Expectation and Preferences with Palliative Systemic Therapy in Recurrent Gliomas

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Abstract

Background: Expectation and preferences of recurrent glioma patients are rarely captured and hence are ill reported in literature. To overcome the above-mentioned deficiency, we undertook a study to capture the expectation and preferences of recurrent glioma patients.

Methods: This was cross-sectional study, with the expectation and preferences, of 40 recurrent glioma patients were captured at a single visit post counseling about the disease prognosis and treatment options. SPSS version 16 and RStudio version 3.4.2 was used for analysis and descriptive statistics was performed.

Results: Prolongation of life as alone or in combination with symptom control was the primary expectation in 90% of patients (n=36, 95% CI 76.2-96.5). The median time patients preferred to devote out of the remaining life span for home, work and hospital were 60% (IQR 60-90), 32.5% (IQR 1.25-50) and 0% (IQR 0-10) respectively. The adverse event most feared by patients and hence not preferred were skin rash (7, 17.5%), numbness (7, 17.5%) and vomiting (6, 15%). Majority of patients (67.5%, 27) were willing to trade off a survival of >4 months for a cheaper regimen if necessitated. Ninety-five (38) percent of patients were willing to participate in the research protocols if they are available.

Conclusion: Prolongation of life either alone or along with symptom control is the primary expectation from systemic therapy of recurrent glioma patients.

Keywords: Expectation; Preferences; Patient wishes; Glioma; Chemotherapy; Recurrent

Introduction

Expectation and preferences of cancer patients are rarely captured and hence are ill reported in literature [1,2]. These are of importance especially when the treatment provided is palliative, as palliative treatment has marginal benefits and leads to adverse events. Currently, palliative systemic treatment in any solid tumor malignancy is provided on the basis of international and national guidelines. The recommendations in these guidelines are based on evidence. Randomised studies provide a major part of evidence, however, the benefit seen is rarely evaluated on the basis of whether it met the patient's expectations [3]. It is assumed that whatever benefit is seen in these studies, however marginal would be accepted by the patients. To overcome this deficiency both European Society for Medical Oncology (ESMO) and American Society of Clinical oncology (ASCO) have now provided the recommendations to stratify the magnitude of clinical benefit seen with an agent [4,5]. These recommendations by ESMO and ASCO may not reflect expectation and preferences of cancer patients as they were not a part of these proceedings.

Limited availability of data on expectation and preferences, has made it impossible to incorporate such data. Narratives from terminally ill cancer patients including recurrent gliomas identify a clear beginning and have anticipated ends [6]. These patients are hopeful about their recovery but have a fear of death [6]. Hence, it is important to know their preferences so that treatment can be individualized accordingly. To overcome the above-mentioned paucity in literature we decided to undertake a study to capture the expectation and preferences of recurrent glioma patients who were taking treatment at our center.

Methods

Selection of cases

Recurrent glioma patients who visited Neuro-Medical Oncology Outpatient Department between December 2018 to March 2019 were invited to provide their expectation and preferences. Patients with cognitive decline, ECOG PS 4 and those without knowledge of English or local language (Hindi) were excluded.

Study design

Cross-sectional study, with the expectation and preferences, were captured at a single visit post counseling about the disease

prognosis and treatment options. No longitudinal data were collected and none of the patients were contacted after this single visit for the purpose of the current study. As this was a non-interventional study, no ethical clearance was obtained from the host institution.

Proforma and its validation

The expectation and preferences were captured using The EXPECT questionnaire. EXPECT proforma was designed by the VP and has been validated and used for capturing expectation and preferences regarding systemic therapy [1,7]. The details about the questionnaire and its method of use are already published. The proforma has a set of 15 questions. The initial 5 questions deal about the primary expectation from the therapy whether it is an increment in survival or symptom control and identifies the minimum benchmarks considered by the patients with respect to the primary expectation. The next set of 10 questions seek preferences regarding adverse events, mode of administration, cost of the therapy and willingness of the patients to participate in research. The proforma was administered to the patient by DK and VS and patients were encouraged to answer all questions.

