CrossMark

CLINICAL STUDY

Coping with a newly diagnosed high-grade glioma: patient-caregiver dyad effects on quality of life

K. Baumstarck[1,2] · T. Leroy[1,3] · Z. Hamidou[1,2] · E. Tabouret[4,5] · P. Farina[4] ·
M. Barrié[4] · C. Campello[4] · G. Petrirena[4] · O. Chinot[4,5] · P. Auquier[1,2]

Abstract Patients with high-grade gliomas (HGG) and their caregivers have to confront a very aggressive disease that produces major lifestyle disruptions. There is an interest in studying the ability of patients and their caregivers to cope with the difficulties that affect quality of life (QoL). We examine, in a sample of patient-caregiver dyads in the specific context of newly diagnosed cases of HGG, whether the QoL of patients and caregivers is influenced by the coping processes they and their relatives use from a specific actor–partner interdependence model (APIM). This cross-sectional study involved 42 dyads with patients having recent diagnoses of HGG and assessed in the time-frame between diagnosis and treatment initiation. The self-reported data included QoL (Patient-Generated Index, EORTC QLQ-C30, and CareGiver Oncology QoL),

emotional status, and coping strategies (BriefCope). The APIM was used to test the dyadic effects of coping strategies on QoL. Coping strategies, such as social support, avoidance, and problem solving, exhibited evidence of either an actor effect (degree to which the individual's coping strategies are associated with their own QoL) or partner effect (degree to which the individual's coping strategies are associated with the QoL of the other member of the dyad) for patients or caregivers. For positive-thinking coping strategies, actor and partner effect were not observed. This study emphasizes that the QoL for patients and their caregivers was directly related to the coping strategies they used. This finding suggests that targeted interventions should be offered to help patients and their relatives to implement more effective coping strategies.

O. Chinot and P. Auquier have contributed equally to this work.

✉ K. Baumstarck
karine.baumstarck@univ-amu.fr

1 EA3279, Self-perceived Health Assessment Research Unit, Aix Marseille Université, 27 bd Jean Moulin, Marseille Cedex 05 13385, France

2 National Clinical Research Quality of Life in Oncology Platform, Marseille, France

3 Social Psychology Research Group (GRePS EA 4163), Université Lumière Lyon 2, Bron, France

4 Department of Neuro-Oncology, Assistance Publique Hôpitaux de Marseille, Timone Hospital, 13005 Marseille, France

5 Aix-Marseille Université, CRO2, 13385 Marseille, France

Introduction

Despite recent advances in diagnoses and treatments, high-grade gliomas (HGG) remain to be very aggressive tumors with a short survival time [1]. The announcement of such a diagnosis and poor prognosis, the effects of the tumor on cognition and functionality, and the toxicity of treatments have rapid and important consequences on the everyday life of patients and their relatives [2, 3]. These social, emotional, psychological and physical consequences have already been described [4–6], indicating an important quality of life (QoL) alteration at a level that is not normally observed in other cancers [7–13]. Due to these major lifestyle disruptions, there is an interest in studying how patients and caregivers handle the problems of daily life and how the

ability to cope with difficulties actually impacts QoL. Coping is commonly defined as the cognitive and behavioral efforts that are implemented to solve problems and reduce the stress that these problems may cause [14, 15]. Several coping strategies can be used in a stressful situation, and the strategies implemented depend both on the individual's cognitive appraisal of the situation [15, 16] and his/her emotional status.

The literature generally distinguished active and avoidant coping strategies [17]. Active coping strategies are thought to be better methods to address stressful events, and avoidant coping strategies appear to be a psychological risk factor for adverse responses to stressful life events.

While there is evidence that a patient's QoL partially depends on the ability of his/her caregiver to properly provide support [18, 19], only a few studies have examined the specific mechanisms of the interconnections among the patient-caregiver dyad. Only one study has truly assessed the effects of coping strategies on QoL demonstrating a strong link between active coping strategies and psychological domains [20] and to date, studies have not been conducted in the specific context of the recent announcement of a HGG diagnosis.

Among a sample of patient-caregiver dyads in the specific context of new diagnoses of HGG in the time-frame between diagnosis and treatment initiation, we examine the following: (i) the relationship between the QoL of patients and their caregivers and (ii) whether the QoL of patients and caregivers is influenced by the coping strategies implemented either by themselves or their relatives using the actor–partner interdependence model (APIM) [21], which is an appropriate method to assess the dyadic effects based on the hypothesis that the scores within the same dyad are not independent but instead are more similar than the scores of two individuals who are not in the same dyad.

