

# Body Self-Image and Reported Socio-Economic Outcomes in Patients With Brain Tumors. Results of A Large Socio-Economic Survey

Enrico Franceschi (✉ [enricofra@yahoo.it](mailto:enricofra@yahoo.it))

AUSL di Bologna: Azienda Unita Sanitaria Locale di Bologna

Vincenzo di Nunno

AUSL di Bologna: Azienda Unita Sanitaria Locale di Bologna <https://orcid.org/0000-0003-4441-9834>

Alicia Tosoni

AUSL di Bologna: Azienda Unita Sanitaria Locale di Bologna

Lidia Gatto

AUSL di Bologna: Azienda Unita Sanitaria Locale di Bologna

Antonella Mura

AUSL di Bologna: Azienda Unita Sanitaria Locale di Bologna

Santino Minichillo

AUSL di Bologna: Azienda Unita Sanitaria Locale di Bologna

Raffaele Lodi

IRCCS Istituto Delle Scienze Neurologiche di Bologna

Alfredo Conti

University of Bologna: Università di Bologna

Stefania Bartolini

AUSL di Bologna: Azienda Unita Sanitaria Locale di Bologna

Alba Ariela Brandes

AUSL di Bologna: Azienda Unita Sanitaria Locale di Bologna

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## Research article

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# Abstract

**Background:** The socioeconomic status involves several aspects related to patient's life, which may impact their quality of life. Very few studies have investigated this issue in patients with brain tumours.

**Methods:** We carried out a survey aimed to explore socioeconomic issues in patients with grade 2 and 3 astrocytoma and glioblastoma (GBM).

**Results:** 202 consecutive patients have been enrolled in this survey. About all patients had a caregiver (96%), which was generally represented by wife or husband (57.4%).

The majority of patients described to feel less attractive after surgery and/or after the start of oncological treatment ( $p = 0.001$ ) and experienced significant modifications of work activities with job loss occurring in 38.9% of patients.

**Conclusion:** Some specific domains such as body self-image, sexual activity, caregiver's condition, and financial impact are too often poorly considered during care path. However, the early recognition of these aspects could be essential to activate measures improving patient's quality of life.

## Background

Quality of Life (QoL) of patients (pts) with solid tumours represents a very complex variable influenced by patient's health, treatment-related toxicity/sequels, psychological state, personal beliefs, and social relationships.

In this context the socioeconomic variables involve a wide amount of patient's related activities ranging from the sexual sphere, financial means, and body self-image [1–4]. Pts with brain malignancies have some specific issues related to their disease. Indeed, sequelae related to surgery, radiation therapy, and systemic treatment received are elements that could affect the socioeconomic status and body self-image.

It has been demonstrated that health QoL influences the prognosis of pts with gliomas [5] while the same correlation seems to not be clearly defined for the socioeconomic status [6–8], even if it deeply impacts the QoL of pts with brain tumours. Neurological and cognitive symptoms may be related to the disease, surgery and/or radiation-treatment and includes a wide range of manifestations and grade, reflecting the site, extension of the disease, and treatments [9–12]. Systemic agents adopted for cancer treatment or for symptoms control (such as corticosteroids) could collide with patient's life often worsening body-self image and social habits [1, 13, 14].

In this study, we report the results of a survey carried out on pts with primary grade 2 or 3 astrocytoma and glioblastoma (GBM) aimed to assess modifications of the socioeconomic status in these pts.

## Methods

## Study design

This is a prospective study aimed to assess socio-demographic indicators in pts with brain tumours who received anticancer treatments at Oncology Department, AUSL-ISNB Bologna. Patients were enrolled from April 2017 to December 2017. Data were collected by means of a socio-demographic survey, completed by the investigators after interviewing the patient. The main endpoint of the present study was to achieve an overall assessment of the modifications of the socioeconomic status of these pts after tumor onset.

## Ethical approval

The study was approved by the Ethical Committee of the Emilia Romagna region (approval number CE 17047) and performed in accordance with national law, institutional ethical standards, the 1964 Helsinki Declaration and its later amendments.

## Patients

All consecutive patients with histologically proven diagnosis of grade 2 or 3 astrocytoma and GBM, who were treated in our Institution from April 2017 to December 2017, were enrolled in this prospective survey. All pts were over 18 years old and provided written informed consent before enrollment. Pts with anamnesis of a secondary malignancies or concomitant tumours (exception for surgically healed cervical carcinoma or squamous cell carcinoma of the skin) were excluded (approval number CE 17047).

