

# Cognitive strategies and quality of life of patients with high-grade glioma

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**Abstract** The purpose of this study was to analyze the psychological well-being, quality of life, and cognitive strategies activated by patients with high-grade glioma. We hypothesized that the self-perceived quality of life is modulated by physical and psychological factors and that in order to understand this modulation more psychometric approaches are necessary. Data were collected from a sample of 73 consecutive patients with a histological diagnosis of primary malignant brain cancer (grade IV glioblastoma and grade III anaplastic astrocytoma) hospitalized in a specialized Italian center. The Functional Assessment of Cancer Therapy (FACT) scale and the Schedule of Evaluation of Individual Quality of Life–Direct Weighting (SEIQoL-DW) scale were used to assess quality of life. The mean FACT-Brain (Br) score was 122.37. Similarly, the median SEIQoL-DW score was 72.9 out of a maximum value of 100. No gender effect was found in relation to overall quality of life. Patients with high depression and/or anxiety scores reported lower quality of life (QoL) scores in all the instruments considered. We did not find any gender effect concerning depression and anxiety levels. However,

we found that men and women, though having similar physical and functional well-being, reported different QoL determinants, since men seem to rely more on physical adjustment, while women activate more introspective strategies. Positive actions, family issues, negative thoughts, health, and positive thoughts were found to be the most reported themes. In conclusion, the present study strongly suggests that a positive psychological adjustment is possible also in the event of a severe diagnosis and during aggressive treatments, but QoL determinants might be considered too in order to help health professionals to understand patients' experience and to meet their needs.

**Keywords** High-grade glioma · Quality of life · Gender

## Introduction

Brain cancers contribute to about 2 % of the cancer mortality in men and 1.4 % of the mortality in women, and within the 15–34 age group, they are the third most common cause of death due to cancer [1]. Primary brain tumors are graded into four histological degrees of malignancy (I to IV):

- Grades I and II are classified as “low-grade glioma.”
- Grades III and IV are called “high-grade glioma.”

The most common types of brain tumors are anaplastic astrocytoma (grade III) and glioblastoma (39 % of all cxxbrain tumors), a high-grade (grade IV) astrocytic tumor that is almost always debilitating and rapidly fatal (6 % survive 2 years) [1] with a surviving median of 26.1 years [2]. Even though more efficacious protocols are now available [3], more

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research is needed to face this cancer and help patients coping with it.

During the last 10 years, numerous studies have highlighted the need to consider quality of life (QoL) issues in the treatment of glioma [4]. Generally speaking, QoL is an increasingly important outcome in cancer [5, 6]. Indeed, patients' health depends on a number of factors (beyond symptoms control) including functional status (the ability to perform daily activities), emotional well-being (controlling anxiety and depression), and social well-being (the possibility to maintain personal, familial, and social roles and to receive social support). All these aspects should be considered when assessing QoL in order to concretely contribute to decisions about cancer treatment.

In particular, the actual cancer-related coping strategy activated by a patient depends both on the amount of personal and interpersonal resources available and on the ability to use them in the context. Many patients find it difficult to activate a proper coping strategy due to specific factors, such as available cognitive resources, gender-related characteristics, and psychological status [7, 8]. Appraising how these factors influence QoL in the care of high-grade glioma should be very useful for sustaining patients' well-being, as well as for improving doctor/patient communication. Unfortunately, we have very poor information in this context [9, 10]. Indeed, only during the last 15 years, a few studies have addressed the question of QoL in high-grade glioma, most of all focusing on physical issues [11]. Others have highlighted the importance of interpersonal relationships, in particular the role of spouses [12]. However, no studies had directly addressed which psycho-cognitive resources (i.e., images, thoughts, metaphors, and emotions that serve the purpose to offset the effects of the contextual demands) patients mobilize and how different cognitive strategies impact QoL, emotional well-being, and individual needs.

However, the aim of studying in depth patients' experience is not easily achievable using standardized questionnaires [13–15]. We argue that a more narrative approach, based on the analysis of cognitive strategies adopted to cope with cancer, would allow collecting meaningful data not previously available. Conversely, standardized questionnaires allow only quantitative analyses—not very useful in a context where poor data are available. Hence, we opted for a mixed methodology, using standardized instruments to measure QoL and a qualitative approach to probe patients' experience.