Methods

Design and settings

We conducted a cross-sectional study with a descriptive/correlative design. The recruitment of patient-caregiver dyads was made in the Neuro-oncology Department of the Public Timone Hospital through the regional glioma cohort implemented in the area of Marseille, in the South of France. This cohort is part of the French "Site de Recherche Intégrée sur le Cancer (SIRIC) gliomas program", which is a research program, certified by the French National Cancer Institute, involving all clinical teams working in the field of glioma for a better understanding of the pathology, a better identification of efficient therapeutic approaches and improved care for patients suffering from gliomas (http://www.

siric-marseille.fr/Gliomes.html?lang=en). In this study, we reported data collected at the first assessment corresponding to the time-frame between diagnosis and postsurgical treatment initiation.

Sample selection

The samples included patient-caregiver dyads. The patient selection criteria were as follows: aged above 18 years; having a newly diagnosed high-grade glioma (grades III and IV) according to the WHO classification; able to speak/read French; not having severe cognitive problems (resulting in obvious difficulties in communicating) based on the physician's opinion; and agreeing to participate. The selection criteria of the caregivers were as follows: aged above 18 years; designated by the patient as the most involved person in his/her life; able to speak/read French; and agreeing to participate. Written consent forms to participate were collected from every patient and caregiver.

Data collection

Inclusion was performed 2–6 weeks after surgery and before chemo/radiotherapy treatment initiation. For the patient, the following clinical data were gathered using the medical records and the examination by a senior oncologist/neurologist: type and grade of the glioma; initial WHO performance status; initial treatment planned; and cognitive dysfunction level (mini-mental state exam score less than 24 [22]). The nature of the relationship between the patient and the caregiver was collected as either the love partner, child, or other. The age, gender, educational level, marital status, and the number of children were recorded for both the patient and his/her caregiver using self-report questions.

Quality of life, emotional status, and coping strategies were collected by means of self-reported questionnaires that were completed by the patients and caregivers.

- Quality of life was assessed using the French version of the Patient-Generated Index (PGI) [23] for both the patient and the caregiver, as well as the EORTC QLQ-C30 [24] for patients and the CareGiver Oncology Quality of Life (CarGOQoL) [25] for caregivers. The PGI is a generic 15-item questionnaire that assesses the QoL of individuals in the areas that are the most affected by the disease. A global index ranges from 0 to 100. The QLQ-C30 is a specific questionnaire assesses the QoL of cancer patients, including 30 items describing five functional scales (physical, role, emotional, cognitive, and social), nine symptom scales, and a global health status scale. The scores for each scale/item range from 0 to 100. We used only the functional scale scores. A high score for a functional scale represents a high/healthy

level of functioning. The CarGOQoL is a well-validated specific questionnaire for caregivers of cancer patients and includes 29 items describing ten dimensions: psychological well-being, burden, relationship with health care, administration and finances, coping, physical well-being, self-esteem, leisure time, social support and private life. An index was computed. All dimension scores and the index are on scales of 0–100. A higher score indicates a better QoL.

- Coping strategies were assessed using the Brief Coping Orientation to Problems Experienced Scale (Brief-Cope) [26, 27]. This questionnaire includes 28 items that explore the following 14 strategies: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. Confirmatory factor analyses conducted among cancer patients and caregivers (unpublished data) have shown a satisfactory goodness of fit, encouraging a reduction to four dimensions that include social support, problem solving, avoidance, and positive thinking. Scores ranged from 0 to 100. High scores in these four dimensions reflect a high tendency to implement the corresponding coping strategies.

- Anxiety and mood were assessed using visual analogic scales that ranged from 0 to 100. Higher scores indicate a higher level of anxiety and more likelihood of mood disorders.

Statistical aspects

After descriptive analyses of the characteristics of patients and caregivers, QoL scores were computed using the algorithms provided by the respective developers of the tools. The scores of coping were provided in four scores corresponding to a four-factor structure previously explored by our team. Comparisons between the scores of caregivers and patients (QoL, coping strategies, anxiety, and mood) were performed using the Wilcoxon test. To assess the relationships between the QoL scores and coping processes for patients and caregivers, two analyses were performed: (i) correlations and multiple comparison corrections (false discovery rate); (ii) APIM to assess the dyadic effects of coping strategies on QoL (PGI scores). The APIM was assessed using structural equation modeling [21]. This model is based on the fact that the scores within the same dyad are not independent but instead are more similar than the scores of two individuals who are not in the same dyad. The APIM is useful to determine how parameters (QoL and coping strategies) among each participant (namely patients and caregivers) are influenced not only by internal factors

but also by factors related to the other member of the dyad. Structural equation modeling simultaneously examines both paths in the APIM: two actor effects (i.e., each person's QoL regressed on their own coping strategies) and two partner effects (i.e., each person's QoL regressed on the other person's coping strategies).

