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Editor  
Patient Education and Counseling

15 July 2009

Dear Editor,

**Re: Resubmission of journal article to Patient Education and Counseling**

Thank you very much for this opportunity to revise our article entitled: “**The information and support needs of patients diagnosed with High Grade Glioma.**” We have made the three requested changes and highlighted these in bold.

Please let us know if there are any additional changes that we need to make.

Thank you again for supporting this paper.

Regards



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# **Resubmission to Patient Education and Counseling**

## **The information and support needs of patients diagnosed with High Grade Glioma**

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## **Information and support needs of patients with High Grade Gliomas**

### **Abstract**

**Objective:** To understand patients' experiences of High Grade Glioma and identify and describe information and support needs along the disease trajectory.

**Methods:** Semi-structured interviews were conducted with nineteen patients. Data was analysed using grounded theory and the constant comparative method.

**Results:** Four major themes were identified: 1) feelings of uncertainty around prognosis and quality of life; 2) the need for individualised information; 3) dependence on carers due to cognitive deficits, loss of balance and inability to drive; and 4) communication with health professionals around prognostic uncertainty and disease progression with communication barriers due to complex language deficits.

**Conclusion:** Previous studies in HGG pre-date the current combined modality standard of care, or examined a mixed population. This study has found that patients with HGG have needs that differ from other patients with terminal malignancy and that these needs change over time with disease progression.

**Practice Implications:** This study has identified that patients with brain tumours may have unique needs. Health professionals need to clarify patients' information and support needs and be aware that these change over and within time.

**Keywords:** High grade glioma, patient perspective, information and support needs, oncology.

## **1. Introduction**

Malignant High Grade Gliomas (HGG) represent approximately 80% of primary brain tumours in adults and are usually fatal, with median survival ranging from 1 to 3 years from diagnosis [1, 2]. Current treatments involve combinations of surgical resection, chemotherapy and radiation therapy, taking about eight months for the primary treatment course [3, 4]. Suitable patients may receive further surgery, stereotactic radiotherapy, or second-line chemotherapy before dying from their disease.

### **1.1 Specific needs of patients with High Grade Gliomas**

Unlike patients with other terminal cancer diagnoses patients with HGG are more likely to have physical or cognitive deficits from the time of diagnosis. For example, memory or speech loss, seizures, lack of balance and visual deficits can impact on their lives from early in the disease trajectory [5]. Loss of independence occurs not only because of physical or cognitive deficits, but because patients can no longer legally drive a motor vehicle, or because carers are reluctant to leave them alone for fear of seizures. Ongoing palliative treatment with corticosteroids can lead to weight gain, mood swings and personality changes. Furthermore, in HGG the prognosis is often uncertain, leading to difficulty in doctor-patient communication.

Common presenting features include cognitive decline, headaches, seizures, and motor deficits [5]. Similarly to other cancer patients, once diagnosed, individuals need to deal with many confronting emotions and make complex treatment decisions. However, more particular to the HGG patients is the need to adjust their lifestyles to accommodate the functional, emotional or cognitive decline that is a feature of this disease. Such decline is often associated with inability to work or participate in previously productive activities [2, 6]. Hence, this diagnosis tends to

have a profound impact on the individual's quality of life and as a result it is likely that these patients have psychosocial needs that differ to those of other cancer patients.

Previous qualitative studies have supported this contention; however, these reports either pre-date the current combined modality standard of care [3], or examined a mixed population of high and low grade glioma patients.

An Australian study examined 18 patient/carer dyads recruited through a brain tumour support service; however, only 11% of patients had HGG and the study pre-dated current standard therapy. The following themes emerged: "a need for information and strategies for coping with uncertainty, practical support, support to return to pre-treatment responsibilities or prepare for long-term care, support to deal with social isolation and organise respite care, support to overcome stigma/discrimination and support to discuss potentially reduced life expectancy"[7, p. 1]. Other studies have found that depression and anxiety are common and are associated with lack of motivation; bodily deterioration; finances; cognition; physical appearance; and marital difficulties [8]. A peri-operative study in Finland described 8 patients' experiences of having a brain tumour and their perceptions of the care that they received using peri-operative interviews. Patients highlighted the importance of receiving treatment and prognostic information, and wanted more opportunities to discuss their illness with other people [9].