The main hypothesis guiding this study was that QoL is strongly affected by the cognitive resources actually activated by patients; consequently, we expected to find QoL to be modulated by a variety of psychological factors other than physical impairments. Secondary, since males and females are known to use different strategies to cope with critical situations [16], we expected to find gender differences: Women should report to use mainly emotion-focused strategies while

men should rely more on physical reactions and external support.

Finally, since we decided to use two different measures of QoL in order to collect both quantitative and qualitative data, we expected to find significant correlations, between these measures, but also divergences due to specific characteristics of the instruments.

## Methods

The study was carried out at the Department of Neuro-Oncology of the Istituto Nazionale Neurologico “C. Besta” in Milan. Eighty-four consecutive patients were involved in the study. All patients admitted were assessed for cognitive status. The study was approved by the local ethics board.

The inclusion criteria for study participants were as follows: diagnosis of high-grade primary brain tumor, 18 years of age or older, possessing the abilities needed to complete all tasks (answering questionnaires and participating in the interview), Karnofsky score  $\geq 70$ , and Mini-Mental State Examination  $\geq 19$ .

Five patients were excluded due to physical and/or cognitive impairments, and six declined to participate due to lack of interest in the themes of the study.

Seventy-three consecutive patients (mean age=51.1, range=26–61) with a histological diagnosis of primary malignant brain cancer (grade IV glioblastoma and grade III anaplastic astrocytoma) agreed to take part in the study.

Once a patient was introduced by his/her physician, a specialized researcher explained the methods, purposes, and ethical aspects of the study. A written form containing all the procedures, methods, and contacts was given to the patients so as to allow them to reflect also with the aim of proxies.

During a second encounter, patients were asked about their decisions. Additional information was provided when requested, and a standard written informed consent was explained and discussed before being signed.

All patients were already informed by their doctor in charge of their diagnosis and the needed treatments. However, to verify if patients were aware of their disease context, the interviewer asked patients to describe their disease and treatments in order to report this information in the study file. In this way, it was possible to test patients' awareness without eliciting emotional distress.

All participants were aware that they had surgery for a primary cerebral neoplasm and that they would need other therapies such as chemotherapy and radiotherapy to prevent recurrences. At the moment of the interview, all patients underwent surgery and radiotherapy and they were in hospital for their chemotherapy treatment.

Patients' physical, functional, and cognitive performance state was assessed by the doctor in charge using the Karnofsky

Performance Status (KPS) and the Mini-Mental State Examination (MMSE).

Patients' mood was measured using the Hospital Anxiety and Depression scale (HAD), while the Functional Assessment of Cancer Therapy Brain (FACT-Br) and the Schedule of Evaluation of Individual Quality of Life–Direct Weighting (SEIQoL-DW) were used to assess quantitative and qualitative QoL aspects and to analyze cognitive strategies.

Interviews were carried out in the same day of the questionnaire administration. Each interview was completed during a single session (mean duration time of the interview, excluding briefing and questionnaire completion, was 22.56 min), and no patient required the support of a caregiver, since they were able to completely understand and answer questions. The interview was audio-recorded for subsequent analysis. Consent for audio recording was also given.

## Instruments

### The Karnofsky performance status scale

KPS is a 100-point rating index widely used by physicians to assess patients' physical and functional performance abilities. The value ranges from 0 (dead) to 100 (no impairment, normal activity).

### The mini-mental state examination

The MMSE is a broadly used test to briefly assess the cognitive status of patients. It is validated for Italian culture and corrected for age and education level. The value ranges from 0 (worst score) to 30 (best score) [17]. This test is used by default by the medical staff for preliminary cognitive screening of patients. As we did not have the objective of assessing the impact of brain cancer on cognitive performances, we decided to use the same test in order to assess whether patients were able to participate in the study, even though the MMSE is not suitable for detecting subtle neuropsychological consequences of glioma. A cutoff of 19 was decided in consideration of the fact that patients are generally able to participate to QoL assessment also in case of some specific neurological impairment affecting the MMSE score.

### The hospital anxiety and depression scale

The HAD is a self-administered questionnaire made up of two 7-item scales, one for anxiety and one for depression, which should be used as two separate measures of emotional distress.

The scale has been validated for Italian culture by Costantini and showed high internal consistency with Cronbach's alpha, ranging between 0.83 and 0.85 [18].

The HAD evaluates symptoms of anxiety and depression, avoiding misattribution due to physical aspects of the illness. The value ranges from 0 to 21 for each scale [19]. Cutoff scores were preliminarily defined as normal (0–5), light (6–8), moderate (9–11), and heavy (greater than 11) for both the anxiety and depression patients [15].