Results

Sample

Between April 2014 and July 2015, 139 patients were eligible to be included in the cohort. Only 58 patients agreed to participate in the present study and gave written informed consent. The reasons for non-inclusion were as follows: language barriers (5); refusals (19); a highly deteriorated health and/or cognition status (26); and reticence of the medical staff to propose participation in the study due to the harshness of the situation (deterioration of health status, troublesome socio-environmental situation, geographical distance, etc…) (31). The included individuals and the non-included patients were not different in terms of sex, age, or tumor grade. The proportion of patients with a Karnofsky performance index higher than 70 was increased for included individuals compared with non-included patients (52 and 25 %, p = 0.001). Of the 58 patients, 42 were able to nominate a caregiver who agreed to participate. Therefore, the final sample was composed of 42 patients and 42 caregivers who were assessed 2–6 weeks after surgery and before treatment initiation and whose main characteristics are presented in Table 1. The flow chart is presented in additional material 1. On average, it took participants 15 min to complete all study assessments.

Quality of life, coping strategies, and emotional status of the patients and caregivers

The QoL scores of patients and caregivers are provided in the additional material 2 (a and b, respectively). All of the correlations between patient and caregiver scores are detailed in Table 2. In general, for all of the questionnaires that were administered (PGI, CarGOQoL, and QLQ-C30), patient QoL was not linked to that of the caregiver; instead, only incidental links were found. The "physical-like" dimension scores reported by the patients (physical functioning and role functioning) did not correlate with the "physical-like" dimension score reported by the caregivers (physical well-being). The same observation was made concerning the "psychological-like" dimensions (emotional functioning and cognitive functioning for QLQ-C30; psychological well-being, coping, and burden for CarGO-QoL) and "social-like" dimensions (social functioning for

Table 1 Sample characteristics

Patients N=42			Caregivers N=42		
Gender	Women	41%	Gender	Women	62%
Age	M±SD	58.3±14.5	Age	M±SD	54.4±3.0
	Min–max	18 from 79		Min–max	20 from 76
Marital status	Couple	38 (91%)	Marital status	Couple	38 (91%)
	Single	4 (9%)		Single	4 (9%)
Children	Without	4 (9%)	Children	Without	9 (21%)
	With	38 (91%)		With	33 (79%)
Educational level	Low (<12 years)	18 (44%)	Educational level	Low (<12 years)	20 (48%)
	High (≥12 years)	23 (56%)		High (≥12 years)	22 (52%)
Tumor grade	III	5 (12%)	Relationship with the patient	Love partner	34 (81%)
	GBM	37 (88%)		Child	5 (12%)
First treatment	Biopsy or surgery	31 (74%)		Friend, family member	3 (7%)
	Radiotherapy	39 (93%)			
	Chemotherapy	42 (100%)			
MMS	<27	31 (76%)			
	≥27	10 (24%)			
Karnofsky index	Med [IQR]	80 [70–80]			

M±SD mean±standard deviation, *Med [IQR]* median [interquartile range], *GBM* glioblastoma, *MMS* mini mental score, *min–max* minimum–maximum

QLQ-C30; relationship with healthcare, leisure, and private life for CarGOQoL).

Globally, patients and caregivers used the four types of coping strategies at similar levels (Fig. 1). The strategies that were based on social support and avoidance were the least used strategies among patients and caregivers. The strategies based on problem solving were the most used among both members of the dyad; however, caregivers used these strategies even more than patients (mean score of 71 and 60, respectively, p<0.05).

Mean levels of anxiety and mood disorders were significantly higher among caregivers compared to patients (anxiety: 6.7±2.7 vs. 5.6±2.9, respectively, p<0.05; mood: 5.7±2.9 vs. 4.0±2.8, respectively, p<0.001).

Relationships between emotional status and quality of life

As expected, for both patients and their caregivers, anxiety and mood disorder scores were significantly and negatively correlated to the respective "psychological-like" QoL scores. More precisely, among patients, the correlation between the emotional functioning scale of the QLQ-C30 and anxiety was R=−0.55, p<0.01, and the correlation to the mood score was R=−0.62, p<0.01. Among caregivers, the psychological well-being dimension of the CarGOQoL was linked to anxiety with a correlation of R=−0.66, p<0.01 and to mood disorders with a correlation of R=−0.70, p<0.01. Caregiver emotional status was not linked to patient QoL

whereas patient anxiety and mood scores were related to two dimensions of caregiver QoL (private life and coping, R=−0.48 and R=−0.33, p<0.01).

Relationships between coping strategies and quality of life

When patients used strategies such as problem solving and positive thinking, they reported significantly higher QoL scores in two dimensions (general health status and cognitive functioning). Being avoidant were not associated with QoL. When patient use of problem solving strategies increased, the self-esteem scores of their caregivers were reduced. The more the patients used avoidance or social support seeking strategies, the lower the scores of psychological well-being, burden, coping scores of CarGOQoL, and PGI index for their caregivers.

When implemented by caregivers, positive-thinking coping strategies were particularly associated with caregiver QoL scores (the PGI index as well as the psychological well-being, physical well-being and coping dimensions of the CarGOQoL). When caregiver use of social support and avoidance strategies increased, the PGI index score of the patient was increased. All these results are presented in Table 3.

