"I'm just waiting..." An exploration of the experience of living and dying with primary malignant glioma

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ABSTRACT

- Purpose:** Referral to supportive and palliative care services for people with high-grade primary malignant glioma (PMG) often occurs late in the illness course, despite significant care needs and overall poor prognosis. This study aimed to understand patient experience at the end-of-life and document supportive and palliative care needs.
- Methods:** Qualitative study involving 10 PMG patients who were at different stages in the illness course including the end-of-life, and had varying levels of physical and cognitive function. Consecutive, eligible patients attending neuro-surgery, oncology and palliative care services of two metropolitan hospitals were recruited. In-depth interviews explored supportive and palliative care needs across the disease trajectory. Interviews were analysed independently by three investigators consistent with a grounded theory approach, and emerging ideas were compared and refined to define key patient experiences.
- Results:** Despite the medical treatment and supportive care available, there remains a gap in services addressing complex existential and psychosocial needs that were markedly valued by patients. Patient experience was characterised by a pervasive loss of all that encompassed their former sense of self, and a focus on immediate needs.
- Conclusions:** Patients in this study had substantial needs, often not shared and not addressed by the current medical system of care. An improved multidisciplinary care model is indicated, which proactively: (1) engages care-coordination and advocacy; (2) minimises patients' sense of waiting and uncertainty through mapping out a plan, including involvement of palliative care in a timely fashion; and (3) actively invites discussion around goals and preferences for care to promote patients' sense of self.

Patients with high-grade primary malignant glioma (PMG) have unique care needs which often differ from patients with other terminal malignancies.[1, 2] Overall median survival is limited,[3] and many patients will live in a prolonged state of dependency with high attendant care needs, early cognitive failure, and prognostic uncertainty.[4, 5] Personality change, seizures, motor deficits, gait impairment and other disabling symptoms are each prevalent in 30-70% of patients at the end-of-life.[4, 6, 7] Unsurprisingly, up to 63% of PMG patients have reported feeling distressed,[8] and the profound impact on their carers is well known.[9]

In Australia, concurrent access to tumour-directed therapies and palliative care management is available. Despite this, PMG patients with recurrent disease have infrequent consultation with specialist palliative care,[6, 10] and are often referred late in the illness course.[1, 11] Few patients therefore have the opportunity to participate in important end-of-life decisions when they are communicative and cognitively intact,[1] including detailing their advance directives and preferences for care.[6, 12]

Previous research has primarily focused on information and support needs,[13, 14] particularly following diagnosis and first-line chemo-radiation treatment. Whilst there are some carer reports detailing the PMG end-of-life phase,[9, 12, 15, 16] patient views are sparse. Retrospective case reviews have described patients' clinical symptoms, medication use and interventional procedures,[4, 7, 10, 11, 17] but their perspectives of palliative care concerns are largely absent. There is some evidence, however, that patients value opportunities to discuss existential issues, which are broadly overlooked outside of palliative care settings.[18-20]

Since a goal of care in this setting must be health-related quality of life,[7] several authors have called for a greater investigation of PMG patients' needs at the end-of-life.[5, 7, 10, 21] This study therefore aimed to understand the lived experience of patients, including their supportive and palliative care needs and perceptions of the current health services.

METHODS

Study Design

We conducted an exploratory qualitative study involving in-depth interviews with patients diagnosed with GBM. This was part of a larger mixed-methods project which aimed to delineate a model of supportive and palliative care for people with PMG, and included the views of carers and health care professionals [1, 9] and a retrospective cohort study. An expert advisory group was appointed to ensure the methodology and interpretation of findings was clinically grounded. The study was approved by relevant institutional human research and ethics committees.

Participants

Consecutive patients with PMG grades III-IV, who were conversant in English, able to provide informed consent (no significant cognitive impairment), and attending neuro-surgery, oncology and palliative care services of two Australian metropolitan hospitals were approached in person (AC, GM) to invite participation (Figure 1). Eligibility was sought from patient records and confirmed with

treating clinicians. The functional status of all patients interviewed was assessed by the researcher using validated clinical tools, including the ECOG [22], RUG-ADL [23] and Barthel Index [24].