### Functional assessment of cancer therapy and FACT brain scale [20]

The FACT-Br comprises a core questionnaire called the Functional Assessment of Cancer Therapy General (FACT-G) and a specific subscale for the brain.

The FACT-G is made up of 27 items on a five-point Likert scale (0 to 4). Higher scores correspond to a better self-perceived QoL.

The FACT-G is divided into four domains: Physical Well-Being (seven items), Social/Family Well-Being (seven items), Emotional Well-Being (six items), and Functional Well-Being (seven items). The scoring range is 0–28; however, Emotional Well-Being ranges from 0 to 24. The specific brain cancer scale includes 19 items of further concern. Each item is based on the same five-point Likert scale and is specific for brain cancer problems. The score range is 0–76.

### The schedule of evaluation of individual quality of life–direct weighting [21]

The SEIQoL-DW is an interview-based tool used to evaluate quality of life. This instrument evaluates, both qualitatively and quantitatively, general QoL based on five areas of life that a patient considers most important to him/herself. The procedure is quite complex, but well-trained interviewers are able to motivate patients, completing the task in less than half an hour. The SEIQoL-DW entails consecutive steps. After a short introduction, aimed at activating thinking processes about quality of life and the disease condition, patients are invited to nominate five areas of their lives they feel to be important in affecting their QoL. If patients are not able to nominate autonomously these areas, a list that they can pick from is introduced by the interviewer. The subsequent step requires to determine cue levels using a 0–100 scale: The higher the score, the better the level of functioning in one QoL area. Finally, patients indicate the level of importance that they place on each area (QoL determinants) by using a direct weighting procedure. To complete this task, subjects use an instrument consisting of five differently colored interlocking discs, labeled with the five areas previously nominated. Patients rotate discs over one another, around a central point to create a sort of pie chart. Each of the five areas is scored by their level of importance (see Fig. 1).

During this procedure, patients are free to talk about their experience and to report their thoughts. However, they are also



**Fig. 1** An example of SEIQoL-Dw discs for direct weighting procedure

asked to score their self-perceived QoL. Indeed, a total weight score of 100 is distributed among the five cues. An overall score (SEIQoL index, range 0–100) is calculated as the sum of cue levels multiplied by cue weights and divided by 100. Higher scores mean a better QoL [21].

Although the scale was developed in a sample of patients with AIDS, most studies in the last 10 years were conducted in cancer. Furthermore, it was previously used in patients with neurological diseases, e.g., in patients with amyotrophic lateral sclerosis [22]. A recent review reported good psychometric properties [23], underlining the feasibility of SEIQoL-DW. Indeed, when patients have the required cognitive abilities, compliance was found to be generally high, with few missing data. A well-trained interviewer and an adequate setting make it possible to collect meaningful data, overcoming the feasibility problems raised in other studies [24]. In our study, two trained interviewers conducted the study. All interviews were audio-recorded and transcribed verbatim for further analysis.

By the use of SEIQoL-Dw, it is possible to collect both rich qualitative data (life area descriptions, feelings about them, well-being, and the like) and a quantitative QoL description. Since patients are explicitly asked to name domains that are most important for their quality of life, the SEIQoL-DW could be considered as a tool to explore relevant determinants of quality of life [25], allowing for deeper analysis of patients' experience than standardized questionnaires. Moreover, this task stimulates patients to think carefully about their physical and psychological well-being and to search for connections and insights about their experience, thus eliciting a useful cognitive work.

### Statistical analysis

To analyze the relationship between KPS, age, cognitive impairment, gender, anxiety, and depression, we used correlation (the Spearman rho coefficient), while linear

regression was used to evaluate the relationship between these variable and QoL outcome. Since not all the scores were normally distributed, a non-parametric test was used to assess differences between these factors. In particular, the Mann-Whitney *U* test was used in case of two-level variables, and the Kruskal-Wallis test for variables with more than two levels.

To analyze the cognitive strategies activated by patients to cope with cancer, we used the patients' descriptions audio-recorded during their SEIQoL-DW interviews related to the five QoL areas reported to be subjectively important. Krippendorff's alpha coefficient was used to calculate inter-rater reliability.

### Qualitative analysis method

An inductive thematic analysis was used [26]. In order to identify coping domains, a panel of three experts (one physician, two psychologists) contemporarily analyzed eight patients' interviews conducted in a preliminary phase. Each transcript was coded according to the specific domain that they were judged to represent.

