

Patient and caregiver perceptions of communication of prognosis in high grade glioma

E. A. Lobb · G. K. B. Halkett · A. K. Nowak

Received: 19 July 2010 / Accepted: 3 December 2010
© Springer Science+Business Media, LLC. 2010

Abstract This study sought the views of patients and their caregivers on their experience of being diagnosed with high grade glioma. Purposive sampling was used to recruit 19 patients and 21 caregivers from the medical oncology unit of a tertiary hospital. A semi-structured face-to-face interview was conducted. Interviews were audiotaped and transcribed verbatim. Data was analysed based on Grounded Theory and using the constant comparison method. This paper focuses on patient and carer perceptions of the initial communication about the diagnosis of high grade glioma and its prognosis. Themes identified included: (a) shock at hearing the diagnosis; (b) trying to

understand and process prognostic information when still in shock; (c) the perception of hope being taken away; (d) individualizing prognostic information; and (e) clinicians' lack of communication skills. This study shows that the first communication of prognosis to patients with high grade glioma and their caregivers requires careful negotiation. It illustrates the inability of individuals to process detailed prognostic information when in a state of initial shock and distress. The importance of balancing honesty with hope in the communication of a poor prognosis is highlighted. We recommend that clinicians seek patient preferences for the amount and type of information they require and that prognostic information be individualized. Detailed discussions of prognosis should only take place with senior medical staff, or advanced trainees who have demonstrated acceptable communication skills.

E. A. Lobb (✉)
Cunningham Centre for Palliative Care, Calvary Health Care
Sydney, Kogarah, NSW 2217, Australia
e-mail: Liz.Lobb@sesiahs.health.nsw.gov.au

E. A. Lobb
School of Medicine, Notre Dame University, Sydney,
NSW, Australia

E. A. Lobb
School of Nursing, Midwifery, and Postgraduate Medicine,
Edith Cowan University, Joondalup, WA, Australia

G. K. B. Halkett
WA Centre for Cancer & Palliative Care, Curtin Health
Innovation Research Institute, Curtin University, Bentley,
WA, Australia

A. K. Nowak
School of Medicine and Pharmacology, University of Western
Australia, Nedlands, WA, Australia

A. K. Nowak
Department of Medical Oncology, Sir Charles Gairdner
Hospital, Nedlands, WA, Australia

Keywords Communication of prognosis ·
High grade glioma · Patient and caregivers ·
Perceptions and preferences

Introduction

Malignant high grade gliomas (HGG) are a common primary brain tumor and represent approximately 80% of all primary brain tumors in adults [1]. Using the World Health Organisation Classifications, the term HGG includes Grade III or Grade IV astrocytic or oligodendroglial tumors [2]. Most patients diagnosed with HGG die from their disease, even if they have received the full range of treatment available including surgery, chemotherapy and radiotherapy [3]. The median survival for patients with these extremely aggressive tumors ranges from less than 1 to 3 years from diagnosis [4].

Previous studies on patient preferences for the communication of prognosis in metastatic disease have been conducted in breast cancer and bowel cancer [5, 6]. Thus, they may not reflect the particular preferences of patients with HGG and their caregivers, a disease where the prognosis is poor at diagnosis. Additionally, a recent review of the literature in high grade glioma found no direct evidence about what patients and relatives wanted to know about the diagnosis or prognosis; however, the qualitative studies reviewed suggest that an individual approach to disclosure and maintaining hope are important [7].

In a recent study which aimed to understand patient experiences of HGG and to describe their information and support needs, we identified communication with health professionals around prognostic uncertainty and disease progression and feelings of uncertainty around prognosis and quality of life as major themes [8]. In this paper we now report on the perceptions of patients with high grade glioma and their caregivers of how they were first told the diagnosis and prognosis. The findings have informed a larger current study on unmet information and support needs of patients with high grade glioma and their caregivers.

Materials and methods

Purposive sampling was used to recruit participants from a tertiary referral centre for neurological cancers. Eligible patients were: within one year of diagnosis of Grade III–IV HGG, 18 years of age or older, able to participate in study interviews, and conversant in English. Patients were excluded if they had a non-primary brain tumor, or severe cognitive impairment. Family caregivers were eligible if they were the person named by an eligible patient as the individual most involved in his/her care, and provided written informed consent.