Data Collection and statistical analysis

The data regarding the baseline demographics, patient's treatment plan, and responses to all 15 questions were entered in the excel database. These were cross-checked by 2 independent persons. SPSS version 16 and RStudio version 3.4.2 was used for analysis. The descriptive statistics were performed. Continuous variables were expressed in terms of the median with interquartile range. Ordinal and nominal variables were expressed in percentage with respective 95% CI. The 95% CI was calculated using the adjusted Wald method.
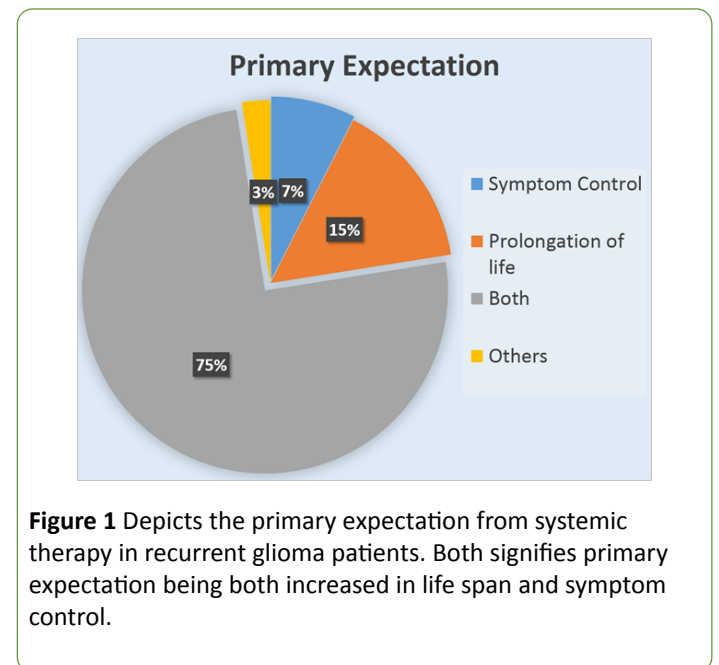
Results

Baseline characteristics

We had 40 patients with recurrent glioma. The baseline characteristics are shown in **Table 1.**

Primary expectation and magnitude

Figure 1 depicts the primary expectation of systemic therapy. Prolongation of life as alone or in combination with symptom control was the primary expectation in 90% of patients (n=36, 95% CI 76.2-96.5). **Table 2** depicts the minimum benefit expected by the patients for prolongation of life and symptom control.

Table 1 Baseline characteristics. *It is inclusive of astrocytoma and oligodendroglioma. ** "General" category at our institute stands for patients taking treatment at subsidized rates while "Private"- stands for patients taking treatment at non subsidized rates. ***One USD (United States Dollar) =69.45 INR (Indian rupee) as per conversion on 8th April 3:34 AM UTC.

Characteristics	Value
Age (yrs)	
Median	41
Interquartile range	34-45
Gender - No (%)	
Male	28 (70)
Female	12 (30)
Baseline Diagnosis - No (%)	
Glioblastoma	21(52.5)
Grade 2-3 glioma*	19 (47.5)
ECOG PS - No (%)	
0-1	28 (70)
43526	12 (30)
Category - No (%)**	
General	29 (72.5)
Private	11 (27.5)
Monthly Income - INR***	
Median	7500
Interquartile range	4000-30,000

Figure 1 Depicts the primary expectation from systemic therapy in recurrent glioma patients. Both signifies primary expectation being both increased in life span and symptom control.
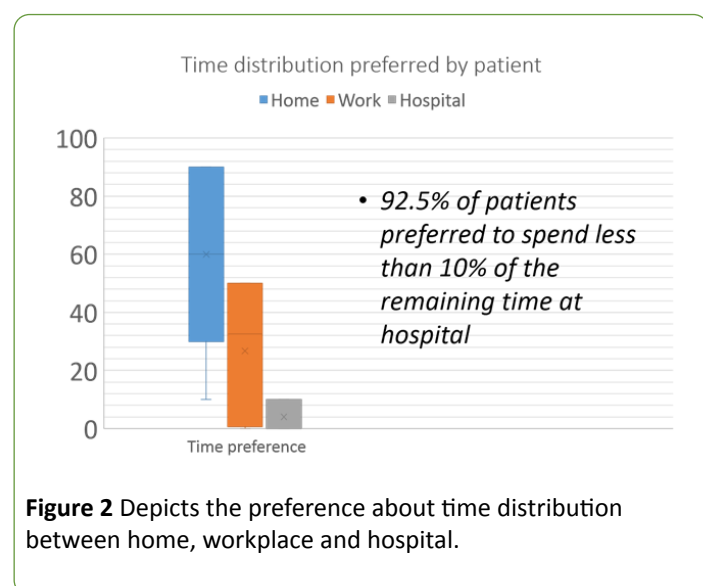
Preferences

Time devotion: Figure 2 shows the box-whisker plot of the preference regarding spending time at home, hospital and work for all patients. The median time patients preferred to devote out of the remaining life span for home, work and hospital were 60% (IQR 60-90), 32.5% (IQR 1.25-50) and 0% (IQR 0-10)

respectively. Thirty-eight patients (95%) preferred to spend 20% or below of their remaining life span in hospital.