## Survey

Our survey consisted of a 20-item questionnaires assessing 8 domains of interest:

1. demographic characteristics (nationality, place of birth, region of residence, age, gender)
2. social characteristics (marital status, number of children, presence of a caregiver, who is the caregiver)
3. educational level (complete primary education, complete secondary education or academic level)
4. professional
5. financial profile (family income-bracket)
6. impact of cancer on Socio Economic Status (financial toxicity due to cancer disease, changing in working ability)
7. dissatisfaction with self-image
8. sexual activity

The survey was compiled by patients in the presence of a medical doctor. The survey was administered 3 and 6 months after primary surgery or tumour diagnosis.

The economic status of all patients enrolled in this survey has been appraised according to their declared household income-bracket.

Year by year, the Ministry of Economy and Finance assigns the value of the income-brackets based on the gross family income declared the previous year. The health ticket is a tool through which the citizen participates in medical services and the income-brackets are necessary to estimate the co-participation in healthcare expenditure.

An income up to 36,152 euro is classified as R1 bracket; between 36,153 and 70,000 euro as R2, between 70,001 and 100,000 euro as R3 and over 100,000 euro as R4.

Oncological patients (including those enrolled in the present survey) were exempt from paying any services applying the exemption code 048, which allows them to receive free medical and health services (at public or affiliated facilities) and any approved drug related to the treatment of tumor pathology and its complications. The complete survey is available on supplementary appendix (document S1).

### **Statistical Analysis**

Variables were reported as frequencies, median values and ranges. Frequencies and percentages for categorical variables were calculated. Differences between groups were assessed through the Chi-square test. As the main outcome of the present study was a description of further items related to the socio-economic status no further analysis have been performed.

## **Results**

A total of 202 evaluable pts diagnosed with glioma were included in the present analysis. Patients' demographic and clinical characteristics are summarized in Table 1. Overall, 126 pts (62.4%) were male and 76 pts (37.6%) were female. The median patient's age was 51 years (range: 21-83 years). A total of 43 pts (19.3%) were diagnosed with grade 2 astrocytoma/oligodendroglioma, 39 pts (N = 17.3%) were diagnosed with anaplastic astrocytoma/oligodendroglioma and 120 pts (59.4%) were GBM.

Majority of pts had an ECOG of 0 or 1 (92.0%), received a partial or complete resection as primary surgery (82.2%), live in an own propriety (88.1%) and had a high educational qualification (39.6% high school degree and 26.2% University degree). About all pts had a caregiver (96%), which was generally represented by their wife or husband (57.4%).

### **BODY SELF IMAGE AND FINANCIAL DOMAIN**

A large number of pts (49.23 % and 50.6% at 3 and 6 months after surgery respectively) reported to feel less attractive after surgery and/or after the start of the oncological treatment (including chemotherapy and/or radiation therapy). This finding was not influenced by the time spent from surgery as it was observed both in patients receiving surgery in the previous 3 months ( $p=0.002$ ) or 6 months ( $p=0.001$ ) (Table 2). Pts feeling less attractive were more frequently women ( $p=0.001$ ) or unemployed patients in the working age ( $p=0.003$ ).

However, this finding was not associated to the worsening of sexual sphere, impoverishment, study degree, age, presence/absence of a partner as caregiver, type of work and modification of work conditions.

Among pts who received surgery at least six months before this survey (n=130), the majority experienced a significant modification of the previous work activities after disease onset. These modifications consisted on a temporary or definitive job loss (38.9%), or in the reduction of the working hours (21.3%). Overall, 46.3% of pts declared a significant worsening of their financial resources after disease diagnosis (Table 3).

## Discussion

Here we report the results of a survey carried out on 202 pts with brain tumours. Notably, this is the largest prospective series investigating the socioeconomic status in this category of pts.

Several studies assessed this issue through retrospective analysis. A register-based assessment carried out on Swedish pts with high-grade glioma concluded that several socio-demographic factors such as: education, income, and country of birth, influenced the care process [6]. A similar series composed of pts with low-grade glioma demonstrated that factors like income, education, and gender affected on clinical outcomes of these pts [7].

Differently to other studies, our series has the quality to be a prospective assessment in which several elements assessed have been pondered according to the patients' own point of view.

Issues like financial toxicity, body self-image are only partially investigated in prospective clinical trials. Questionnaires are generally adopted to assess these outcomes, but the majority of them are mainly focalized on the assessment of symptoms or treatment-related adverse events impacting pts' QoL. As a consequence, some of key socioeconomic elements could be underestimate [15,16]. Our study revealed that the diagnosis of primary brain tumours impact financial status and body self-image.

About the financial toxicity, 46.3% of pts who had received surgery at least six months before the survey reported a worsening of their economic conditions. This was often a consequence of a temporary or definitive job loss (table 3). The high financial impact detected in our study assumes particular interest considering that our National healthcare system is public and free. Furthermore, the system of social safety nets provides several economic and social supports to pts with cancer diagnosis and especially to pts under active anticancer treatment. The development of disability due to the illness allows additional economic and social supports (according to the gravity of the disability), which are completely free of charge.