Building on these studies, Davies and Higginson [10] published a systematic review on the communication, information and support needs of patients diagnosed with HGG. Twelve observational studies were found for the period until 2000. This review concluded that patients require tailored information and support. A second review was conducted by Catt et al. [11] for the period from 2000 to 2007. Both reviews concluded that additional research in this area was

needed, in order to develop and assess psychosocial and supportive interventions to meet patients' information and support needs and to educate staff caring for these patients.

In Australia, temozolomide has been available for adjuvant use in grade IV HGG since 2005. While there have been previous studies exploring the needs of HGG patients, such studies have not been reported in an Australian population, or since the advent of a new standard of care including chemoradiotherapy and subsequent adjuvant chemotherapy. In order to develop appropriate psychosocial interventions, we first need a detailed understanding of the needs of patients at various points along the disease trajectory. Therefore, the aims of this study were to: (1) gain an understanding of patients' experiences of living with HGG and (2) identify and describe the information and support needs of these patients.

## **1.2 Theoretical Framework**

The theoretical framework that informed this study was Maslow's hierarchy of needs[12], recently adapted to palliative care by Zalenski and Raspa [13]. The five levels of need as described by Zalenski and Raspa are: (1) managing distressing symptoms; (2) fears for physical safety, of dying or abandonment; (3) affection, love and acceptance; (4) esteem and respect and (5) self actualisation and transcendence[13]. HGG patients are likely to have similar needs and may need to work through lower level needs before they can move forward and live with their disease. This theoretical framework will be used to understand the different needs that patients describe.

## **2. Method**

The study was approved by relevant Human Research Ethics Committees.

### **2.1 Participants:**

Eligible patients were: within one year of diagnosis of Grade III-IV HGG, 18 years of age or older, able to participate in interviews, and conversant in English. Patients were excluded if they had a non-primary brain tumour, or cognitive impairment as reported by the clinician or carer.

## **2.2 Recruitment:**

**Patients were recruited through the medical oncology department of a tertiary referral centre for neurological cancers. Acknowledging the difficulty in recruiting patients with brain cancer, we attempted to capture patients at different stages of their disease process (e.g. during chemo-radiotherapy, adjuvant chemotherapy or at disease recurrence) and with differing socio demographic features. The clinician involved offered participation to consecutive patients until a variety of clinical and social situations were represented; recruitment then became purposive to ensure that patients with under-represented clinical or social settings were able to be included in the study. The social situations we focused on were: young versus mature patients, patients with dependent children versus children who have left home or no children, patients living alone versus patients with carers, female patients versus male patients and patients living in metropolitan locations versus rural locations. Within the disease limitations of physical and cognitive impairment we continued the interviews until no new data emerged.**

Patients were initially identified as eligible for the study by their treating clinician. If eligible, the treating clinician provided the patients and carers with an information sheet about the study and requested their permission to provide their contact details to the research officer. The research officer then contacted the participants to explain more about the study and organize a time to meet and conduct the interviews. Prior to commencing the interview the research officer provided additional information about the study and obtained written informed consent.



### **2.3 The interview**

One semi-structured interview was conducted with each participant to gain an understanding of patients' experiences and determine their needs as they progress through treatment. The interview guide is provided in Figure 1. All interviews were conducted by health professionals who had experience in conducting semi-structured interviews for research purposes. Face-to-face interviews were conducted where possible (in the patient's home or another convenient location), otherwise interviews were conducted via telephone (n=1 patient). Patients were asked about their cancer experience and the difficulties they have faced, and their information, support and practical needs during their illness. Prompt questions were used when required.