The study employed an emergent qualitative design, using theoretical and procedural direction from grounded theory research [9, 10]. Semi-structured interviews were used to elicit information about patient and caregivers' experiences of being told the diagnosis and subsequent prognosis. Interviews were tape recorded and transcribed verbatim.

The interview

One semi-structured interview was conducted with each participant to gain an understanding of their experiences. The full interview guide is provided in Table 1. Questions relating to the communication of prognosis were as follows: (a) What information about prognosis has been provided? Was this information helpful? Why/why not?; (b) Do you feel that you were told the right amount of

information about prognosis?; (c) Did you feel the timing of this information was appropriate?; (d) How much of this information do/did you understand?

Data analysis

Data analysis was iterative and commenced after the first interview and was ongoing throughout the study with all investigators participating in this process, using the selected interview transcripts and additional excerpts to identify and agree upon emergent themes. The analysis took place concurrently with data collection and was used to suggest additional questions/prompts in subsequent interviews to ensure divergent points of view would be expressed.

Data analysis was conducted using grounded theory and the constant comparative method [10]. Transcripts were uploaded into the software program QSR NVivo, Version 7 (2006). Open, axial and selective coding was used to analyze the data [10]. Open coding involved repeated reading of the sections of the interviews relating to the patient's needs and a line-by-line analysis of this data. Axial coding was used to link data and determine the mechanisms that existed. Selective coding was then used to link data together and develop the themes.

Results

Nineteen patients and 21 caregivers were interviewed. Demographic details of the sample are reported in Tables 2 and 3. The following themes emerged: (a) shock at hearing the diagnosis; (b) trying to understand and process prognostic information when still in shock; (c) the perception of hope being taken away; (d) individualizing prognostic information; and (e) clinicians' lack of communication skills.

(a) Shock at hearing the diagnosis

All of the patients ($n = 19$) and caregivers ($n = 21$) interviewed recounted their feelings of shock and disbelief when they were given the diagnosis of HGG. The exemplar below demonstrates how patients' felt.

And I don't think when you're in this state of shock, which unless anyone's been faced with this disastrous disease, can understand the shock that hits you. It is just like you've put your finger in a light socket and somebody wants you to sit an exam all at once and you can't do that. The brain won't let you do that, your heart, your brain everything is, you know gone... You just can't compute those things at that time that all takes time. Patient 09

Table 1 Interview guide for patient and carer interviews

Introduction

- How did you feel when you were diagnosed?
- Do you feel that your role in the family has been affected by the diagnosis of brain cancer? If so, how?
- Do you perceive yourself and your life differently since your diagnosis?

The experience of making decisions

- What treatment have you received so far?
- Have you felt involved in making decisions about your treatment? How much have you been involved?
- How have you been involved in making decisions?
- How satisfied are you with your level of involvement in making decisions? Why?
- Are you concerned about anything? If so what is/are your major concerns?

Information needs

- Overall, what sort of information have you found most useful? Why was this?
- Can you identify what information has helped you to reduce your fears and/or concerns during consultations?
- What sort of information was most useful initially?
- So far, who has provided you with information?

Information on diagnosis

- What information have you been provided with about brain cancer?
- How prepared do you feel for what is likely to happen in the future? What information has helped you to feel prepared?

Information on treatment

- What information has been provided about treatment so far? Prompts—Was this information helpful?
- How do you feel about receiving treatment? Do you feel well informed at the moment? Are you concerned about anything?

Information on prognosis

- What information about prognosis has been provided? Was this information helpful? Why/why not?
- Do you feel that you were told the right amount of information about prognosis? Too much? Too little?
- Did you feel the timing of this information was appropriate?
- How much of this information do/did you understand?

Information in general

- What other information needs do you have? Is there anything you feel you don't understand?
- Have you read the written information that the doctors have given you? Has this been useful? In what way?
- Have you looked for/found additional information? What about? Where? When? Why?
- Which information sources have you found most useful/beneficial?—written, verbal, on line, videos. Why?
- Would you have preferred information to have been provided to you in a different way or using a different type of media?
- When was information provided to you? Did you feel the timing was appropriate? Would you have preferred to receive information earlier/later?
- Have you had to ask for any information at a particular time? What sort?

