



Emotional concerns and coping strategies in Low Grade Glioma patients and reliability of their caregivers in reporting these concerns: Findings from a cross-sectional study



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ABSTRACT

Purpose: To explore the emotional concerns and coping strategies of patients with Low Grade Glioma (LGG) and whether or not their caregivers are reliable in reporting these concerns as surrogate informants.

Methods: An explorative cross-sectional study. Patients who had undergone a neurosurgical procedure at least one year before this study for LGG and who were capable of participating in a face-to-face interview were included. Each patient nominated a reference caregiver. Both the patient and the caregiver were interviewed independently, using the Beck Depression Inventory Scale, the State – Trait Anxiety Inventory, and the Jalowiec Coping Scale.

Main results: Forty-six patients and 46 caregivers were included. The average scores of the Beck scale were homogeneous between patients and caregivers (7.76 [CI 95% 5.76–9.75] vs. 6.23 [CI 95% 4.57–7.90]; $p = 0.102$). Patients reported significantly greater state and trait anxiety (44.26 [CI 95% 40.21–48.31] and 37.95 [CI 95% 34.97–40.94]), respectively compared to their caregivers (40.28 [CI 95% 36.64–43.91] and 35.17 [CI 95% 32.16–38.18]). The coping strategies enacted were homogeneous between patients and caregivers (82.78 [CI 95% 77.21–88.35] vs (80.93 [CI 95% 76.32–85.55]; $p = 0.102$) while the kind of strategies adopted were significantly diverse.

Conclusions: Patients suffer from depression and greater state anxiety as compared to trait anxiety; moreover, they enact less than half of the available coping strategies. Caregivers may be involved as surrogate informants when necessary for health-care professionals to detect depression while more caution is advised for what concerns anxiety and the coping strategies enacted by patients.

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1. Introduction

Brain cancer is a rare neoplasm with a documented prevalence from 4.5 to 11.2/100,000 among men and 1.6–8.5/100,000 among women (Crocetti et al., 2012). Specifically, low grade glioma (LGG) is diagnosed among 10%–20% of patients with a primary brain neoplasm (Kumthekar et al., 2015) and occurs mostly in the 4th decade of life (Sanai et al., 2011). The median survival length has been reported as being from 4.7 to 10 years (Kumthekar et al., 2015); after five years from diagnosis, between 60% and 70% of

patients are still alive (Prabhu et al., 2014).

From the clinical point of view, LGG presents some peculiarities that make patients affected unique: the low growing neoplasm often infiltrates areas responsible for higher cognitive functions (e.g. motor, language) and this may affect emotional states; moreover, in order to protect the aforementioned areas, awake craniotomy is often performed (Khan et al., 2016). Survival rates are associated with the extent of the resection and, in order to achieve maximal effectiveness, the surgery itself may impair some functions (Skrap et al., 2012).

Factors influencing prognosis also include the patient's age, tumour location, size, histology (Crocetti et al., 2012), Karnofsky score (Sanai et al., 2011) and existing neurologic deficits prior to surgery (Kumthekar et al., 2015). With improvements in surgical

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techniques, the neoplasm-free period has increased over the years; however, after surgical procedure, patients' (Giovagnoli et al., 2014; Schiavolin et al., 2014) and caregivers' quality of life may negatively change (Walbert and Chasteen, 2015). Furthermore, when the patient clinical condition worsens and communication issues arise (Piil et al., 2015), it may become difficult for health-care professionals to understand patients' concerns and caregivers are always considered as privileged informants specifically regarding those emotional needs and coping strategies that may increase patient comfort which has been widely documented in patients suffering from different cancer (e.g., Hermont et al., 2015). However, no studies to date have evaluated the caregivers' reliability in reporting emotional concerns and coping strategies adopted by LLG patients.

Available studies in the field of brain neoplasm have investigated separately the emotional state of caregivers (e.g. Petruzzi et al., 2013; Pawl et al., 2013) and patients (e.g. Palma et al., 2015; Petruzzi et al., 2015). Among caregivers, both positive (increased sense of self-accomplishment) and negative outcomes (depression, anxiety, sleep disturbance, decrease of quality of life, physical illness) have been reported (Pawl et al., 2013; Petruzzi et al., 2013). Among patients, depression, anxiety, mood disorders, memory and attention impairments have been the most common symptoms documented (D'Angelo et al., 2008; Mainio et al., 2003; Molassiotis et al., 2010; Palma et al., 2015; Petruzzi et al., 2015).