**Where possible, the carer was interviewed first and alone. After this interview was complete the patient was invited to participate. The interviewer did request that they conduct the interviews separately, however, in some cases the carer choose to remain and in these situations the researchers did not think it was appropriate to ask the carers to leave. In some cases the carer stayed out of concern for the patient (whether this was concerns over the patient's physical or emotional state we could not determine). The patient's decision to participate in the interview was individual, therefore if a patient decided they were fit enough to participate and signed the consent form they were interviewed.**

Interviews with patients lasted between 30 and 90 minutes. Carers who remained with the patients during these interviews acted as informants for the patients and added to the richness of the data. Interview questions/prompts were amended slightly as data analysis continued and we began to understand the needs of the patients and the areas where we required further information. The researchers remained open during the interviews and gave the participants many opportunities to describe their own individual concerns as well as respond to interview questions

that were asked. The researchers were also flexible in terms of the interview structure. For example, if a patient started discussing their support needs first, the researcher discussed these issues and then moved on to talk about information needs.

*Insert Figure 1 here*

#### **2.4 Data Analysis**

Interviews were tape recorded and transcribed verbatim. Data analysis was iterative and commenced after the first interview. 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 [14].

Data analysis was conducted using grounded theory and the constant comparative method [15]. Transcripts were loaded into the software program QSR NVivo, Version 7 (2006). Open, axial and selective coding was used to analyse the data [15]. 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. Interpretation of the themes and data collected was then informed by Maslow's hierarchy of needs as described above [12].

### **3. Results**

Thirty patients with HGG were invited to participate. Six declined due to deteriorating health, four refused and one died before the scheduled interview, leaving 19 participants. The mean age was 55 years (range 31 to 74, SD = 10). Table 1 summarises the patient characteristics. All patients had, or were having, treatment with seven weeks combined chemo-radiotherapy using

temozolomide and a further six months of temozolomide chemotherapy; however, some patients' disease progressed during treatment or were unable to tolerate treatment, leading to cessation of therapy or second-line treatment.

*Insert Table 1 here*

Four overriding themes emerged: feelings of uncertainty; the need for information; dependence on their carer and communication with health professionals. Each of these themes was comprised of interrelated sub-themes that related specifically to the diagnosis of HGG. It was evident that throughout the experience of HGG patients were re-evaluating their futures and what would happen to them as their disease progressed. Figure 1 provides a diagrammatic representation of the themes and sub-themes relating to HGG.

*Insert Figure 2 here*

### **3.1 Feelings of uncertainty**

At the point of receiving the diagnosis everything was unfamiliar and uncertain for HGG patients. The main areas that patients were uncertain about included their prognosis and future, the effect the diagnosis would have on their quality of life and treatment side effects.

#### *3.1.1 Uncertainty about prognosis*

Patients highlighted the feature of an unclear prognosis in HGG:

*“We still don't know what we're going to have to look forward to in the future because, you know when you do ask you still get a little bit of a vague answer...” Patient011*

*“It’s like you’ve hit a brick wall... it’s not like it’s sponge foam and you can tear it apart and go through it. It’s been a brick wall and it’s been a fight to me, devastating, hit this brick wall and sort of knowing, but not knowing what’s on the other side.” Patient017*

These two exemplars demonstrate that receiving an unclear prognosis was frustrating for patients because they did not know what to expect in the future and therefore could no longer plan their lives. The following sub-themes further demonstrate the uncertainty experienced by patients.

#### *Uncertainty about how the diagnosis would affect their quality of life*

Patients not only experienced uncertainty in relation to their prognosis, but also in relation to how their diagnosis and the symptoms they would experience would impact on their quality of life. Patients reported that they were particularly concerned that they would experience a stroke or seizure:

*“Like I want to know, would I have a stroke or would the symptoms just come back because the tumour was just growing back... you know I wanted to know what was going to happen to me, would I have a seizure, because I wanted to tell my children, what to do if they’re home alone with me and something happens.” Patient014*

As this exemplar demonstrates, patients were not only concerned about how their condition would affect their own lives, they were also concerned about the impact that their condition would have on their family members and friends.