Emotional and practical support needs

- Can you identify who has provided you with support since your diagnosis?
- What sort of support have they provided you with? How has this been helpful?
- What (if any) practical supports do you currently need in your home?
- What sorts of activities have you required support for recently?
- Can you identify any additional practical supports you may need in the future? (prompts-mobility aids, hygiene assistance, bathroom/house access, increasing levels of supervision, etc.)
- Can you identify who will provide these supports?
- So far, have you accessed support from sources outside of the hospital? If so, what? Did you find these sources helpful? Why/Why not?
- What has been the impact of being unable to drive on your life? What transport supports do you need?

Table 2 Patient demographics

	Frequency
Diagnosis	
Glioblastoma multiforme Grade IV	16
Astrocytoma Grade IV	1
Anaplastic gemistocytic astrocytoma Grade III	2
Gender	
Male	12
Female	7
Marital Status	
Married	18
Divorced	1
Country of birth	
Australia	15
United Kingdom	1
New Zealand	1
South Africa	1
Italy	1
First language	
English	18
Italian	1
Highest level of education	
Primary school	5
High school	6
Vocational training	4
Undergraduate	2
Postgraduate	2
Employment status in month before diagnosis	
Full time	12
Part time	3
Retired	3
Medical discharge	1
Current employment status	
Full time	1
Casual	1
Self employed	2
Unemployed	2
Retired	4
Sick leave	2
Leave without pay	4
Disability pension	3

(b) Trying to understand and process information on prognosis when in shock

The timing of the discussion of prognosis was identified as a concern by participants. They reported that shortly after surgery they were given the diagnosis and brief and general prognostic information at the same time. The majority of participants interviewed spoke of the difficulty in trying to

Table 3 Demographic characteristics of carers ($n = 21$)

	N (%)
Gender	
Male	4 (19)
Female	17 (81)
Age range (years)	
30–39	2 (9.5)
40–49	2 (9.5)
50–59	10 (47.6)
60–69	6 (28.6)
70+	1 (4.8)
Relationship to patient	
Spouse/partner	20 (95.2)
Parent	1 (4.8)
Employment status	
Full-time employment	4 (19)
Part-time employment	3 (14.3)
Not employed	11 (52.4)
Employed with changed conditions relating to caregiver responsibilities	3 (14.3)
Caring status	
Also caring for dependant children	6 (28.6)
Not caring for anyone else	13 (61.9)
Information not available	2 (9.5)
Geographical location	
Rural Western Australia	5 (23.8)
Metropolitan area (Perth)	16 (76.2)

take in and make sense of prognostic information when they were still in shock from receiving the diagnosis. This caregiver was able to recall this moment in time as this exemplar illustrates:

Ok, initially when you hear the news it's a terrible shock and you start to feel like you're staring in somebody else's movie, or it's, you get a feeling of unreality, of this is not happening to you, you're like looking it, like you're looking at it from a, it's like looking at a movie and you start operating in neutral. Carer 10

While patients and caregivers had an expectation to receive information on the outcome of surgery this carer spoke about the shock of being given the prognostic information over the telephone while her husband was still in the Intensive Care Unit.

So you can imagine, I've got 3 little kids .. we're not from the city, we're from the country. Four days into this, this doctor rings me on the mobile, and they'd already told us that we were going to get the results a few days later so, for[doctor] to ring me while (husband) was still in recovery and say... "it's a high

grade cancerous tumour” and when I said “what does that mean?” [doctor] said “he probably has between four and nine months to live”. I just, I literally, I was outside recovery..... I just slid down the wall in that hospital. Carer 16

Some patients could not recall the details on their diagnosis or prognosis, believed they had not been given complete information or choose not to seek further information as this exemplar illustrates:

The information I’ve got is basically what they’ve told me, that it’s the most aggressive one around, and what more information do I need? I’m not a doctor. Patient 04

(c) Taking away hope

Around half of the participants reported feeling that their hope was being taken away when they were told the prognosis, as this exemplar illustrates:

One day we did have a family meeting with some doctor...she overlooked us with her glasses like, looked like this and just said there’s no hope, no hope.... Just gave you no confidence, gave you no encouragement. More or less he’s going to go home and die, get over it and you know. Carer 018

In particular, they needed to be reassured that they would not be abandoned and that everything that was possible would be done for the patient as this caregiver was able to articulate:

So [doctor] called me away from the bed and said to me “Do you realise this is hopeless” and I said to [doctor] “But you’re still going to do whatever you’ve got at your disposal, I’m not giving it up right now.” Carer 010

(d) Individualizing prognostic information

In hearing the diagnosis of this aggressive tumour and the poor prognosis, patients and their caregivers often tempered this distressing information with the belief that people were individuals and that general statistics did not apply to them.