However, only a few authors have explored depression in LLG patients documenting its association with female gender (Arnold et al., 2008), post-surgical period (D'Angelo et al., 2008), and its strong impact on 5-year survival (Mainio et al., 2005). Also, the role played by anxiety has not been extensively documented in LLG patients, except for it being associated with female gender (Arnold et al., 2008) and more frequent in right-sided neoplasms (Mainio et al., 2003). Specifically, Mainio et al. (2003) have reported a decline in anxiety over time in the post-operative period while D'Angelo et al. (2008) did not report changes in state and trait anxiety between the pre- and post-surgical periods.

The above-mentioned emotional concerns may activate different coping strategies (Keeling et al., 2013). Coping is a multifaceted phenomenon of how humans think, feel, and act in a specific stressful situation, and its aim is to reduce the level of perceived stress (Lazarus and Folkman, 1984). Edvardsson and Ahlström, 2005 interviewed 39 patients with LGG reporting that these patients adopted different coping strategies such as "refraining from and avoiding", "laughing and joking", "caring about self" and "seeking social affinity". The same research group (Gustafsson et al., 2006) found that emotion-focused coping dominated among LGG patients, and a significant relationship emerged between coping by escape-avoidance and a lower level of emotional functioning. <https://www.ncbi.nlm.nih.gov/pubmed/16710652> - comments However, to date, only the above-mentioned studies have examined the post-operative coping strategies used by patients with LGG.

Therefore, the aim of this study is to advance knowledge in the field of depression, anxiety and coping strategies enacted by LGG patients by measuring their prevalence in their post-surgical period and to explore whether or not their caregivers can reliably report these concerns as surrogate informants.

2. Methods

2.1. Study design and setting

An explorative cross-sectional study design was performed from 2013 to 2014 at the Neurosurgical Department, Teaching Hospital of Udine, Italy.

2.2. Patients and caregivers

Eligible patients were those who a) had undergone a neuro-surgical procedure for LGG at least one year before; b) understood Italian and could participate in a face-to-face interview; c) attended for regular follow-ups accompanied by a reference caregiver; and d) were willing to participate in the study. Each patient nominated a caregiver as a reference person who provided care at home for physical, emotional and social needs. Nominated caregivers who were capable of responding to a face-to-face interview in Italian Language and who were willing to participate in the study, were included.

Patients who reported changes from LGG to High Grade Glioma (HGG) at follow-up or those living at a distance that made them eligible for follow-up in other health centers were excluded. No exclusion criteria were set for the nominated caregivers.

Recruitment was performed by informing each couple (patient and his/her caregiver) arriving at the hospital for a routine follow-up with regards to the aims of the study; those willing to participate signed a written informed consent form. A total of 64 dyads were eligible in the period considered for the study: 46 agreed to participate; three refused to participate and 18 were followed-up elsewhere and therefore were not contacted.

2.3. Variables and data collection procedures

Four main set of variables were collected from the patient:

- Socio-demographic data: gender, age, level of education, brain neoplasm localisation (side and lobe), time elapsed from the diagnosis to the interview (in months); functional dependence after the surgical procedure; working conditions; degree of kinship with the reference caregiver (e.g. husband) and the intensity of relationships as the degree of closeness (from 0 minimal, to 10 greatest) with the caregiver before and after the surgical procedure.
- Depression: the Beck Depression Inventory Scale (Beck et al., 1996) was used; it is composed of 21 items with a total score from 0 to 63 (0 = any symptom; 63 = severe depression). Its psychometric properties were established also for the Italian version (Ghisi et al., 2006).
- Anxiety: the State – Trait Anxiety Inventory (STAI, Spielberger et al., 1983) was used; it is composed of 20 items measuring the level of state anxiety (*temporary discomfort* derived from situations perceived as dangerous) and 20 items measuring trait anxiety (*an enduring disposition* to stress/worry) using a 4 point scale. For both subscales, each item was scored from 1 to 4, thus resulting in total scores from 20 (any state or trait anxiety symptom) to 80 (severe state or trait anxiety). The tool validity and reliability of the Italian version was ascertained on a preliminary fashion (Pedrabissi and Santinello, 1989).
- Coping: the Jalowiec Coping Scale (JCS) (Jalowiec, 2003) was applied; it is composed of 60 items expressing coping behaviors used in the last two weeks, ranked from 0 (never used) to 3 (often used) and a total score from 0 (no coping strategies used) to 180 (all coping strategies used). The tool investigates eight coping styles: confrontive (=10 items) such as constructive problem-solving; evasion (=13) including avoidant activities; optimism (=9) based upon positive thinking; fatalism (=4) based upon pessimism and negative thinking; emotional (=5), such as expressing/releasing emotions; palliative (=7) trying to reduce or control distress by making the individual feel better; supportive (=5) using personal, professional and spiritual support systems; and self-reliant coping (=7) depending on yourself to deal with the situation, rather than on others. The

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