#### *3.1.2 Uncertainty about the side effects of treatment*

The period after surgery was a particularly uncertain time for patients, as this exemplar illustrates:

*“If you think about what part of your body you don’t want surgery on it’s your brain and you know that’s what I ended up having. The question is OK you come out of it,*

*you've gotta have this operation, you've got a surgeon that you know is a good surgeon, that's great. But at the end of the day you find out what your new condition is like when you wake up and, am I going to be able to speak, am I going to be able to move my arms and legs, am I going to be able to swallow, and I going to be able to do these things..." Patient007*

Although this patient was informed about the side effects of surgery they reported that they felt unsure about how they would recover and were concerned that surgery might affect their physical abilities.

Patients experienced uncertainty about treatment decisions, post-operative recovery and adjuvant treatments and what would happen as the disease progressed. Patients were particularly concerned about seizures, vision loss, memory loss, speech difficulties and lack of mobility. They also expressed uncertainty about their ability to return to work, financial stability and resumption of previous activities.

### **3.2 The need for information**

Patients had varying information needs over disease progression and symptomatic deterioration. Patients discussed the need for different sources of information and variety in the way that information is provided. While some preferred written information, others highlighted the importance of verbal repetition and access to health care professionals (e.g. the Neuro-oncology Cancer Nurse Coordinator) for specific information. The following sub-themes related specifically to HGG: the need for information relating to prognosis and the need for information to be provided using different types of medium.

#### *3.2.1 The need for information relating to prognosis*

Patients expressed concern about delays in receiving prognostic information, and the uncertainties of such information. One patient explained their need for information while awaiting a confirmed histopathological diagnosis:

*“I never got really good confirmation of my condition... They thought it was the bad one; which I worked with in my own head until eventually and it’s quite right they’ve got to do it until they get confirmation it’s such a long winded thing. ...over a week to get a biopsy confirmed. And a week is a long time to hover around - thinking ... and that was after having all the, up to the operation, having the operation and then the thing gets sent away another week. After that you get told that you have got whatever it is and then, then you get the right information.”* Patient004

This patient wanted information as soon as they received an initial diagnosis of brain cancer. They found it difficult to wait for their diagnosis. However, once they received their diagnosis they reported that adequate information was provided to meet their needs. Other patients similarly reported that they found this waiting period difficult because they wanted additional information to be provided.

### *3.2.2 The need for information to be provided using different types of medium*

Some patients desired more specific written information about HGG:

*“I was just looking at trying to find something to read and I couldn’t find anything about brain cancer or anything like that.”* Patient014

However, other patients expressed a specific need for verbal information because they had difficulty with their vision, or processing written information:

*“I’ve got a loss of little peripheral vision he thinks...”* Patient017

*“I’m not very good at reading. I want them to tell me.” Patient001*

It was essential that health professionals were aware of the patient’s individual needs and tailored the way they provided information. Information needs to be presented in a way that is relevant to the patients as this quote illustrates:

*“The nurse just gave me a book and she said “read about brain tumours” don’t do this and don’t do that, don’t wash your hair, don’t blow dry your hair, but you know it’s not enough. I want to know why you don’t do this.” Patient001*

*Continuity in the provision of information was also highlighted:*

*“Well, everybody else seems to know what they stand...I think what happened was the doctor who was in charge retired and they put somebody in charge and then they think he told me but he didn’t.” Patient 001*

### **3.3 Dependence on their carer**

Patients’ physical and psychological integrity changed as their disease progressed; the following exemplars demonstrate that patients felt unable to fill their previous roles, became more dependent on their carers, and varied in their acceptance of this dependency:

*“I just left everything up to her...I mean I’m totally dependent on her.” Patient010*

The patient’s carer was present in this interview and similarly reported that she needed to care for him and make decisions for him.

