

on a 0–100 scale, whose minimum and maximum values reported were the same (58.33 and 100) for both sources of information.

The software package employed for the estimations was Stata 17.0 (23) and the results can be seen in Table 2.

Overall, the coefficients estimated and the regression itself showed a good level of significance.

About the results obtained for the control variables, a higher HRQoL is associated with the female gender: this result does not correspond to the indications from the literature, which suggests significantly better physical and emotional outcomes in male patients and that female gender is a predictor of impaired overall HRQoL (24). However, studies in cancer patient groups that consider gender aspects in HRQOL as a primary outcome are few, partly because adherence to guidelines for reporting outcomes by gender and including the latter as covariate in modelling is still poor. Some findings indicate higher prevalence rate of cancer-related depressive symptoms and fatigue among women compared to men as well as gender differences in pain sensitivity and tolerance.

The result concerning the last control variable, namely the time from the disease onset, suggests that the longer the time elapsed from the diagnosis, the higher the reported HRQoL, supporting the idea that oncology patients learn to cope with the disease.

Looking at the hypotheses that this research aimed at verifying, it is possible to answer each of them. About H1 (some dimensions of EQ-5D as pain or anxiety/depression have a significant impact on HRQoL), the higher the score of the EuroQol dimensions concerning “pain” and “anxiety/depression”, the lower the HRQoL. This result supports the view that a higher HRQoL score is associated with a health status characterized not only by low levels of pain, but also by high level of psychological wellbeing.

A policy indication that emerges from these results is that, together with chemo, radio and hormone treatments, aiming at curing cancer, but imposing on the patients a high burden in terms of unpleasant collateral effects often generating psychological stress and discomfort, an adequate support therapy to reduce anxiety and depression experienced should be implemented.

About H2 (HRQoL relies on some features of uncertainty in illness, such as unpredictability and complexity), the impact and effect of uncertainty might need to be investigated more in detail. The three MUIS items included in the estimation, related to unpredictability and complexity are positively correlated with the dependent variable: a reverse score has to be attributed to these items, so that a higher score represents a situation characterized by higher levels of certainty. In particular, the highest value has been estimated for the coefficient related to the item predicting an active role played by nurses.

This evidence leads to the verification of H3 (the effect of the information conveyed to oncology patients on HRQoL is different if the source of the same information is physician or nurse). This circumstance makes it necessary to strengthen these skills by health professionals, the coefficient estimated for the information provided by nurses has a higher value compared to the coefficient related to information provided by physicians (0.277 vs. 0.121, respectively) and shows a greater level of significance. These results may be justified, as it has been said earlier, by what is expected from these two professional figures (25), overall, a higher impact on HRQOoL is exerted by the communication with nurses.

Finally, about H4, although weakly significant, the feeling of participation is positively correlated with HRQoL, hence, involving the patient in crucial choices related to the treatment and the type of assistance is a strategy likely to increase patients’ compliance (26).

DISCUSSION

This analysis has outlined the importance of subjective factors, such as age and gender, as well as objective measures of patients’ disease stage, such as the time elapsed from the disease onset, which have been treated as controls to focus on specific dimensions of the oncological hospital care that have been measured through validated scales, that play a relevant role in allowing patient-centeredness.

The results obtained, in fact, outline the relevance of understanding the treatment path provided at cancer centres for patients’ HRQoL and, in this light, healthcare professionals need to be actively engaged in communication efforts. From the analysis, the notion of person-centred healthcare emerges with the twofold aspect of a compassionate and scientific approach to care. It represents a high ethical ideal and it is, intuitively, the right approach to the management of chronic illness (27). As the results suggest, patient centeredness may be better achieved focusing on the interaction/communication aspects of the treatment path, in which the role of nurses is paramount.

Information and communication are basic aspects of care, in particular, in the end-of-life setting, as oncology patients experience, substantial research and teaching efforts have focused on this specific aspect of the patient-physician relationship (28). The latter encompasses more than communication alone, patients whose health conditions are likely to deteriorate irreparably, attribute a high value to being seen as a whole person by the physician, receiving care from one’s personal physician, having a physician to discuss one’s fears, overall, establishing a relationship based on mutual respect, trust, and humility (26).

Our results enrich the existing evidence, by suggesting a major role of the nurses who should be empowered, by training, not only to assist patients but also to listen and exhaustively answer to their doubts. This would allow patients not only to understand how the course of their illness could develop but also what will be their role in obtaining the possible best outcome. Nurses can therefore be a source of greatest values added in designing a personalized path of patient-centred care in which the patient feels to participate in a project focusing on the attainment/maintenance of the possible higher standard of her/his quality of life.

CONCLUSIONS

The present research was aimed at outlining some of the possible factors impacting oncology patients’ HRQoL for a sample of cancer patients in Bulgaria in a Tobit model estimation; it can be framed within the literature considering HRQoL as result of physiological/objective conditions and subjective elements that may be largely determined by the patients’ participation, in the perspective of a delivery process of oncology care focused on patients’ need (29). The latter can be achieved by a good interaction of the patient with both physicians and nurses.

The econometric analysis has outlined the relevance for oncology patient’s HRQoL not only of subjective factors related to the same patients, but it has also stressed the importance of the information provided by both physicians and nurses and the diverse aspects of uncertainty in illness, i.e., the unpredictability of the illness course and the complexity of the illness treatment, play a significant role. Physicians' and nurses' communication efforts may help the patients in ameliorating their understanding of the future course of events related to their illness and allow them to fully participate in their cancer treatment rather than to be subject of a cancer treatment.

In this setting, the present work further suggests that uniquely focusing to treat patient, though with high professional standards, without actively involving her/him in the delivery of the health service is not viable anymore. Patients need to be cared and ask for supportive assistance, a good communication between the patient and the professional figures who will accompany her/him along the treatment path is at the bases of a process of care co-produced by the patient. Communication must be seen as a process in which there is not only transmission of pieces of information to the patient, but also feedback from the patient to the professional figures (30).

In this perspective, further deepening of the analysis might concern the collection of data from a wider sample, including information collected at other medical centres and/or in other geographical areas in Bulgaria as well as in other European countries.

Then, the investigation of other cultural and clinical determinants of the perceived deterioration of patients' health status could be carried out.

Interviews with caregivers and patient's family members could help to investigate the burden imposed by cancer on the patient's family members and how a good communication with all health professional figures could reduce such burden.

Conflict of Interests

None declared

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