The actor effect of coping strategies refers to the degree to which an individual's (patient or caregiver) coping strategies are associated with their own QoL. The partner effect refers to the degree to which an individual's coping

Table 2 Correlations between caregivers' QoL (CarGOQoL) scores and patients' QoL functioning (EORTC QLQ C30) scores

| | Caregivers CarGOQoL | | | | | | | | | | | | |
	Psy WB	Burden	Rel HCare	Adm & fin	Coping	Phy WB	Self-est	Leisure	Soc sup	Priv life	Index
Patients' QLQ C30											
General health status	0.00	0.247	0.091	−0.067	0.177	−0.136	−0.179	−0.064	−0.025	0.021	0.024
Physical functioning	0.012	0.281	0.173	0.087	0.096	0.07	−0.318*	−0.073	−0.117	0.178	0.098
Role functioning	0.021	0.054	0.204	−0.07	0.092	−0.103	−0.222	0.234	−0.046	0.076	0.041
Emotional functioning	−0.15	−0.013	0.058	−0.175	0.148	−0.054	−0.225	0.175	−0.15	0.281	0.036
Cognitive functioning	−0.21	0.07	0.173	−0.360*	−0.074	−0.205	−0.21	−0.034	−0.118	0.024	−0.189
Social functioning	−0.088	0.1	0.098	−0.072	0.104	−0.204	−0.347*	0.191	−0.123	0.026	0.003

All scores ranging from 0 to 100, the higher the score the better the QoL

Bold values indicated p<0.05

CarGOQoL CareGiver Oncology Quality of Life, *Psy WB* psychological well being, *Rel HCare* relationship with healthcare, *Adm & fin* administration and finances, *Phy WB* physical well being, *Self-est* self-esteem, *Soc sup* social support, *Priv life* private life
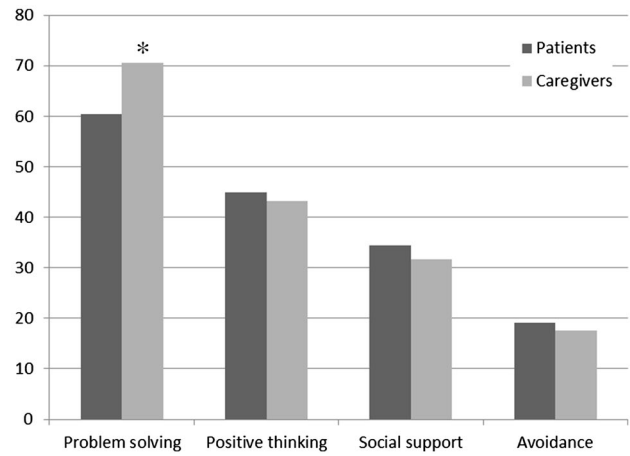
Fig. 1 Coping strategies (Briefcope) used by patients and caregivers (scores range from 0 to 100; high score reflects high implementation of the strategy) *p value <0.05 (Wilcoxon paired test)

strategies are associated with outcomes among the other member of the dyad. The coping strategy by patients to look for social support was associated with a decrease in their own and their caregivers' QoL scores; however, the use of this strategy by caregivers was linked to higher patient QoL scores only (Fig. 2a). The use of avoidance strategies by caregivers was associated with an increase of both their own and the patients' QoL scores (Fig. 2b); however, the use of problem-solving strategies by caregivers was only associated with a decrease in their own QoL level (Fig. 2c). For positive-thinking coping strategies, neither an actor effect nor partner effect was observed (Fig. 2d).

Discussion

The first finding of this study indicates that the QoL and the emotional status of patients at the time of HGG diagnosis is not clearly linked to that of their principal caregivers. The events that occur immediately following diagnosis impact specific domains in the life of the patient that differ from the domains impacted in the life of the caregiver. During the time between the diagnosis and the initiation of the first treatment, a plethora of information was provided to patients and their caregivers, including the immediate consequences of the diagnosis, initiation of the treatment, prognosis, and existing care support. Patients and caregivers may have a psychologist support. However, the sequence and the nature of the information provided varied, and this difference may partially explain the discrepancies between patients and caregivers as it relates to daily life consequences. Given that previous studies did not retrieve these discrepancies [13, 28], longitudinal approaches will determine whether the observed discrepancy diminishes during later stages of the disease [8].