During the coding process, applied to the eight preliminary phase interview transcripts, three raters identified distinct categories reflecting distinct QoL areas and gave them code labels. After individual coding, the raters shared the assigned codes and chose a unique categorization. Using this process, codes were continually refined in an effort to maintain reliability and fidelity to the data.

In a second phase, coders worked together to reach consensus on emergent themes. Seven domains were defined:

**Family:** the positive psychological and physical support that a patient found within familial relations (e.g., "My relatives: my sons, my sisters. During the last month they all were close to me, around me").

**Social:** positive support of friends and the social context (e.g., "The relationships with other people. During my everyday life I enjoyed staying with friends and even to share experience with people I met for the first time. Everybody gave me strength and support").

**Awareness:** when a patient realizes that their own lifestyle or way of thinking has been modified to manage the situation, e.g., realizing the need to be cared for implies the adoption of a new social or familial role (e.g. "From September is all about my disease. I know that many things have changed and that I need help to cope with this cancer").

**Positive actions:** when a patient describes actions performed aimed at maintaining autonomy and/or a given social role (e.g., "I keep on working and I take care of my life everyday").



**Health:** all descriptions in which a patient only describes concerns with symptoms, therapies, collateral effect, surgery, health services, and so on (e.g., “For me is important to recover my physical wellbeing. Now I’m feeling better, just a bit of headache”).

**Spiritual:** when patients’ descriptions rely on faith, prayer, and spiritual resources to face the cancer in order to maintain hope and personal equilibrium (e.g., “Faith is my anchor. During the last month my faith absolutely supported me”).

**Positive thoughts:** when a patient describes his/her positive thoughts, for instance, talking about future work-related projects (e.g., “I have found new resources deep in me. I know that I’m not dying now”).

**Negative thoughts:** if a patient reports negative feelings such as fear, depression, sadness, anxiety, and the like. We considered all the negative psychological reactions that a patient reported as affecting his/her QoL. We also put all the patients’ issues related to the difficulty of accepting life changes due to the illness in this domain (e.g., “I’m ashamed, but I’d like to die, but I try to resist for my young daughter”).

Three researches independently performed the analysis of patients’ transcript interviews.

Coders independently coded all of the transcripts using the above themes followed by a meeting to discuss discrepancies and reach consensus. Inter-rater reliability was strong ( $\alpha=0.82$ ).

We obtained a series of domain labels indicating the main themes raised during the interview. In this way, for each patient, we had a set of data about their cognitive strategy.

## Results

Demographic and clinical characteristics of the 73 included patients are reported in Tables 1 and 2. All patients included in

**Table 1** Characteristics of participants

	Characteristics	No. of patients	Percent
Age (years)			
Mean	48.9		
Range	26–65		
Sex			
Male		48	66
Female		25	34
Education (years)			
8		32	44
13		28	38
>13		13	18

**Table 2** Clinical characteristics of patients

	No. of patients	Percent
Histology		
GBM	49	67
AA	24	33
Functional status (KPS)		
Median	80	
Range	70–100	
Cognitive status (MMSE)		
Mean	28.16	
Range	22–30	
Adjuvant treatment		
Radiotherapy and chemotherapy	73	100

*KPS* Karnofsky Performance Status, *MMSE* Mini-Mental State Examination

the study had a time of disease of less than 12 months and underwent a surgical intervention and radiotherapy and chemotherapy. About 55 % of our patients experienced anxiety and 39 % depression; moderate to heavy depressive or anxious symptoms were present in 14.9 and 20 %, respectively. The mean FACT-Br score was 122.37, while the median SEIQoL-DW score was 72.9 out of a maximum value of 100.

The two QoL measures adopted were found to be positively correlated as expected. However, the correlation is only partial, since using a Spearman correlation coefficient we found  $r=.467$  ( $p<.001$ ). Exploring correlations between the global SEIQoL-DW score and FACT subscale scores, we also obtained significant values, but interestingly, the higher correlations were found with emotional and functional well-being subscales (see Table 3), suggesting that SEIQoL-DW targets mainly these two QoL dimensions.

Considering the relationship between QoL and psychological distress as measured by the HAD scale, the FACT-Br scores were found to be significantly different between patients with or without moderate to severe anxiety ( $p=.002$ ) and between patients with or without depression ( $p<.001$ ; Table 4). Patients with low level of depression and anxiety reported better QoL.