Like one of my friends said that the population of statistics do not apply to a personal individual, which is true, it’s just like I’m unique and I’m different to everybody else. (Patient 07)

Caregivers in particular, did not believe doctors could predict how long an individual might survive and preferred to remain positive, as this exemplar illustrates:

Because with him being diagnosed with that, and like it was hard because he’s only been given this amount of time, you know to live and I was saying, well that’s the doctor’s say that, it doesn’t mean that it’s so. A lot of people have been diagnosed with you know cancers, saying well they’ve only been given this amount of time and then going for years and years. Carer 20

(e) Clinicians’ communication skills

Many of those interviewed commented on the communication skills of staff when first given the diagnosis and prognosis with only two out of 19 patients and 21 caregivers who were interviewed reporting a positive experience. These quotes illustrate that many wanted clinician communication to be more compassionate and empathic.

Well you know if we had to listen to exactly what they, how they said it {patient} wouldn’t be here now you know. It’s just the way it’s, to them you’re just a number that’s how I feel. You’re just another person coming in the system you know. Having more compassionate or saying look you know we’re sorry this is the outcome you know. Carer 18

In addition, this exemplar illustrates the importance patients and caregivers placed on receiving some positive messages when discussing the prognosis.

But {doctor} came back and she sat down and she said (patient) she said I want you to, believe you’ve got at least six months, hone in on that six months, she said you haven’t got two months you’ve got six months left. Patient 15.

Discussion

This study interviewed patients with high grade glioma and their caregiver on their experiences of receiving the diagnosis and prognosis. Our findings have highlighted the importance of timing in communicating diagnosis and prognosis in this setting. Treatment for HGG is often initiated rapidly, leaving little time for patients and relatives to adjust to the diagnosis and to consider treatment options [11, 12]. Thus, many of the patients and caregivers in our study were given prognostic information while they were still in the Intensive Care Unit or in the Recovery Ward.

We have previously reported a strong desire in this patient group for information regarding their diagnosis, and concern over the inevitable waiting period for histological confirmation of a diagnosis [8, 13]. It is likely that, pre-operatively, clinicians reassured patients and families that they would give immediate information on surgical

outcomes. The inability of individual patients and/or caregivers to absorb information under conditions of high stress and emotions have been reported elsewhere [14]. Our findings that caregivers were more vocal, or had better recall of how prognosis was communicated are similar to findings in studies of patients with HGG which reported that just over half the patients were aware of their diagnosis and prognosis [15, 16]. It has been suggested that the patient's impaired cognitive abilities may contribute to this lack of awareness [7, 15]. Whilst patients with a terminal illness frequently have misunderstandings about their illness, prognosis and goals of treatment [17] the patients in our study were earlier on in their disease trajectory, thus their report of "*being in shock*" may have contributed to their inability to process prognostic information. This poses a challenge for clinicians, as a previous study with patients requiring craniotomy for benign brain lesions has shown that patients had specific information needs as well as expectations of direct reassurance from the surgeon in the immediate post-surgery period [18].

However, our data suggest that clinicians should avoid detailed discussion of diagnosis and prognosis in these high stress settings. A proposed alternative information-giving strategy is to focus on the safety outcomes of the operation, whilst making a commitment to full discussion of results and prognosis when histological confirmation is available.

Guidelines for the Communication of Bad News recommend that language such as "months" to "years" be used rather than a specific timeframe [19]. In our study patients and caregivers reported being given a specific time frame e.g. "two months" or "six months" and this was perceived as hope reducing. Our findings are consistent with other studies that report patients with advanced cancer seeing statistics as potentially hope destroying [5, 6]. In studies specific to the glioma setting, caregivers equated hope with less information, with some patients deliberately avoiding inquiring about progress or symptoms in order to maintain hope for the future [7]. A requirement for information about prognosis to be tailored to the individuals' coping abilities has emerged [20, 21] as has the importance of maintaining hope, despite a poor prognosis [22, 23]. It has been recommended that the key to discussing prognosis may be to offer information to patients, ascertain how much information they want, respect that preference and re-negotiate this at multiple time-points, rather than considering this as a one-off communication episode [23].