While some patients were grateful for such support:

*“It takes a load off my mind to have that person right next to you that you can trust and love and looking after things for you. It just means so much... couldn't do it without them, as a helper, no way you could not do it. ” Patient013*

The patient's carer was also present in this interview. Patient 013 reported that they felt that they could not manage all of the physical tasks required and therefore needed to rely on their carer to assist them. They also indicated that they would need to rely on their carer further in the future.

Others struggled with a loss of independence:

*“She's a little bit probably too much at times...you know “Are you cold”, “Can I get you a rug” ... I'm not dead yet. So, yeah, just a little bit over the top with some of that sort of stuff.” Patient019*

This patient's carer was not present at the interview.

Another patient similarly described how he was struggling with a loss of independence:

*“I get heaps of support from them, but its sympathy which I don't want. Since this started (wife) hasn't cooked a meal, I've cooked all the meals, I'm not going let her carry on and I hate sympathy.” Patient 004*

### *3.3.1 Managing weight gain*

Many patients were conscious of the need to monitor weight gain, resulting from corticosteroids:

*“If you didn't have some work activities by gosh you'd be blown out and I mean I would have eaten anything...now you just force yourself to eat fruits and dried biscuits and the nice sweet biscuits and all those sorts of things.” Patient017*



Other patients similarly reported that they were concerned about managing weight gain and the role that their carers had in ensuring that they ate properly.

*“There is only one (handle) bar on the bath. I knew I would be able to get in, but I always thought, knew with my weight, the way it’s blossomed, mushroom, whatever you’d like to say, that I would have trouble getting out...I left the door unlocked so if I needed help, my husband would have had to come, I don’t know how he would have done it, pulled me out.” Patient015*

*“They give you a steroid to shrink the tumour and you loose control of your appetite so you just want to eat sort of 24 hours a day, you just feel like eating and so you have to control that otherwise you just blow up like a balloon and then they dump anti-nausea drugs on you so you can cope with the chemo and that slowed down my metabolism down again so I not only ate, it just didn’t go anywhere.” Patient 004*

### 3.3.2 Managing medication

Patients were also dependent on their carers to manage complex medication regimes including intermittent, home-administered chemotherapy and anti-emetics, anticonvulsants and corticosteroids:

*“My husband does it all... That’s what I say to him, “Thank goodness I’m not doing all this, because, Oh God I could give myself anything.” It’s wonderful that he does it all for me.” Patient011*

Other patients similarly reported the difficulty they had in managing their medications. Carers played an essential role in being informed about medications and ensuring appropriate medication management.

### 3.3.3 Loss of balance

HGG patients became physically reliant on carers because of loss of balance and lost physical function:

*“Yeah, I’ve got to sit here all day, listen to the radio and watch television, I can’t do anything at all (tearful mumbling), it’s affected all my balance, my nerves in my arms and my legs and I just can’t do anything, it’s very upsetting...”* Patient001

HGG had an impact on the patient’s whole lives. It was particularly distressing for them when they lost their physical ability because this limited them so much and indicated that they had lost their independence.

### 3.3.4 Inability to drive

A brain tumour diagnosis has legal implications for driving, and many patients were dependent on others for transport to appointments and social events. One rural patient explained how he had become dependent on his wife to drive, which was difficult because she was uncomfortable driving in the city:

*“You know we have got a driving issue. We are from the country and suddenly I cannot drive and I have got a wife and who has only driven in a country town, driving in the main streets of the city and it is just chaotic. So I’m having to try to say: “You do not do that” and we’ve driven home in tears and the pattern is almost everyday.”* Patient004

This loss was associated with a loss of control, increased reliance on others, and inability to function independently:

*“It is frustrating having to rely on other people to be able to get to places.”* Patient014

## 3.4 Communication with health professionals

Both patients and carers needed to communicate with the health professionals to ensure that their information needs were met. Health professionals were seen to be able to provide expert opinion, treatment and support.