**Table 3** Correlations between quality of life and coping strategies for patients and caregivers

	Patients' coping (BriefCope)[b]				Caregivers' coping (BriefCope)[b]			
	Social support	Problem solvings	Avoidance	Positive thinking	Social support	Problem solvings	Avoidance	Positive thinking
Patients' QLQ C30[a]								
General health status	−0.122	0.530***(*)	−0.062	0.376*	−0.036	−0.013	−0.038	0.083
Physical functioning	−0.239	0.31	0.017	0.071	0.031	0.067	0.047	0.108
Role functioning	−0.337*	0.254	−0.008	0.21	0.167	0.135	0.08	0.104
Emotional functioning	−0.203	0.287	−0.081	0.206	0.042	0.026	−0.087	0.023
Cognitive functioning	0.006	0.396*	−0.125	0.125	0.252	0.319*	0.116	0.262
Social functioning	−0.283	0.309	−0.012	0.244	0.112	−0.011	0.152	0.068
Patients' PGI[a]	−0.442*(*)	0.100	0.028	−0.032	0.396*(*)	−0.126	0.408*(*)	0.121
Caregivers' CarGOQoL[a]								
Psychological well being	0.236	0.008	−0.351*	−0.037	−0.032	0.146	−0.215	0.448**(*)
Burden	−0.339*	0.006	−0.185	0.017	−0.265	0.009	−0.196	−0.05
Relationship with healthcare	0.063	0.006	0.004	0.121	0.361*	0.025	0.19	0.188
Administration and finances	−0.182	−0.097	−0.047	0.008	−0.265	−0.062	−0.217	0.019
Coping	0.115	0.062	−0.336*	0.178	0.014	−0.017	−0.154	0.383*
Physical well being	0.044	−0.078	−0.041	−0.259	0.06	0.028	−0.06	0.442**(*)
Self-esteem	0.168	−0.385*(*)	−0.057	−0.19	−0.08	0.073	−0.009	0.129
Leisure time	−0.074	0.061	−0.008	0.185	0.29	0.131	0.176	0.167
Social support	0.14	−0.185	0.034	−0.003	0.226	0.342*	−0.134	0.131
Private life	−0.286	−0.102	−0.06	0.224	0.205	0.142	−0.094	0.154
Index	0.055	−0.099	−0.137	0.164	0.137	0.092	−0.067	0.444**(*)
Caregivers' PGI	−0.538**(*)	0.073	−0.174	0.206	−0.023	−0.423*(*)	0.236	0.012

PGI Patient-Generated Index; *CarGOQoL* CareGiver Oncology Quality of Life

[a]Scores ranging 0–100, the higher the score the higher QoL

[b]Scores ranging 0–100, the higher the score the higher coping strategy is used

*p < 0.05 before correction for multiple testing; **p < 0.01 before correction for multiple testing; (*)p < 0.05 after correction for multiple testing
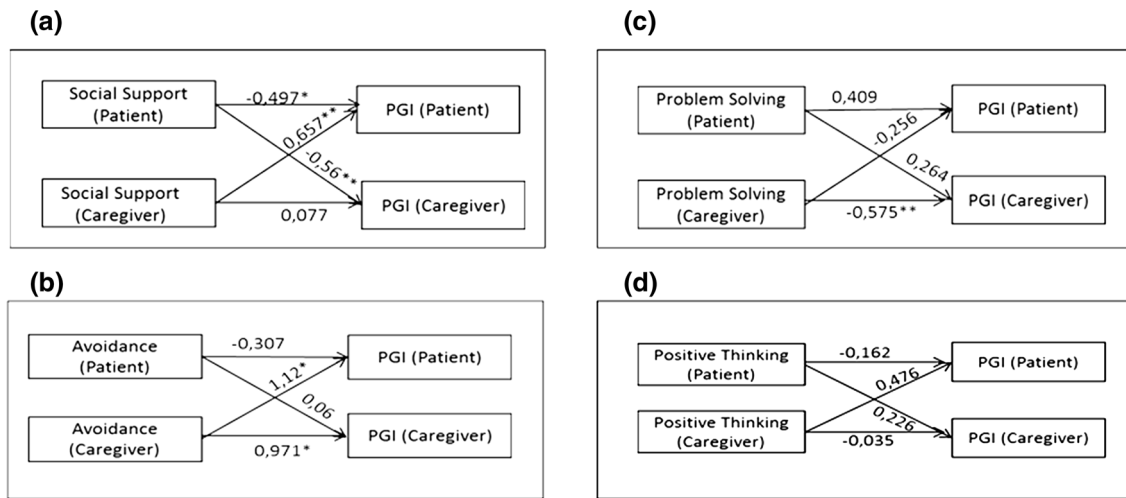
Fig. 2 Illustration of relations between coping and QoL using the actor–partner interdependence model. Numbers are standardized coefficients: β. *p < 0.05; **p < 0.01

The second interesting result of this study is that patients and their caregivers were found to implement similar coping strategies at the time of the assessment, using strategies based on problem solving and positive thinking more than the strategies based on looking for social support or avoidance. So, while patients and their caregivers do not perceive the disease diagnosis events in the same way, as attested by their self-reported differences in QoL and emotional status, they implement the same coping strategies following diagnosis. This result suggests that people who know each other very well and who are faced with the same difficult event tend to cope with it similarly; however, the effectiveness of the employed coping strategies depends on the cognitive, behavioral and social resources that the patients and caregivers are able to mobilize.