The communication of distressing news is demanding for clinicians, patients and caregivers [24, 25]. In one study caregivers of palliative care patients reported that they experienced erosion of hope when they had difficulty communicating with health professionals, felt depersonalised or received too many negative messages [26]. The quoted use of language by some clinicians such as

"*hopeless*" and being given short survival time-frames reinforced this perception. Caregivers in the current study perceived the messages they were given were "*blunt*," "*brutal*" and "*uncaring*." Our study took place in a public teaching hospital, and was unable to distinguish whether clinicians giving prognostic information were junior medical staff, nursing staff, or consultant staff. At a junior level, clinicians are likely to vary in their communication skills training and ability, have a more limited understanding of the patient's prognosis themselves, as well as minimal experience with long-term survivors of HGG. This highlights the need for health professionals to role play communication of bad news in a setting where they can safely practice these skills [27].

Future directions

Although recently published Australian clinical practice guidelines advocate the implementation of generic cancer communication skills [28], future research may require the development of guidelines specific to high-grade glioma patients and their caregivers with particular emphasis on methods of information delivery suitable for people with cognitive deficits. In addressing a call for future research into developing communication-skills training to help staff deal with the difficult task of breaking bad news and talking about poor prognosis in HGG [29] a useful resource for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers has been produced [30].

Limitations

Participants were recruited from a single site; however, this site treats most neurological cancers in Western Australia. The use of purposive sampling to identify participants with differing clinical and social situations and at different points in the disease trajectory ensured a more complete understanding of patient and caregiver needs. We acknowledge that the experiences of patients and their caregivers were likely to over-emphasise poor communication skills, as when prognostic information was conveyed well, this topic did not become a focus of additional interview questions. We also acknowledge that the study interviews usually took place some months after the conversations reported, and patient perceptions may be influenced by recall bias, even if information was conveyed sensitively and appropriately at the time. Clinical encounters described took place with both nursing and medical staff, at junior and senior levels. To de-identify the data we have randomly used the terms "he", "she" and "doctor".

Conclusion

Communication about prognosis is important, and without such communication, patients, and their partners are unable to openly deal with the severity of the situation [11]. However, individuals have widely differing needs for communication and information [31]. Unlike patients, most caregivers look to the future and try to plan ahead, but may defer to the patient's information preferences and some consequently, wish for, or seek, separate meetings to resolve unanswered questions [29].

We recommend that detailed discussions of prognosis only take place with senior medical staff, or advanced trainees who have received communication training and demonstrated acceptable communication skills. Clinicians without detailed knowledge of a patient's individual disease characteristics or with limited experience in the field should avoid damaging discussions of median survival with patients or their caregivers. Whilst formal communication skills training is a compulsory part of advanced training in medical oncology, such workshops are not compulsory for neurosurgical trainees, although the Neurosurgery Statement of Competence recognises the value of effective communication. (http://www.nsa.org.au/training/docs/Curriculum_Competence.pdf) We recommend that all disciplines involved in the care of patients with HGG undertake formal communication skills training incorporating the principles of breaking bad news.

Acknowledgments This project was funded by an unrestricted educational grant from Schering Plough Pty. Ltd. We would like to thank Sky Dawson, Jenny Clarke, Celine Fournier and Sylvia Heavens for their assistance in data collection.