#### *3.4.1 Involvement in decision-making*

Health professionals tried to include patients in decision-making and address their information needs. However, as this patient explained they found it difficult to be actively involved in the decision-making process:

*“I think I’ve been involved with it (decision-making) but at the end of the day it’s like, we’ve got this choice of doing this or not; like well at the end of the day it’s your decision. It’s one of those things where you do have a decision but at the end of the day you really don’t.” Patient007*

Decision-making was difficult for patients because there was prognostic uncertainty.

Although health professionals tried to include them in the decision-making process, they did not feel they really had treatment alternatives. Patients tried to gather the information that they required during consultations where decisions needed to be made. As demonstrated in the previous theme, patients relied on their carers to gather information and take responsibility for their treatment decision-making.

#### *3.4.2 Opportunities to communicate and ask questions*

Although patients were often not actively involved in decision-making they appreciated the opportunity to gain information and ask questions from medical staff:

*“They had a family consultation which I knocked back and made an individual consultation and got down to the nitty gritty straight away and I wanted to know what it*

*was all about... They told me what would happen eventually when the inevitable happens. They were real up front...The doctor spent nearly an hour and a half answering every question that I had.” Patient004*

This patient lives in a rural location and was interviewed separately from their carer. This patient reported that they felt it was important to be informed as much as possible so that they could try to prepare themselves for what was going to happen in the future.

### *3.4.3 Difficulties with communicating effectively*

Although patients reported that they were satisfied with their communication with their doctor, cognitive and memory deficits hampered effective communication with health professionals. One patient recalled:

*“Now whether that was related to my memory retention I don’t know. I sometimes wonder if people said something to me and I just didn’t remember it or whether I didn’t want to hear it so I blocked it.” Patient023*

Some patients were unable to participate because they were unable to communicate effectively due to expressive dysphasia. Carers of these patients therefore acted as surrogate patients and provided both perspectives. The carer explained how difficult it was for their partner to communicate effectively:

*“Cause my husband really can’t make himself understood at times and other times he can. But it’s very frustrating when he can’t speak and use words, and he puts in all the wrong words ... Very frustrating and he also finds that humiliating because it’s quite indecipherable when he does that.” Carer024*

As these exemplars demonstrate, the patient's ability to obtain information and support was sometimes affected by communication deficits. Therefore, carers were often involved in communicating with health professionals and participated in decision-making on behalf of the patients.

The timing of information provision was also raised by many of those interviewed, particularly around the time of diagnosis, as this exemplar illustrates:

*“ And the first I knew about all of this sort of woke up in the bed in hospital and Dr (name) introduced himself and straight away there was a whole group of other doctors. He straight away said to me I'm very sorry to tell you but you've only got two months to live. I was shocked, I was shocked.” Patient015*

## **4. Discussion and Conclusion**

### **4.1 Discussion**

This study addresses a need for research focusing on patients with HGG. As identified by Catt et al. [11], further research is required to first understand these patient's needs and secondly develop and assess psychosocial and supportive interventions.

The main themes that emerged were: feelings of uncertainty; the need for information; dependence on their carer and communication with health professionals. Throughout the patients' experience of HGG they continued to re-evaluate their futures. Although each of the main themes can be related to all cancer diagnoses, the sub-themes presented in Figure 2 and throughout the results demonstrate the specific needs of HGG patients.

Consistent with previous research [9], patients in this study were shocked by their diagnosis and experienced fear and anxiety. Unlike patients with early stage cancer, these people made a sudden transition to being a patient with an uncertain prognosis, often with permanent intellectual and physical deficits which impacted on their lifestyle immediately. Patients with brain tumours may experience a sub-acute but substantial decline in function over the illness. In contrast, many other patients with metastatic non-brain cancers can experience periods of continued good cognitive and physical function, with a rapid functional decline in the terminal phases of the illness.

Patients experienced uncertainty about many aspects including treatment options, prognosis, symptoms and side effects and how they could cope with the changes that were occurring. Uncertainty is defined by Penrod [16] as ‘a state that people experience, where they are unable to assign probabilities to what is going to happen in the future’. This feeling of uncertainty continued throughout the patients’ experience of HGG because they were unable to assign probabilities to how long they would live or what would happen to them.