Because of the very quick disease process, patients with HGG and their caregivers only have a short time to adapt and are therefore required to develop specific coping strategies [19]. While coping strategies were already studied among children with brain tumors [29] and in patients with low-grade gliomas [30], only limited amounts of data are available concerning the strategies used by people with a HHG [31]. While Molassiotis et al. [32] reported that patients usually begin to organize their lives more, accept their limitations and find ways to manage limitations after 6 months of the disease diagnosis, limited information is available related to the onset of the disease.

Interestingly, we observed that the nature of the coping strategies individuals use is associated with the QoL of their relatives. When caregivers used the coping strategies of avoidance and looking for social support, patient QoL was impacted. Similarly, the coping strategy of looking for social support by patients is associated with caregiver QoL. We found that the QoL of the caregiver is inversely correlated with the use of social support by the patient, indicating that the caregiver feels badly when the patient finds external resources but feels valued when the patient does not utilize external support. A growing body of research has shown the importance of examining dyadic models of stress, specifically investigating the ways the coping strategies implemented by individuals from a social group (couples, families, etc.) influence outcomes among the other members of the group [33].

We found that individuals who used problem-solving or positive-thinking strategies reported higher QoL scores. This finding encourages a systematic assessment of patient and caregiver coping styles to identify individuals who do not use healthy coping strategies and to offer targeted psychological interventions [34, 35]. Combined cognitive-rehabilitation and problem-solving therapy interventions for patients with brain tumors and their caregivers have reported positive findings [36]. Psychoeducation and cognitive behavioral therapy helped caregivers of HGG patients to maintain a stable QoL level [37]. Lucchiari et al. [38] showed that brain cancer patients who were satisfied with the clinical decision process seemed to be better able to cope with their disease. Developing a better understanding of the ways patients and their relatives support each other and cope together during stressful situations may aid in the development of couple-focused interventions. Future research will benefit from a greater focus on the interactions between patients and their relatives to address the ways a family adaptively copes with a serious disease [39].

Finally, we observed that standardized measures of QoL, such as QLQ-C30 or CarGOQoL, were not correlated with the individualized PGI measure. The standardized instruments typically include a pre-defined set of items exploring pre-defined domains. These more traditional instruments

have been criticized for possibly missing some domains that may prove important for the individuals' QoL or including domains of less importance. To overcome this limitation, individualized measures have been developed that allow the respondent to spontaneously identify the aspects of their life that are relevant to their QoL [40, 41].

Strengths and limitations

Herein, the high proportion of non-included individuals raises the issue of the representativeness of our results. This study highlighted a major difficulty in the assessment of patients newly diagnosed with a very serious illness who have to very quickly integrate a large amount of disastrous information related to disease prognosis, severity of treatment and the potentially bad evolution of their health status that may occur over a short time period. In addition to the direct refusal of some patients, some of the researchers and neuro-oncologists involved in this project were unwilling to approach some of the families eligible for the study in this specific period. Thus, because the more severe patients in terms of fatigue, cognition, or general health status were probably not included, the QoL levels reported in this paper may overestimate the true QoL levels among a more global population of patients with a newly diagnosed HGG. In consideration of this limitation, we compared some of the characteristics of the included individuals and the non-included patients and found that they were not different in terms of sex, age, or tumor grade.

Because we hypothesized that cognitive deficits might influence coping strategies implemented by the patients themselves and/or their relatives, excluding patients with severe cognitive dysfunction deprived us of a relevant issue that should be examined in future research. A qualitative approach based on face to face interviews may be more appropriate than standardized questionnaires to obtain pertinent and valid information.

As an illness such as cancer can be considered as a "dyadic stressor" [39], this study used specific dyadic analyses based on APIM that was specifically developed to study the dyadic relationships that integrate a conceptual view of interdependence in two-person relationships [42, 43]. People involved in this type of dyadic relationship strongly influence each other's cognitions, emotions, and behaviors; patients' and caregivers' QoL are thus correlated and interdependent However, the APIM approach preferentially requires a large sample size and assesses effects within longitudinal designs.

Another limitation of this study was the observational, cross-sectional nature of the design, which does not allow for causality inferences to be made between coping strategies and QoL. Thus, it remains unknown whether an individual's coping strategies actually influence QoL and that

of his/her relatives over time. The small sample size and exploratory nature of our analysis do not allow for a deeper investigation of several associations with QoL or coping, especially investigations regarding sociodemographics, performance status, and the nature of the dyadic relationship. We will perform future researches from the cohort to consider the longitudinal design and higher sample size.

Conclusion

This study emphasizes that the quality of life for patients and their natural caregivers is directly related to the coping strategies that they use. This finding suggests that targeted interventions should be offered to help patients and their relatives who experience emotional difficulties to implement more efficient coping strategies.

Compliance with ethical standards

Ethics Regulatory monitoring has been performed in accordance with the French law that requires the approval of the French ethics committee (Comité de Protection des Personnes Sud Méditerranée II, 6/6/2014, reference number 2014-A00585-42).