It should be considered that the reduction of the financial resources is an indirect outcome, which could only partially reflect the worsening of patient's social habits and QoL [17-19]. Studies on pts with brain tumours mainly focused on how the worsening of the financial capabilities impacted on clinical

outcomes and none of them directly assessed the economic implications induced by brain tumour diagnosis and management [20,21].

The high number of patients reporting a negative financial impact suggests that this element could be a crucial hidden toxicity occurring after primary brain tumour diagnosis.

Modification of the own body image is an issue rarely assessed in pts with brain tumours. In the present cohort we discovered that the pts felt less attractive regardless time from surgery. Moreover, worst body self image was more frequently reported in women ( $p=0.001$ ) and pts unemployed ( $p=0.003$ ).

Several aspects may affect this outcome, including scars or neurological sequelae following surgery or radiation therapy other than sequelae, and adverse events related to oncological treatments. Neurocognitive toxicity depends on the site and the extension of curative loco-regional treatments performed. Long-term toxicities related to radiation therapy have been assessed in pts with low-grade glioma and consisted mainly in an attentional functioning [9]. Adverse events related to anti-cancer treatments can profoundly change social habits of pts. Some specific side effects may also worsen patient's body self-image [22-23].

Even the treatment adopted to prevent and treat symptoms onset may worsen patient's body self-image. Steroids are commonly adopted to reduce symptoms related to tumour-associated oedema. Chronic administration of these drugs lead to weight gains and impaired distribution of adipose tissue resulting in a Cushing phenotype [14]. Alopecia areata could be another important toxicity resulting in worse body self-image perception [13].

All these factors could modify the body image impacting on patient's intimacy and QoL [24]. The early recognition of this element would allow activating dedicated support aimed to rebuild the patient's healthy body image. This outcome has been investigated in pts with breast cancer. For these pts has been also suggested a scale assessing body image and relationship [25,26].

In our series, worst modifications of body self-image affected the majority of pts and were observed mainly in women (table 2) but no gender differences emerged in sexual sphere assessment. On the other hand, about half of pts with brain tumours reported a worsening of their own sexual sphere (table 2). Considering the results of our survey, this problem may affect a large percentage of pts and should be further investigated. Measures aimed to improve body self-image should be encouraged and prospectively evaluated. Surgical and radiation techniques aimed to reduce the adverse sequelae related to treatment without interfere with clinical outcomes are elements that should be considered [27]. Hippocampal sparing radiation could be a key technique to consider as could be associated to less long-term neurocognitive toxicity without a reduction of clinical activity and outcomes [28].

The administration of steroids should be restricted only when clinical necessary and for the shortest possible time. Some alternatives anti-inflammatory drugs have been assessed but to date none of them can substitute corticosteroids administration [29]. Physical activity, muscle relaxation techniques,

occupational therapy, cognitive behavioural therapy and physiological supports (also provided by web platforms) are measures which showed to be effective in other solid tumours and which could improve mental and physical well-being of pts with brain tumors [23,30-33].

## Conclusion

Socioeconomic domain involves a series of elements that are only partially assessed by questionnaires and tolls adopted for QoL evaluation. Nonetheless, data about social conditions are crucial as strongly impact on patient's life. In our series, we demonstrated that the worsening of financial status, distress related to their own body image, and sexual sphere are common and emerged in about one in two patients.

More efforts should be spent to develop reliable instruments able to assess socioeconomic variables. The early recognition of these aspects by clinicians could also allow activating specific support, improving patient outcomes, and QoL.

## Abbreviations

ECOG: Eastern Cooperative Oncology Group, GBM: Glioblastoma, QoL: Quality of Life, patients: pts.

## Declarations

**Ethics approval and consent to participate:** The study was approved by the Ethical Committee of the Emilia Romagna region (approval number CE 17047) and performed in accordance with national law, institutional ethical standards, and the 1964 Helsinki Declaration and its later amendments. Due to the retrospective nature of the present study the informant consent was not required.

**Consent for publication:** Not applicable.

**Availability of data and materials:** The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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**Author's details:**

<sup>1</sup>Department of Medical Oncology, Azienda USL- Bologna, Italy;

<sup>2</sup> IRCCS Istituto delle Scienze Neurologiche di Bologna

<sup>3</sup> Alma Mater Studiorum University of Bologna, IRCCS Istituto delle Scienze Neurologiche di Bologna.