Data collection

In-depth interviews exploring patients' supportive and palliative care needs and concerns were conducted by one researcher (AC) over 12 months during 2011. An interview guide was developed to aid fluency of discussions, but was flexible to follow new lines of emerging enquiry and evolved according to the analysis. The broad areas of enquiry included: care service needs, gaps, and preferences; health professional roles; receipt of information and communication; experience of symptoms; use of support services; goals for future; and experiences of palliative care.

Interviews were held in the patient's preferred location (home, n=3; acute hospital, n=4; hospice, n=3) for 35–80 minutes duration. For two patients, carers were present at the interview, however only patient reflections were included in the analysis, as carer data are presented elsewhere.[9] Interviews were recorded, transcribed verbatim, and checked for accuracy. Given the sensitive nature of interviews, patients were made aware of their option to cease the interview at any time, or to decline responding to questions without consequence. Patients were also informed of the option to be referred for supportive counselling should they experience any significant distress.

Data analysis

Consistent with a grounded theory approach [25], we began with few assumptions relating to anticipated care needs, but rather sought patient experiences. Independent coding of all transcripts was undertaken after each interview by three investigators (AC, JP, GM), including two researchers and one palliative care physician. Regular coding meetings enabled investigators to cross-check, compare and refine independent analyses, ensuring consistency, and thereby the representativeness of the data in the analysis. Emergent ideas informed subsequent interviews, and over time, were grouped into key patient experiences. Recruitment of patients and analysis was ceased when no new ideas emerged in the data and a variety of perspectives had been sought. Reviews with the expert advisory committee took place throughout to provide clinical and consumer perspectives upon the findings.

RESULTS

Patient characteristics

Ten patients including six males and four females ranging in age from 40–70 years (median 59.5 years) and living between 11–100km (median 22km) from the hospital were interviewed. Patients were at different stages across the illness trajectory: two following diagnosis/during active treatment; four whose disease had plateaued; and four receiving end-of-life care. They had differing levels of physical and cognitive functioning, with ECOG scores ranging from 0-4,[22] Barthel from 0-20,[24] and RUG-ADL from 4-17 [23]. At the time of interview, patients were between 3 months and

13 years from diagnosis (median 12 months). Five patients were cohabiting with a partner, and five either lived alone or had moved in with family since diagnosis.

Patient experiences

1. Loss of self (Table 1)

Patients expressed a profound sense of loss of who they were before the illness, and all that encompassed and defined their former sense of self. Associated physical deterioration and restriction to their ability to undertake everyday tasks contributed to this loss of self. In perceiving themselves as less than their former self, patients grieved the burden this created for those they loved. The result of being changed and dependent was feelings of isolation and loneliness.

[Insert Table 1 here]

Impending loss and decline

All patients expressed feelings of great loss and vulnerability as a result of their illness state regardless of when in the course of the illness the interview took place. This vulnerability was evident in patient descriptions of the difficulty grappling with increasing deterioration and disability, their inability to plan for the future, and sometimes a poor quality of life. Accepting life changes such as giving up work, driving, and previous household responsibilities represented a profound loss of independence, and served as a daily reminder to the patient, of their vulnerable position. With increasing dependence, feelings of helplessness and indignity were common. Patients described the sequelae of the tumour as a violation to their sense of self. Those with insight into their condition spoke of the sense and uneasiness of having no control over this “thing” which was slowly overcoming them, and with it, taking away their abilities.

Fear of being a burden to others

Along with the need for help came great concern about being a burden to people - family, friends, and doctors. Patients spoke of trying to persevere unaided, particularly those without a long-term partner. One participant reported declaring herself homeless in an effort to gain urgent public housing and remain independent, rather than continue to “burden” her daughter with the perceived chore of providing care. Another participant spoke of her preference to be admitted to a hospice, instead of asking her partner to modify his home with the necessary equipment she required. In each case, patients felt unable to communicate their needs to others.