Patients needed information about their diagnosis and prognosis. Lepola et al. [9] and Janda et al. [7] similarly reported that brain cancer patients placed high importance on prognostic information. However, the timing of such information was often questioned, particularly when the “bad news” was delivered immediately after surgery when they were recovering and often not in a position to take in the information. Patients in our study also highlighted the uncertainty they faced around their prognosis, as indeed, even the doctors could not predict when or how rapidly their physical or cognitive decline may occur. They were uncertain about potential consequences of their illness such as loss of independence, seizures, weight gain, diet, loss of mobility, inability to drive and how HGG would impact on their quality of life.

Patients required verbal and written information about treatment, support services, and what happened as the disease progressed. However, again, timing was an issue as many patients were “not ready” to discuss palliative care services or the introduction of support services into the home. This was perceived as generating a “loss of hope”. Patients valued the presence of a carer when receiving information, particularly if they had cognitive impairment. For the same reason, information needs to be framed simply and positively.

This study has illustrated that the provision of information is not a simple task for the clinician. Some of the patients interviewed wanted their doctor to “tell it like it is”, while others only wanted to know positive information, or minimum information. Some patients reported that they searched the internet for information, while others did not want to know. This highlights the importance of clinicians informing patients of the type of information they can provide and eliciting how much information the patient required [17]. There is evidence that patient’s information and decision making preferences change over time [18]. This was highlighted in our study, where patient’s needs varied not only because of their disease status or cognitive decline, but often because patients moved from wanting to know and then not wanting to know. This is challenging for clinicians, however; as the communication guidelines highlight, the importance of individualising information and eliciting concerns is vital to the communication process [17].

HGG patients became increasingly dependent on their carers as they progressively lost physical and/or intellectual functions. This paper expands on research by Janda et al. [7], demonstrating that some patients felt totally dependent on their carers, while others tried to maintain independence. The legal requirement to cease driving on diagnosis inflicts dependence even on those who remain physically or cognitively intact in the early treatment stages. The loss of

control over many aspects of their lives was raised by those interviewed with many struggling to maintain their independence and continue in their daily activities. Their ability to maintain control was further eroded with the uncertainty of the disease trajectory.

Continuity of communication with health professionals was essential for obtaining information and support. Patients highlighted the importance of being able to discuss issues with the treating doctor and their need to have someone they could contact when necessary. Several patients commented on the importance of keeping their general practitioner in the loop. Previous studies [7, 19] have similarly reported that patients would find it beneficial to have a readily available designated contact person. Health services need to be mindful of the importance that these key roles play in addressing patients' needs.

The current study was informed by Zalenski and Raspa's [13] adaption of Maslow's hierarchy of needs [12]. Consistent with this adaption our participants experienced distressing symptoms and had needs in terms of restoring their lives. After receiving their diagnosis patients feared experiencing debilitating symptoms, and were aware of the possibility of death. Patients were dependent on their carers, while carers provided physical and emotional support, reaffirming their love and support of the patient. Patients reflected back on their experiences, and some were able to frame their diagnosis positively because they were able to reassess and reconstruct their future personal goals and relationships to maintain an acceptable level of physical and psychological integrity. Finally, patients worked through their feelings about the prognosis they had been given and started to come to an acceptance of the possibility of their death.

#### **4.1.1 Limitations**



Participants were recruited from a single site; however, this site treats most neurological cancers from a population of approximately 1.5 million people. Nevertheless, data saturation was achieved by continuing data collection until no new themes emerged to describe the information and support needs of patients diagnosed with HGG. The inclusion of participants at different time points following diagnosis ensured a more complete understanding of patient's needs, as did purposive sampling of patients with differing clinical and social situations. **The presence of a carer during some of the patient interviews may have limited the patients' responses; however, this was unavoidable for this group of participants with the carer needing to be present to assist when the patient had physical limitations.** While data collection at three time points was informative, further longitudinal research is required to determine how individual patient's needs change over time and as they progress through treatment. Future research by the authors will use quantitative methods to ascertain these needs.