Conflict of interest No author of this report had any conflicting or competing interest.

References

1. Davis ME, Stoiber AM (2011) Glioblastoma multiforme: enhancing survival and quality of life. Clin J Oncol Nurs 15:291–297. doi:10.1188/11.CJON.291-297
2. Sherwood P, Given B, Given C, Schiffman R, Murman D, Lovely M (2004) Caregivers of persons with a brain tumor: a conceptual model. Nurs Inq 11:43–53
3. Schmer C, Ward-Smith P, Latham S, Salacz M (2008) When a family member has a malignant brain tumor: the caregiver perspective. J Neurosci Nurs 40:78–84
4. Catt S, Chalmers A, Fallowfield L (2008) Psychosocial and supportive-care needs in high-grade glioma. Lancet Oncol 9:884–891. doi:10.1016/S1470-2045(08)70230-4
5. Soothill K, Morris SM, Harman JC, Francis B, Thomas C, McIlmurray MB (2001) Informal carers of cancer patients: what are

their unmet psychosocial needs?. Health Social Care Community 9: 464–475

6. Cavers D, Hacking B, Erridge SC, Morris PG, Kendall M, Murray SA (2013) Adjustment and support needs of glioma patients and their relatives: serial interviews. Psychooncology 22:1299–1305. doi:10.1002/pon.3136

7. Veilleux N, Goffaux P, Boudrias M, Mathieu D, Daigle K, Fortin D (2010) Quality of life in neurooncology—age matters. J Neurosurg 113:325–332. doi:10.3171/2010.2.JNS091707

8. Piil K, Jakobsen J, Christensen KB, Juhler M, Jarden M (2015) Health-related quality of life in patients with high-grade gliomas: a quantitative longitudinal study. J Neurooncol 124:185–195. doi:10.1007/s11060-015-1821-2

9. Dirven L, Aaronson NK, Heimans JJ, Taphoorn MJ (2014) Health-related quality of life in high-grade glioma patients. Chin J Cancer 33:40–45. doi:10.5732/cjc.013.10214

10. Brown PD, Decker PA, Rummans TA et al (2008) A prospective study of quality of life in adults with newly diagnosed high-grade gliomas: comparison of patient and caregiver ratings of quality of life. Am J Clin Oncol 31:163–168

11. Minaya Flores P, Berbis J, Chinot O, Auquier P (2014) Assessing the quality of life among caregivers of patients with gliomas. Neuro-oncol Pract 1:191–197. doi:10.1093/nop/npu027

12. Munoz C, Juarez G, Munoz ML, Portnow J, Fineman I, Badie B, Mamelak A, Ferrell B (2008) The quality of life of patients with malignant gliomas and their caregivers. Soc Work Health Care 47:455–478. doi:10.1080/00981380802232396

13. Janda M, Steginga S, Langbecker D, Dunn J, Walker D, Eakin E (2007) Quality of life among patients with a brain tumor and their carers. J Psychosom Res 63:617–623. doi:10.1016/j.jpsychores.2007.06.018

14. Folkman S, Moskowitz JT (2000) Positive affect and the other side of coping. Am Psychol 55:647–654

15. Lazarus M, Folkman S (1984) Stress, appraisal and coping. Springer, New York

16. Folkman S, Lazarus RS, Gruen RJ, DeLongis A (1986) Appraisal, coping, health status, and psychological symptoms. J Pers Soc Psychol 50:571–579

17. Holahan CJ, Moos RH (1987) Personal and contextual determinants of coping strategies. J Pers Soc Psychol 52:946–955

18. Lang DA, Neil-Dwyer G, Garfield J (1999) Outcome after complex neurosurgery: the caregiver's burden is forgotten. J Neurosurg 91:359–363. doi:10.3171/jns.1999.91.3.0359

19. Schubart JR, Kinzie MB, Farace E (2008) Caring for the brain tumor patient: family caregiver burden and unmet needs. Neuro Oncol 10:61–72. doi:10.1215/15228517-2007-040

20. Baider L, Kaplan De-Nour A (1997) Psychological distress and intrusive thoughts in cancer patients. J Nerv Ment Dis 185:346–348

21. Cook WL, Kenny DA (2005) The actor-partner interdependence model: a model of bidirectional effects in developmental studies. Int J Behav Dev 29:101–109

22. Crum RM, Anthony JC, Bassett SS, Folstein MF (1993) Population-based norms for the mini-mental state examination by age and educational level. JAMA 269:2386–2391

23. Botella M, Zenasni F, Pocard M, Gledill J, Rodary C (2007) French adaptation of the patient generated index: metric characteristics and practical limitations. Psycho-Oncologie 2:131–140

24. Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, Filiberti A, Flechtner H, Fleishman SB, de Haes JC et al (1993) The European organization for research and treatment of cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. J Natl Cancer Inst 85:365–376