This sense of vulnerability did not escape those who were supported in hospital, and even patients admitted to inpatient services described feelings of helplessness and difficulty advocating for themselves. Such patients spoke of trying to limit their requests of staff to avoid being seen as too demanding and risk not getting help when they most needed it. Those who had a partner to advocate and care for them expressed feelings of sincere gratitude. Those without such a person clearly identified a gap, since they were often unable to fully express their needs to others, or manage without help at home.

Loneliness & Isolation

Patients expressed feelings of loneliness and isolation throughout their illness, which were made worse by the associated physical limitations. Some patients noted that their relationships with close loved ones had changed as a result of others not understanding their concerns, or their physical limitations. One man felt distant from his children as he could no longer climb the stairs to the room where they played. Another was unable to speak to his wife as often as he wished because he couldn't use his arm to operate a phone.

2. Focus on the here and now (Table 2)

Patients focus was overwhelmingly directed to the 'here and now', such that their immediate, everyday needs were consistently emphasised. Patients described coping day-to-day with needs as they arose, an approach which they perceived to be preferred by health care professionals. As a result, patients described how they were always 'waiting' in a constant state of uncertainty about their future. Failing to acknowledge future needs meant when crises inevitably occurred, patients, with hindsight, felt let down and disappointed.

[Insert Table 2 here]

Coping day-to-day

Patients commonly reported coping day by day with the disease and its attendant problems, and had limited preparedness for what might happen in the future. Unless told otherwise, patients felt all was going well, leading to a sense that "it's all good, until it's not." Despite acknowledging that the cancer diagnosis was unexpected and unheralded, patients could still not imagine that any tumour progression would happen in the same manner without warning.

Patient concerns were focused on their immediate world, with often little insight into broader issues or implications for care. When asked if they had any additional requirements from the current system of care, patients often reported they had no care needs, or that they or their carer was able to manage any needs they had. Yet, when asked more immediate experiential questions such as whether they had experienced any symptoms or changes since their diagnosis, or how they felt in that moment in time, patients reported a high number of concerns.

In particular, the effects of dexamethasone were noted to be debilitating. Patients often remarked upon their profound weight gain, swelling, constipation, and weakness, which they attributed to the medication. Some had developed diabetes and noted poor sleep, fatigue, and feelings of depression, which added a significant burden to their other physical limitations.

Perceived health care professionals focus on the here and now

Following disappointments after treatment, some patients' perceived their health care professionals as lacking openness when talking about the future, including how events relating to the treatment of their tumour may unfold. This was particularly expressed by patients whose tumour had progressed quickly despite treatment.

This temporal focus on the immediate sat alongside an underlying feeling that doctors had a narrow focus of care, concentrating on “treating brains”, without giving time to discuss the future, address existential concerns, or provide comprehensive care. Discussion of such concerns was perceived to be unwelcome by treating physicians, and yet patients reported they did not know of any other professional available who could address questions.

For this reason, a personal relationship was sometimes missing in the care provided. Patients wanted to know there was a person in the system available to provide genuine care and support as it was needed. Patients also reported that they needed consistency and personalised help to think through complex treatment decisions.

Patients perceived acute care providers to be reluctant to provide information about palliative care, particularly if still receiving treatment. Those who were interviewed whilst receiving palliative care noted some acute doctors seemed uncomfortable talking about death and palliative care, or wondered why it had never been mentioned. Those interviewed at an earlier stage of their illness, were unaware of what palliative care offered.

Waiting and uncertainty

Participants described their illness experience as one of ongoing uncertainty and disappointment, which began with a sudden, unexpected diagnosis, and often progressed over time with a series of treatment failures. Time was characterised by a sense of ‘waiting’ – waiting for scan results, for doctors, for a bed to become available, for prognostic news. Patients’ expressed frustration that each period of waiting was often followed by another disappointment.

This ‘waiting’ continued for patients right across the trajectory, including at the end-of-life, when still they spoke of waiting for care decisions to be made, and waiting for death. Patients perceived negative prognostic information was withheld at times to save them distress, yet revealed this simply meant they ‘waited’ longer.