Conflict of interest None

References

- Klein M, Taphoorn MJ, Heimans JJ, van der Ploeg HM, Vandertop WP, Smit EF et al (2001) Neurobehavioral status and health-related quality of life in newly diagnosed high-grade glioma patients. *J Clin Oncol* 19(20):4037–4047
- Kleihues P, Cavenee W (2000) Editorial and Consensus Conference Working Group, Pathology and genetics of tumours of the nervous system. In: World Health Organization classification of tumours of the nervous system. IARC Press, Lyon
- Osoba D, Brada M, Prados M, Yung W (2000) Effect of disease burden on health-related quality of life in patients with malignant gliomas. *Neuro Oncol* 2:221–228
- Krex D, Klink B, Hartmann C, von Deimling A, Pietsch T, Simon M et al (2007) Long-term survival with glioblastoma multiforme. *Brain* 130:2596–2606
- Hagerty RG, Butow PN, Ellis PM, Lobb EA, Pendlebury SC, Leigh N et al (2005) Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. *J Clin Oncol* 23(6):1278–1288
- Butow PN, Dowsett S, Hagerty R, Tattersall MHN (2002) Communicating prognosis to patients with metastatic disease: what do they really want to know? *Support Care Cancer* 10(2): 161–168
- Davies E, Higginson IJ (2003) Communication, information and support for adults with malignant glioma: a systematic review. *Support Care Cancer* 11:21–29
- Halkett GKB, Lobb EA, Oldham L, Nowak AK (2010) The information and support needs of patients diagnosed with High Grade Glioma. *Patient Educ Couns* 79:112–119
- Glaser B, Strauss A (1967) The discovery of grounded theory. Weidenfeld & Nicholson, London
- Strauss A, Corbin JM (1991) Basics of qualitative research. Sage, London
- Salander P, Spetz A (2002) How do patients and spouses deal with the serious facts of malignant glioma? *Palliat Med* 16(4): 305–313
- Salander P, Bergenheim AT, Hamberg K, Henriksson R (1999) Pathways from symptoms to medical care: a descriptive study of symptom development and obstacles to early diagnosis in brain tumour patients. *Fam Pract* 16:143–148
- McConigley R, Halkett GKB, Lobb EA, Nowak A (2010) Caring for someone with high-grade glioma: a time of rapid change for caregivers. *Palliat Med* 24(5):473–479
- Dunn SM, Butow PN, Tattersall MHN, Jones QJ, Sheldon JS, Taylor JJ et al (1993) General information tapes inhibit recall of the cancer consultation. *J Clin Oncol* 11(11):2279–2285
- Davies E, Clark C, Hopkins A (1996) Malignant cerebral glioma, II: perspectives of patients and relatives on the value of radiotherapy. *BMJ* 313:1512–1516
- Salander P (1996) Brain tumour as a threat to life and personality: the spouse's perspective. *J Psychosoc Oncol* 14:1–18
- Gattellari M, Butow P, Tattersall MHN, Dunn SM, MacLeod CA (1999) Misunderstanding in cancer patients: why shoot the messenger? *Ann Oncol* 10(1):39–46
- Rozmovits L, Khu KJ, Osman S, Gentili FM, Guha A, Bernstein M (2010) Information gaps for patients requiring craniotomy for benign brain lesion: a qualitative study. *J Neurooncol* 96:241–247
- Girgis A, Sanson-Fisher RW (1995) Breaking bad news: consensus guidelines for medical practitioners. *J Clin Oncol* 13(9): 2449–2456
- Davies E (1997) Breaking bad news—the perceptions of health professionals. In: Davies E, Hopkins A (eds) *Improving care for patients with malignant cerebral glioma*. RCP Publications, London, pp 15–25
- Salander P, Bergenheim AT, Bergstrom P, Henriksson R (1998) How to tell cancer patients: a contribution to the theory of communicating the diagnosis. *J Psychosoc Oncol* 16:79–81
- Salander P, Bergenheim AT, Hendrikson R (1996) The creation of protection and hope in patients with malignant brain tumours. *Soc Sci Med* 42:985–996
- Clayton JM, Hancock K, Parker S, Butow PN, Walder S, Carrick S et al (2008) Sustaining hope when communicating with terminally ill patients and their families: a systematic review. *Psychooncology* 17:641–659
- Buckman R (1984) Breaking bad news. Why is it still so difficult? *BMJ* 288:1597–1599
- Ptacek HJT, Eberhardt TL (1996) Breaking bad news. A review of the literature. *JAMA* 276:496–502
- Holtstlander L, Duggleby W (2005) The experience of hope for informal caregivers of palliative patients. *J Palliat Care* 21(4): 285–291
- Butow PN, Cockburn J, Girgis A, Bowman D, Schofield P, D'Este C et al (2008) Increasing oncologists' skills in eliciting and responding to emotional cues: evaluation of a communication skills training program. *Psychooncology* 17:209–218

28. Australian Cancer Network Adult Brain Tumour Guidelines Working Party (2009) Clinical practice guidelines for the management of adult gliomas: astrocytomas and oligodendrogliomas. Cancer Council Australia, Australian Cancer Network and Clinical Oncological Society of Australia Inc, Sydney
29. Catt S, Chalmers A, Fallowfield L (2008) Psychosocial and supportive-care needs in high grade glioma. *Lancet* 9:884–891
30. Clayton JM, Hancock KM, Butow PN, Tattersall MHN, Currow DC (2007) Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their care-givers. *Med J Aust* 186(12):S77–S108
31. Janda M, Eakin EG, Bailey L, Walker D, Troy K (2006) Supportive care needs of people with brain tumours and their carers. *Support Care Cancer* 14:1094–1103