About 21 % of patients showed moderate to severe anxiety state while 15 % of subjects showed moderate to severe depression symptoms. In particular, we found only a small percentage (6 %) of patients with severe depression, suggesting that mood state was well regulated in our patients. No differences in FACT-Br, SEIQoL-DW, and HAD scores were found between women and men.

In order to analyze the possible determinants of QoL, we performed a linear regression model, using the FACT-Br total score as dependent variable, and KPS, depression, anxiety, and age as predictors. Data showed that anxiety ( $\beta=-.260$ ,  $p=.006$ ), depression ( $\beta=-.389$ ,  $p<.001$ ), and KPS

**Table 3** Correlation matrix (Rho di Spearman coefficients) between QoL scores

	FACT-Br	SEIQoL	FACT-G	Physical w.	Social w.	Emotional w.	Functional w.	Brain scale
FACT-Br	1	.467**	.839**	.630**	.569**	.574**	.775**	.854**
SEIQoL-DW		1	.365**	.239*	.260*	.405**	.419**	.359**
FACT-G			1	.624**	.565**	.569**	.665**	0.484**
Physical w.				1	.207*	.364**	.462**	.396**
Social w.					1	.247*	.466**	.344**
Emotional w.						1	.376**	.348**
Functional w.							1	.548**
Brain scale								1

*FACT-Br* Functional Assessment of Cancer Therapy Brain, *SEIQoL-DW* Schedule of Evaluation of Individual Quality of Life–Direct Weighting, *FACT-G* Functional Assessment of Cancer Therapy General

\* $p < .005$ ; \*\* $p < .001$

( $\beta = .372$ ,  $p < .001$ ) were all significantly associated with QoL as measured by the FACT-Br. Considering the SEIQoL-DW score as QoL measure, only anxiety ( $\beta = -.234$ ,  $p = .031$ ) and KPS ( $\beta = .204$ ,  $p = .033$ ) were found to be significantly associated to QoL variability.

Looking for gender differences, we performed the same analyses considering men and women separately in order to verify whether different determinants could be found in these two groups. Actually, men's QoL as measured by both FACT-Br and SEIQoL-DW was found to be associated only with KPS ( $\beta = .468$ ,  $p = .002$ , and  $\beta = .394$ ,  $p = .008$ ). A different pattern was found for women. It emerged that the FACT-Br score is associated with anxiety ( $\beta = -.260$ ,  $p = .016$ ), depression ( $\beta = -.389$ ,  $p < .001$ ), and KPS ( $\beta = .372$ ,  $p < .001$ ). The SEIQoL-Dw score was found to be modulated by anxiety ( $\beta = -.368$ ,  $p = .007$ ) and KPS ( $\beta = .245$ ,  $p = .022$ ). These data are particularly interesting, since we did not find any gender-related statistical differences in QoL, anxiety, and depression scores.

The SEIQoL-DW content was further analyzed to find differences in cognitive resources and strategies. The most reported themes were as follows: positive actions (22 % of all codes), family (18 %), negative thoughts (17 %), health (15 %), and positive thoughts (14 %). Consequently, most patients reported that they relied on positive actions and on

the support of family. However, negative thoughts are often present. Interestingly, men and women reported different themes, suggesting the use of differential psychological resources to cope with the cancer. Actually, comparing women and men for each single psychological theme, we found two very different distributions (see Fig. 1). It is quite evident that men particularly rely on positive actions ( $U = 1.090$ ,  $p = .015$ ), while women especially refer to positive thoughts ( $U = 2.2380$ ,  $p < .001$ ), spiritual issues ( $U = 1.991$ ,  $p < .001$ ), and family ( $U = .020$ ,  $p = .020$ ) (Fig. 2). Health-related themes and social support are equally mentioned by men and women.

## Discussion

First of all, the FACT-Br data presented above are similar to others previously described. The mean score on the total scale (121.5) is comparable with data found by Pelletier and colleagues [8] as well as more recent studies [27, 28]. Furthermore, considering only the core instrument (i.e., the FACT-G score), we found that a mean of 71.7 is congruent with other cancer patients with severe prognoses. This leads to the conclusion that besides the poor prognosis with a median survival of 18 months, our subjects showed a life period with discrete QoL even if significantly lower than the normal population. The brain subscale showed worse scores than other subscales, indicating the presence of several specific concerns deserving attention (e.g., sensory or motor impairments).