DISCUSSION

This study is among the first to detail patient perspectives of living with PMG at the end-of-life, and collectively provides insights of the patient experience from diagnosis until just days before death. It reveals that patients with PMG have substantial needs often not shared and not addressed by the current medical system of care, where disease monitoring and treatment planning is the mainstay of patient consultations. Patients in this study felt unable to speak of their needs or request help with needs outside this medical focus, leading to subsequent neglect of existential issues and future planning. Despite the medical treatment and supportive care available, there remains a gap in services addressing these complex and important issues that are fundamental for patients.

In this study, participants revealed there was an implicit agreement between the doctors and patients to manage the illness by dealing with issues at hand. This approach may be very useful as a means of coping with the difficult and uncertain disease circumstances, indeed in most settings it is. However it has particular limitations in the setting of PMG. Namely: (1) Patients miss out on

appropriately planning their future; (2) Carers miss out on opportunities to be linked into support; and (3) Health care professionals miss out on matching medical care with patients' goals.

Notable in this study was the wide variation in levels of patient insight into their supportive and palliative care needs. Despite patients' inability to explicitly voice this lack of insight and to comment on broader system-wide conceptual concerns, the themes revealed that patients were more easily able to discuss day-to-day concerns. This finding differs to previous reports of this patient group, such that other cohorts appeared to have more insights and greater discussion of conceptual issues.[19, 26, 27] Given the careful attention directed to cognitive ability during recruitment, a likely explanation for this difference relates to the uniqueness of our sample, which includes adequate representation from patients who don't have a spouse, and detailed perspectives that were mostly collected without a carer present. It is possible that prior reports offered a collective voice of patients and their carers, different to the voice of patients alone.

Furthermore, our sample also included people who were well beyond the initial disease and treatment stages previously studied, allowing us to capture the vulnerabilities and disappointments that evolve as a person reflects on their illness experience. Finally five patients in this study had survived beyond the median prognosis. Our results may therefore, also capture some of the needs of longer term survivors, which have previously been recognised as a separate group of patients needing further exploration.[28]

Implications for a model of care

Given the vulnerabilities of this cohort and their acknowledged difficulty in expressing and advocating their own needs, this study suggests that the current patient-centred, medical model of care may have limitations for people with PMG. Those without a carer had no effective voice, and fewer avenues to be supported at home. A system of care therefore needs to provide a formal advocate within the health service to enable patients' preferences to be fully realised, and to lessen, at least in part, their sense of loss and vulnerability. It also requires a formalised, routine screening method to ensure that neuro-cognitive, social and existential issues are given necessary attention alongside a treatment-driven approach which offers patients hope for effective disease control. With this, comes an openness to provide information about and referral to palliative care.

Limitations

As an exploratory qualitative study, we report on a small number of patients in total and at each stage across the illness trajectory, and this limits generalizability. An inherent aspect of the qualitative study methodology is the role of the researcher and the impact of this on all levels of the study method and results. Despite this, there was a commonality to the views expressed by patients and a variety of perspectives were sought. We were also not able to capture the experiences of patients from non-English speaking backgrounds, those treated solely in the private system of care, or the views of those who were deemed too impaired to participate. Importantly however, patients within days of death were able to offer their insights providing a unique and rich understanding to this illness experience.

Conclusions

Patients in this study accepted the incurability of their illness and the inherent limitations of the medical treatment available. Yet with some poignancy, they wished for another dimension to their care - namely care that recognised them in all their humanity, and acknowledged them as a valued, active member of their community and family. We believe patients' needs and series of challenges are best met by a system which proactively: (1) engages care-coordination and advocacy; (2) minimises patients' sense of waiting and uncertainty through mapping out a plan, including involvement of different components of the health care system such as palliative care in a timely fashion; and (3) actively engages patients and their families in their care to promote a sense of self. In doing so, the system of care should invite discussion around the future and address each person's goals and preferences for care within this setting of a short prognosis.