Corresponding Author: Enrico Franceschi, enricofra@yahoo.it, via Altura 3 Bologna Italy 40139, +39 0516225769

\* Co-primary First Authors

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## Tables

### Table 1

Dermographic and clinical baseline features of patients enrolled in the study. ECOG: Eastern Cooperative Oncology Group; GBM: Glioblastoma.

R1 = up to 36,152 euros/year; R2: between 36,153 and 70,000 euros/year; R3: between 70,0001 and 100,000 euros/year; R4: over 100,000 euros/year.

<b>Gender</b>	
Male	62.4% (n=126)
Female	37.6% (n=76)
<b>Nationality</b>	
Italian	96.5% (n=195)
Other	3.5% (n=7)
<b>ECOG</b>	
0	75.7% (n=153)
1	16.3% (n=33)
2	2% (n=4)
Notassessed	5.9% (n=12)
<b>Surgery</b>	
Biopsy	8.4% (n=17)
Complete resection	23.8% (n=48)
Partial resection	58.4% (n=118)
Not assessed	9.4% (n=19)
<b>Grade</b>	
Grade 2 astrocytoma	19.3% (n=43)
Grade 3 astrocytoma	17.3% (n=39)
GBM	59.4% (n=120)
<b>Marital Status</b>	
Single	19.8% (n=40)
Married/cohabitant	72.3% (n=146)
Widow/er	4% (n=8)
Divorced	4% (n=8)
<b>Lives</b>	
Alone	7.4% (n=15)
With partner	32.2% (n=65)
With friends	1.5% (n=3)
With family	58.9% (n=119)

<b>Home</b>	
Own property	88.1% (n=178)
Rent	9.4% (n=19)
Other	Other 2.5% (n=5)
<b>Educational qualification</b>	
None	1% (n=2)
Elementary/middle school	33.2% (n=67)
High school	39.6% (n=80)
University	26.2% (n=53)
<b>Sons</b>	
None	24.3% (n=49)
One	31.7% (n=64)
Two	30.7% (n=62)
Three	9.9%(n=20)
More than 3	3.5% (n=7)
<b>Income bracket</b>	
RE 1	38.1% (n=77)
RE 2	42.6% (n=86)
RE 3	7.4% (n=15)
RE 4	11.9% (n=24)
<b>Work condition</b>	
Worker	42.1% (n=85)
Unemployed	4% (n=8)
Retired	38.1% (n=77)
Unfit	9.9% (n=20)
Student	1.5% (n=3)
Other	4.5% (n=9)
<b>Transports</b>	
Private	80.7% (n=163)

Public	5.0% (n=10)
Train	9.9% (n=20)
Airplan	3.0% (n=6)
Ambulance	1.5% (n=3)
<b>Caregivers</b>	
Yes	96.0% (n=194)
No	4% (n=8)
<b>Cargivers specified</b>	
Wife/husband	57.4% (n=116)
Patner	5% (n=10)
Son/s	11.4% (n=11.4%)
Relatives	18.8% (n=38)
Friends/other	3.5% (n=7)
<b>Caregivers work conditions</b>	
Worker	62.9% (n=127)
Unemployed	3% (n=6)
Retired	21.3% (n=43)
Students	1.0% (n=2)
Other	7.9% (n=16)

**Table 2**

Patients reported modifications of sexual sphere and self body imagine.

patients who received surgery at least six months before survey; \*\* patients who received surgery at least three months before survey.

Score	Patients feel less attractive*		Patients feel less attractive**		Worsening of sexual sphere *		Worsening of sexual sphere **	
	Male	Female	Male	Female	Male	Female	Male	Female
Not at all	62.5% (n=51)	31.3% (n=15)	58.9% (n=56)	32.7% (n=18)	46.3% (n=38)	56.3% (n=27)	44.2% (n=42)	52.7% (n=29)
A little	31.7% (n=26)	47.9% (n=23)	34.7% (n=33)	43.6% (n=24)	30.5% (n=25)	14.6% (n=7)	28.4% (n=27)	18.2% (n=10)
Quite a bit	6.1% (n=5)	16.7% (n=8)	5.3% (n=5)	20.0% (n=11)	17.1% (n=14)	18.8% (n=9)	18.9% (n=18)	18.2% (n=10)
Very much	0% (n=0)	4.2% (n=2)	1.1% (n=1)	3.6% (n=2)	6.1% (n=5)	10.4% (n=5)	8.4% (n=8)	10.9% (n=6)
Fisher test	<b>P= 0.001</b>		<b>P=0.002</b>		P=0.182		P=0.396	

**Table 3**

Modifications on work activities due to the disease. \* patients who received surgery at least six months before survey.

Modifications on work activities due to the disease *	Quit work	Change work	Develop new skills	Reduce time of work	Financial impact
		2.8%	3.7%	21.3%	46.3%
	38.9%				