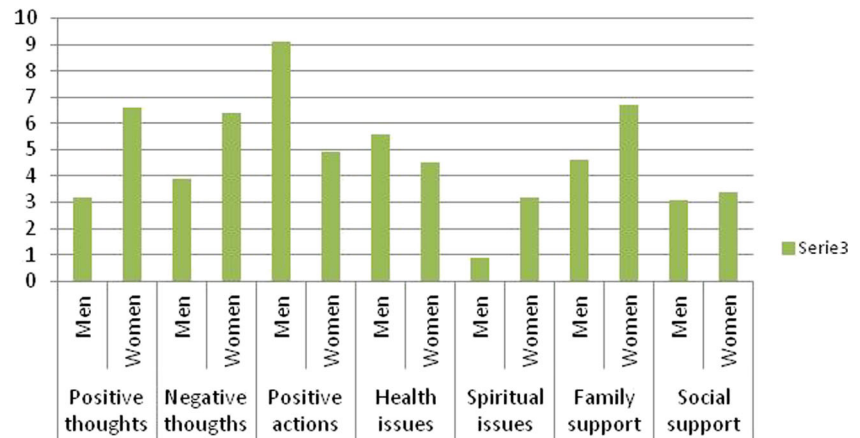
Since this study is the first using both FACT and SEIQoL-DW on brain cancer patients, it is interesting to highlight that both the FACT-G and FACT-Br total scores were found to be positively correlated with the SEIQoL-DW measure. These two instruments (FACT and SEIQoL-DW) are different QoL measures, with the FACT scale being more linked to physical concerns. However, the fact that the SEIQoL-DW correlates with the KPS index may suggest that the final score of this tool is affected also by physical and functional aspects. Actually,

**Table 4** Differences in FACT-Br standardized scores for HAD level (Mann-Whitney test)

	Mean	SD	M-W	p
HAD-D <8 (no signs of depression)	108.3	13.87	182.5	.000
HAD-D ≥8 (moderate to severe depression)	87.92	13.13		
HAD-A <8 (no signs of anxiety)	109.66	12.95	403.3	.000
HAD-A ≥8 (moderate to severe anxiety)	93.65	16.33		

*HAD* Hospital Anxiety and Depression scale

**Fig. 2** Means of QoL-related cognitive resources reported by men and women



patients' experience is a mix of emotional and physical reaction to the cancer.

The psychological distress found in our study, as measured by the HAD scale, may be considered comparable with a similar study by Giovagnoli and colleagues (1996) and other international data [29, 30], even though, in studies based on self-reporting measures, the prevalence of depression shows high variability, ranging from 25 to 93 % [31].

Our data revealed that subjects with high depression and/or anxiety scores reported lower QoL scores in all the instruments considered. In particular, depression and anxiety showed higher interaction with FACT scores (both general and brain score) and a lower association with SEIQoL-DW scores. These data confirm that SEIQoL-DW and FACT actually measure different domains of patients' well-being. Interestingly, we did not find any gender effect concerning depression and anxiety. These data are not consistent with other studies [32] reporting significantly higher depression in women. However, important differences between men and women were found in QoL determinants and psychological resources activated to cope with the cancer. Indeed, in women, the QoL score seems to be associated with psychological distress more than the KPS, while in men, only KPS is closely associated with QoL.

Furthermore, men and women reported that they used different psychological mechanisms to cope with the illness. Generally speaking, two main coping categories may be described [33]: a category including adaptive strategies, in particular so-called fighting spirit and fatalism; and a category including maladaptive strategies, such as hopelessness and avoidance. Although we did not address directly these coping styles, our patients are mostly able to express both positive and negative emotions. Hence, they seem to adopt an adaptive style. In particular, our patients reported to activate a number of different cognitive, emotional, and social resources to face the situation instead of despairing. Most patients were able to mention different emotions, both positive and negative, when approaching QoL issues, and this suggests that they were

using an adaptive strategy, even when important physical impairments are present. For instance, patients reporting positive actions are clearly able to accomplish concrete activities in order to face their difficulties, thus showing a fighting spirit. Similarly, patients reporting spiritual issues as well as positive thoughts suggest the use of a fatalist style. Most of our patients reported a combination of these strategies. At the opposite, in case of maladaptive styles, patients find it difficult to mobilize personal resources, and this often leads to a specific inability to describe their situation and to develop awareness.