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Figure 1. Patient consort

Table 1: Key issues and quotes revealing patients' 'loss of self'

Loss of Self	
1a) Impending loss and decline	
Loss of control over physical and mental functions challenge patient's sense of self.	<ul style="list-style-type: none"> • "What's it like, life on your back? It's not nice. Everyday it gets progressively worse, it sort of creeps. Each morning you wake up with a little bit extra and it's as if overnight, something goes into your brain and starts to scratch little bits away." P4 • "You know you're not yourself because you've got no memory." P2 • "I find I get quite tongue tied sometimes but I never know if I'm tongue tied because I'm not speaking to yourself." P5
Difficulty grappling with increasing deterioration, disability, and dependence on others.	<ul style="list-style-type: none"> • "One of the things that strike me is how difficult it is to come to terms with feeling incapacitated. Going from an able bodied person, to suddenly having someone cut up your meal and feed you or shower you – that's very hard to come to terms with." P8 • "Giving up my independence, that was the worst part of it." P3 • "I don't want it to get to the stage where we have to move house because of my condition – you shouldn't move because of that...I'll never accept it, as simple as that." P6
1b) Fear of being a burden to others	
Fear of burdening family, friends and health care professionals with caring duties.	<ul style="list-style-type: none"> • "You've got to be careful when you press the buzzer, because the nurses – I know it is unfair to say it – but if you're too demanding, they start to ignore you." P4 • "Going to a care place is better than, you know, expecting your friends to have to have look after you, you know, the chore of doing it." P3 • "Look, this is unbearable, you know? My partner has to stop work and drive me. It's totally interfering with her work." P1
Need for someone to advocate on their behalf because patients felt unable to communicate their needs to others.	<ul style="list-style-type: none"> • "There were questions about if I could really stay at home. But it was really difficult to communicate that, and I really needed a third party to do that. The emotional stuff is the hardest stuff to deal with– the emotional fatigue from anticipating and thinking about the effect this is having on other people." P8 • "I've just got to the point where I say to [my carer], 'you manage it,' because I've lost a bit of my thought, and I've lost a bit of my speech." P9 • Someone came to home to help. But she just sat there. And I was thinking, "Aren't you supposed to be doing something? Like, give me a shower?" Yeah, but I was only thinking that. I wasn't saying that." P2
1c) Loneliness and isolation	
Changed relationships with loved ones, as people fail to understand limitations.	<ul style="list-style-type: none"> • "People look at me and can't tell any difference, I look normal, even now. And yet I can hardly see, and can hardly walk. Like even my brother, I've only seen him twice. He doesn't even stand in the right spot where I can see him. He doesn't even know where my vision is." P9

	<ul style="list-style-type: none"> • “My partner visits [the hospice] a little bit. Well, I don’t really see a lot of him, but anyway, that has to be his decision, and I don’t know it’s hard.” P8
Physical limitations inhibit social being and exacerbated isolation.	<ul style="list-style-type: none"> • “The real company is [the sound of] the bed - as it shuffles you one way, and then shuffles you back. It’s actually a bit of company because you hear it let the air in and out...it’s an extreme sound, but you know it’s there, so it’s a comforting sound. It’s something that’s actually happening, rather than just silence and nothing else.” P4 • “I can sometimes feel like an alien, alone, depressed. And it’s even worse because I can’t get out and I can’t drive, having to rely on my dad all the time.” P7

Table 2: Key issues and quotes revealing patients’ ‘focus on the here and now’