Table 2 Magnitude of benefit expected by patients from systemic therapy.

Variable	Value
Minimum prolongation of life expected from chemotherapy - No (%)	
>6 months to 1 year	1 (2.5)
>1 year	39 (97.5)
Minimum number to treat to benefit prolongation of life expected from chemotherapy - No (%)	
One person in 100	11 (27.5)
One person in 50	8 (20)
One person in 20	2 (5)
One person in 10	3 (7.5)
One person in 5	12 (12)
Not answered	4 (10)
Minimum number to treat to benefit symptom control expected from chemotherapy - No (%)	
One person in 100	9 (22.5)
One person in 50	10 (25)
One person in 20	5 (12.5)
One person in 10	2 (5)
One person in 5	10 (25)
Not answered	4 (10)

Figure 2 Depicts the preference about time distribution between home, workplace and hospital.

Adverse event: Details regarding the adverse events preference are shown in **Table 3.** The adverse event most feared by patients and hence not preferred were skin rash (7, 17.5%), numbness (7, 17.5%) and vomiting (6, 15%). Most of the patients (23, 57.5%) were willing for 1-2 admissions during the whole course of systemic therapy for adverse events. While 30% (12) were not willing for any admission due to adverse events and 12.5% (5) were willing for 3-4 admissions.

Table 3 Adverse event magnitude preferences of patients.

Variable	Value
Preferred maximum risk of death with systemic therapy - No (%)	
1% risk	13 (32.5)
2-5% risk	13 (32.5)
6-10% risk	8 (20)
11-20% risk	6 (15)
Preferred maximum risk of adverse events affecting daily living activities with systemic therapy - No (%)	
1-10% risk	19 (47.5)
11-20% risk	9 (22.5)
21-30% risk	9 (22.5)
31-40% risk	3 (7.5)

Drug administration mode, finances and research preferences: Oral mode of administration was preferred by 32 patients (80%). Ninety percent (36) of patients preferred the treatment cost to be below 1000 INR to 100000 INR per month and 72.5% (29) patients preferred not to take a less effective

treatment even if it was cheaper. However, the majority of patients (67.5%, 27) were willing to trade off a survival of >4 months for a cheaper regimen if necessitated. Ninety-five (38) percent of patients were willing to participate in the research protocols if they are available.

Discussion

A PubMed search was carried out with these terms, "(Expectation) AND Glioma" AND "(Preference) AND Glioma", without any filters on 3rd April 2019; 137 and 109 articles were found respectively. However, none of these articles addressed the issue of expectation and preference for systemic chemotherapy in recurrent gliomas. To the best of our knowledge, the current study is the first ever report of expectation and preference for systemic chemotherapy in recurrent gliomas.

One important component of capturing expectation and preferences is awareness of the prognosis. In the current study, all patients were counseled about the prognosis, likely outcomes, chemotherapy side effects, and its cost. Prognostic awareness is variably reported in literature among glioma patients. In a systematic review by Diamond et al., the prevalence of accurate prognostic information was found to be between 25-100% [8]. The inability to provide accurate and complete prognostic information to patients, who want to know it, is likely to lead them to false hope [3]. These false hopes then influence the decision making of the patients. To avoid such collusion, we provided complete and accurate information prior to collecting the expectation and preferences. Provision of such information is likely to induce distress and hence distress screening is required.

The study showed some interesting results. In spite of the knowledge of limited benefit from chemotherapy, prolongation of life was desired as sole or in combination with symptom control as the primary expectation from chemotherapy. Patients were willing for a trade of a higher number of patients to be treated to benefit ratio but wanted the benefit to be in the range of increment in the survival of 1 year or above. Access to treatment is an issue in low and middle-income countries and financial status is one of the deciding factors in the selection of therapy. This is reflected in the preferences were patients were willing to take a cheaper treatment even if less effective and would trade off a survival of a quarter year if required for same. An overwhelming majority of patients were willing for participation in research reflecting the understanding of the disease process and the importance of clinical trials.

The study has its own strengths and limitations. Limitations being that the study captured expectation and preference at a single time point. Hence it does not reflect on the expectation and preferences across the longitudinal course of the disease. The second limitation is that the expectation of caregivers was not captured. Third, no formal sample size calculation was done. The strength of the study is that a homogenous cohort of recurrent glioma was selected. The expectations were captured after detailed counseling.

Conclusion

Prolongation of life either alone or along with symptom control is the primary expectation from systemic therapy of recurrent glioma patients.

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