In addition, we found interesting gender differences, since men and women pursue their goals mobilizing different cognitive and emotional resources. Men's style is mostly linked to the ability to recover physical and functional well-being (what the KPS index is supposed to measure), suggesting the use of a fighting spirit approach. In this sense, we may expect distress to arise as a consequence of a physical impairment. Women, instead, typically use introspective strategies (mobilizing emotional and spiritual resources) and show more fatalism. This coping style probably contribute to a positive response to a physical decrement, for example, as a result of a treatment side effect. However, introspective strategies are more vulnerable to psychological distress due to contextual stressors. These issues deserve particular attention in future research. Finally, all patients reported to find fundamental support in relatives and friends (social support).

Our data are naturally limited due to the size of the sample, which does not allow us to fully appreciate the real effects of some critical variables, especially coping styles, on the different QoL measures used. Further research is needed to truly understand how cognitive resources can modulate the ability of a patient to adjust to a severe diagnosis. Equally, we need to know how to use this knowledge to improve patients' QoL or to help them adapt their cognitive strategy to the contextual demands. However, tailored and validated intervention strategies are not available at the moment in oncology settings.

Eventually, prospective studies are needed to confirm our suggestions and to analyze the complex relationship between

coping styles, QoL, and positive and negative effects of treatments. Within this research line, we are now working on a longitudinal study protocol on a lung cancer population and projecting a similar one on brain cancer to be launched in 2015.

## Conclusion

The aim of our study was to provide innovative insights in the comprehension of brain cancer experience. Hence, we analyzed QoL through a variety of instruments in order to gather data to describe self-reported QoL, functional status, and psychological resources in patients with high-grade glioma who undergo aggressive therapies (surgery, radiotherapy, and chemotherapy). We therefore collected data from 73 patients, allowing us to find interesting and in some cases original data.

QoL evaluation should be considered particularly important in brain cancer patients with a severe diagnosis and poor prognosis, since maintaining good quality of life and supporting psychological well-being are fundamental goals of treatments. Our data confirm that patients with high-grade glioma may report an acceptable self-reported QoL also during aggressive therapies [28]. This allows them facing the situation without engendering severe depression and/or anxiety symptoms. Patients are thus able to use different psychological strategies to adjust to such a difficult moment, often maintaining a positive perspective. They are generally able to talk about their emotions and difficulties using a first-person perspective. Furthermore, even when negative experiences are reported, an adaptive coping strategy help patients to find out positive reactions (positive feelings or concrete actions) instead to passively accept them. Although we cannot claim that this approach clearly impacts survival, we argue that a positive psychological status contributes to a good self-perceived QoL. Patients using an adaptive coping strategy, indeed, are able to recognize a potentially disruptive emotional reaction to stressors also in the case of major physical impairments.

We found that men and women having similar physical and functional states reported similar FACT scores but different QoL determinants and psychological strategies. This is a particularly important consideration in approaching patients. Indeed, physicians should pay attention not only to physical-related QoL aspects but also to the specific coping strategy used by patients to sustain their self-reported QoL. Even though patients are found to report good QoL as measured by objective instruments such as the FACT scale, the adjustment process could be weak and vulnerable to later failures.

Our data allow us to open a window on the experience of patients with high-grade glioma. We indeed showed how relevant issues as QoL may be differently characterized by the use of different instruments. We argue that these differences are due to the different QoL constituents captured by each

single measure. We also suggested how different tools may serve different aims.

Finally, we want to remark the gender differences we found. Men and women reported to experience different emotions and have different needs even when they have a similar QoL score. This is the first study finding a so relevant difference in the context of high-grade glioma. We claim that this insight should guide future studies in the experience of brain cancer also within the more general approach of narrative medicine.

Finally, we claim that a more narrative approach to QoL, including both quantitative and qualitative information, should help health professionals to better understand patients' experience and needs. Standardized questionnaires might be considered as screening tools, useful at beginning of the disease and to evaluate changes after critical events, while SEIQoL-DW or another interview-based instrument might be used during treatment in order to understand patients' experience and prevent heavy psychological burden.

Although only a prospective study should be able to assess the strength of our suggestions, we argue that the analysis of emotions and cognitive strategies may contribute to understanding patients' risk factors and to foreseeing future psychological breakdowns. For instance, the use of weak psychological resources (e.g., the perception of a good physical situation) could cause subsequent poor adjustment to the illness due to physical changes.

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