Focus on the here and now	
2a) Coping day-to-day	
Patient’s coped day-by-day with limited preparedness for what the future might hold.	<ul style="list-style-type: none"> • “I’m taking it step by step, because I feel well. I can’t imagine that it would be such a sudden onset that I would just go down really quickly. I can’t imagine that.” P5 • I’m just going with the flow. But I think, “Oh, how long is this going to go for? Will I get to the six months period and then it declines?” P1
Limited insight into care needs and ‘system’ concerns, rather focus on everyday symptoms and limitations	<ul style="list-style-type: none"> • “The more dex you take, the weaker you get. And you get very depressed, very quickly, because dex takes you down very low, plays with your emotions...All of a sudden you’re watching what you’re eating and all you’ve really got left, when you have a GBM, is that sort of small pleasure, like eating.” P4 • “Fatigue is the biggest thing... but you can live with that.” P10 • “I’ve got five brain tumours...but I don’t really notice too much, only thing I remember is tiredness.” P2
2b) Perceived health care professionals focus on the here and now	
Narrow focus of care provided, with no time given to existential concerns.	<ul style="list-style-type: none"> • “You get caught up in appointments, blood tests, urine tests and things like that. Sometimes you just need someone to say, ‘OK, we’re doing really good, the outcome so far is good, but you know, what about you, what’s on your bucket list?’ It’s just a trigger for people think this is a death sentence. So what am I going to do with my time? Where do I want to be in six months?” P10 • “I find doctors just don’t like it when you start asking them questions. But people need options, to have a choice for their self.” P1 • “I’d be very happy to have an opportunity to talk with someone about what I’m going through and what it all means.” P7
Disappointments and their implications later perceived as lack of openness from health	<ul style="list-style-type: none"> • “The danger of being paralysed by the biopsy would’ve been something I would’ve liked to have known...big time. But he [the surgeon] sort of brushed over it. He said there may be a bit of paralysis on my left hand side which would last for about three

care professionals.	<p>weeks. But it's just a little bit longer than that, and a little bit more than minor." P4</p> <ul style="list-style-type: none"> • [The surgeon] said, "I operated on you in the theatre...We didn't get it all out." That was really heart wrenching. I thought, "What is he talking about, he didn't take it all out?" And I could have asked him, but I wouldn't have gotten the questions that I needed to be answered. Because they like to protect you and make sure you don't know. P2
Provision of information about palliative care felt to be guarded. Those patients further along the illness trajectory felt it was inevitable and could have been helpful sooner.	<ul style="list-style-type: none"> • "Steer people towards palliative care. They must have palliative care, even though they're scared of the meaning of the word, they will get the assistance they need. 'OK, I've got a GBM, how long have I got?' They won't tell you that, they avoid the answer. But I think over a period of time you work out your own answers." P4 • "Refer to palliative care at the earliest possible time I think. I don't know, soon after surgery? It would've been helpful then, having that support could help you manage." P8 • "We had to ask about it [palliative care]. We don't want to be morbid, but we just want to plan. It's about setting your life up for what it should be, so that the time we've got is our time." P10 • "I would have no idea what palliative care has to offer. How could I know?" P6
2c) Waiting and uncertainty	
Sense of always waiting, from the time of diagnosis, right up to the time death	<ul style="list-style-type: none"> • "At this stage there's no decision about whether to go ahead with treatment, so this [the hospice] is basically just a nice, comfortable, pleasant place to be while waiting and seeing what's going on, while waiting for their [the doctors] decisions about further treatment." P8 • "I feel like I'm just sort of waiting and so I'm a bit anxious, and I'm depressed. I'm anchored here, dependent on everyone else...so I feel disempowered, it's not a nice feeling." P7
Ongoing feelings of continually being 'let-down', as treatment fails and disability increases.	<ul style="list-style-type: none"> • "I've had chemo, I've had radiation but now they've decided they can't do anything more so it's just - up to the Gods. I'm just waiting. You know, you're waiting, waiting, waiting, for things to happen and they just don't." P3 • "I was supposed to be off those tablets [steroids] after 3 or 4 months. And I said well when are you going to give me back my licence, and they said oh 3 to 6 months, 6 months at the most. Well it's been 6 months and nothing's happened. Still on the tablets and still no licence." P9
Unpredictability of illness meant patients couldn't plan.	<ul style="list-style-type: none"> • "If you know what the odds are, you know how to plan – the annoying thing about this is it says, "All these things may, may, may." Nothing says can help, will help. I don't know where I should be, where I'm supposed to be, where I'm predicted to be. I mean, how am I supposed to be feeling at this stage?" P1 • "With my condition I don't know how you could form a plan too much, because it could change like that." P6