25. Minaya P, Baumstarck K, Berbis J, Goncalves A, Barlesi F, Michel G, Salas S, Chinot O, Grob JJ, Seitz JF, Bladou F, Clement A, Mancini J, Simeoni MC, Auquier P (2012) The CareGiver

Oncology Quality of Life questionnaire (CarGOQoL): development and validation of an instrument to measure the quality of life of the caregivers of patients with cancer. Eur J Cancer 48:904–911. doi:10.1016/j.ejca.2011.09.010

26. Carver CS (1997) You want to measure coping but your protocol's too long: consider the brief COPE. Int J Behav Med 4:92–100. doi:10.1207/s15327558ijbm0401_6

27. Muller L, Spitz E (2003) Multidimensional assessment of coping: validation of the Brief COPE among French population. Encephale 29:507–518

28. Boele FW, Heimans JJ, Aaronson NK, Taphoorn MJ, Postma TJ, Reijneveld JC, Klein M (2013) Health-related quality of life of significant others of patients with malignant CNS versus non-CNS tumors: a comparative study. J Neurooncol 115:87–94. doi:10.1007/s11060-013-1198-z

29. Macartney G, Stacey D, Harrison MB, VanDenKerkhof E (2014) Symptoms, coping, and quality of life in pediatric brain tumor survivors: a qualitative study. Oncol Nurs Forum 41:390–398. doi:10.1188/14.ONF.390-398

30. Edvardsson T, Ahlstrom G (2005) Illness-related problems and coping among persons with low-grade glioma. Psychooncology 14:728–737. doi:10.1002/pon.898

31. Sterckx W, Coolbrandt A, Dierckx de Casterle B, Van den Heede K, Decruyenaere M, Borgenon S, Mees A, Clement P (2013) The impact of a high-grade glioma on everyday life: a systematic review from the patient's and caregiver's perspective. Eur J Oncol Nurs 17:107–117. doi:10.1016/j.ejon.2012.04.006

32. Molassiotis A, Wilson B, Brunton L, Chaudhary H, Gattamaneni R, McBain C (2010) Symptom experience in patients with primary brain tumours: a longitudinal exploratory study. Eur J Oncol Nurs 14:410–416. doi:10.1016/j.ejon.2010.03.001

33. Randall AK, Bodenmann G (2009) The role of stress on close relationships and marital satisfaction. Clin Psychol Rev 29:105–115. doi:10.1016/j.cpr.2008.10.004

34. Vanderwerker LC, Laff RE, Kadan-Lottick NS, McColl S, Prigerson HG (2005) Psychiatric disorders and mental health service use among caregivers of advanced cancer patients. J Clin Oncol 23:6899–6907. doi:10.1200/JCO.2005.01.370

35. Tiemensma J, Kaptein AA, Pereira AM, Smit JW, Romijn JA, Biermasz NR (2011) Coping strategies in patients after treatment for functioning or nonfunctioning pituitary adenomas. J Clin Endocrinol Metab 96:964–971. doi:10.1210/jc.2010-2490

36. Locke DE, Cerhan JH, Wu W, Malec JF, Clark MM, Rummans TA, Brown PD (2008) Cognitive rehabilitation and problem-solving to improve quality of life of patients with primary brain tumors: a pilot study. J Support Oncol 6:383–391

37. Boele FW, Hoeben W, Hilverda K, Lenting J, Calis AL, Sizoo EM, Collette EH, Heimans JJ, Taphoorn MJ, Reijneveld JC, Klein M (2013) Enhancing quality of life and mastery of informal caregivers of high-grade glioma patients: a randomized controlled trial. J Neurooncol 111:303–311. doi:10.1007/s11060-012-1012-3

38. Lucchiari C, Botturi A, Pravettoni G (2010) The impact of decision models on self-perceived quality of life: a study on brain cancer patients. Ecancermedicalscience 4:187. doi:10.3332/ecancer.2010.187

39. Badr H, Carmack CL, Kashy DA, Cristofanilli M, Revenson TA (2010) Dyadic coping in metastatic breast cancer. Health Psychol 29:169–180. doi:10.1037/a0018165

40. Waldron D, O'Boyle CA, Kearney M, Moriarty M, Carney D (1999) Quality-of-life measurement in advanced cancer: assessing the individual. J Clin Oncol 17:3603–3611

41. Wettergren L, Kettis-Lindblad A, Sprangers M, Ring L (2009) The use, feasibility and psychometric properties of an individualised quality-of-life instrument: a systematic review of the SEIQoL-DW. Qual Life Res 18:737–746. doi:10.1007/s11136-009-9490-2

42. Kashy DA, Kenny DA (1999) The analysis of data from dyads and groups. Handbook of research methods in social psychology. Cambridge University Press, New York

43. Campbell LJ, Kashy DA (2002) Estimating actor, partner, and interaction effects for dyadic data using PROC MIXED and HLM5: a brief guided tour. Pers Relatsh 9:327–342