#### **4.2 Conclusion**

This study provides health professionals with an understanding of the information and support needs of patients living with HGG. The data suggest that patients were shocked, uncertain about the future, could not get a clear prognosis, did not know how their disease would progress or how to make plans. However, not all patients had these experiences, and some patients did not want to know about their disease in detail. Other concerns such as weight gain, seizures, visual and speech deficits, and inability to drive are more unique to patients with brain cancer. Each of these concerns had an impact on the patient's whole lives and limited their independence and quality of life. For each of the participants, carers played an essential role in assisting patients with decision making, managing their health and assisting them physically.

#### **4.3 Practice Implications**

This study has identified the need to individualise information with awareness of cognitive, visual, communication and memory deficits. Early and ongoing concerns about seizures, loss of independence and communication difficulty are more particular to patients with brain tumours and differ from other patients with terminal malignancy. Carers therefore play an essential role from the time of diagnosis and also need to be involved in each step of the patient's journey.

#### **4.4 Future directions**

The authors are now conducting a longitudinal survey with a larger sample of patients and carers to better understand how these patients information, support and practical needs change as their disease progresses, and to determine what tailored interventions could be used to specifically meet the needs of patients diagnosed with HGG.

We confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

#### **Conflict of Interest statement**

We declare that there are no conflicts of interest for this study.

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**Legend**

**Table 1: Patient demographics**

**Figure 1: Interview guide**

**Figure 2: Themes and Sub themes for HGG patients**

**Figure 1: Interview Guide for patient 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?

**Info 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?

**Info 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?

**Info 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?

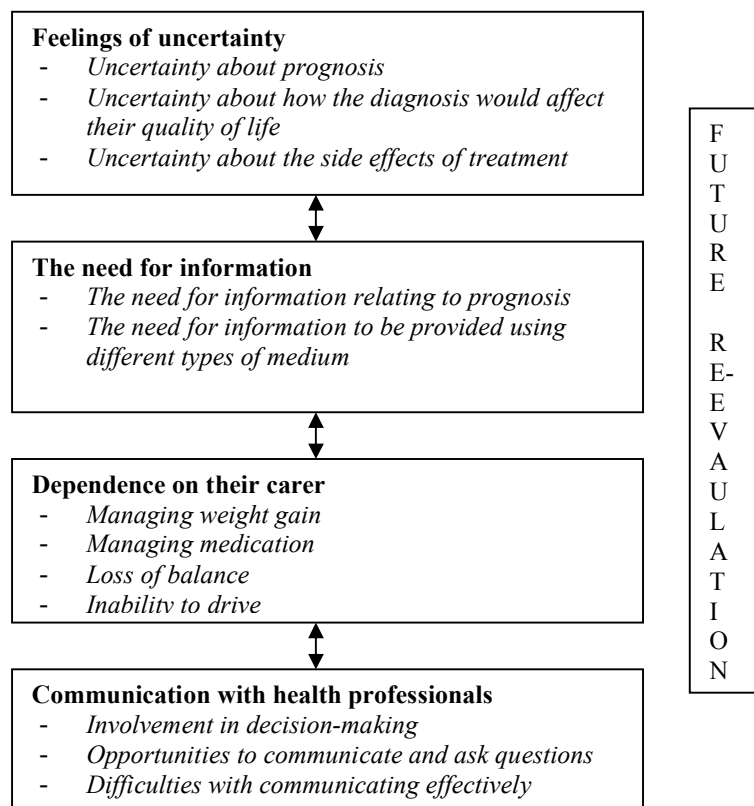
**Info in general**

- 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?

**Figure 1: Themes and Sub Themes for HGG patients**



**Table 1: Patient demographics**

		Frequency
Diagnosis	Gioblastoma multiforme Grade IV	16
	Astrocytoma Grade IV	1
	Anaplastic gemistocytic astrocytoma Grade III	2
Sex	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