



Review

Palliative and supportive care needs of patients with high-grade glioma and their carers: A systematic review of qualitative literature

Gaye Moore^a, Anna Collins^{a,*}, Caroline Brand^{b,c}, Michelle Gold^d, Carrie Lethborg^{e,f}, Michael Murphy^{e,g}, Vijaya Sundararajan^h, Jennifer Philip^{a,e}

^a Centre for Palliative Care, St Vincent's Hospital, Melbourne, Australia

^b Melbourne EICentre, University of Melbourne and Melbourne Health, Melbourne, Australia

^c Centre of Research Excellence in Patient Safety, Monash University, Melbourne, Australia

^d Palliative Care Service, Alfred Hospital, Melbourne, Australia

^e The University of Melbourne, Australia

^f Social Work Department, St Vincent's Hospital, Melbourne, Australia

^g Department of Neurosurgery, St Vincent's Hospital, Melbourne, Australia

^h Department of Medicine, Monash University, Australia

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ABSTRACT

Objective: Patients diagnosed with Primary Malignant Glioma (PMG) face substantial challenges with poor prognosis, high symptom burden and care needs. This study aims to collate current literature detailing the supportive and palliative care needs of patients with PMG and their carers, and to subject it to a novel approach of formal evaluation.

Methods: Medline, EMBASE, CINAHL, PsychInfo were searched with core concepts: (1) glioma, (2) high-grade disease, and (3) palliative and supportive care needs. A narrative synthesis approach was undertaken including a quality appraisal of the 21 included studies.

Results: Key themes related to the need for consistent well-delivered information around disease sequelae, treatment, and resources available; health service needs including a key professional identified to coordinate care; the need for psychological and social supports, and clear avenues of communication with treating professionals.

Conclusion: The literature remains limited in the number and quality of evidence with two Level I, eight Level II, and eleven Level III studies. The findings call for improved information, communication and support practices to address the complexity and breadth of needs.

Practice implications: Specialised and individually tailored information, attention to clear, consistent communication and support practices should be incorporated into a future needs-based model of care.

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1. Introduction

People diagnosed with Primary Malignant Glioma (PMG) experience a high symptom burden, characterised by an uncertain prognosis, rapid decline of physical function and behavioural and neuro-cognitive changes. Despite advances in treatment, survival for Grade IV disease remains limited, with median survival reported to be 48.2 weeks [1,2]. Supportive and palliative care services and the provision of evidence-based information, communication and support practices are therefore an important component of multidisciplinary care for this patient group.

Palliative care seeks to improve quality of life of patients and their families facing a life-threatening illness through identification, assessment and treatment of physical, psychosocial and spiritual needs [3]. Supportive care encompasses those services, both generalist and specialist, that assist patients and family to cope at any stage of disease including palliative care [4]. Palliative care and supportive care are therefore terms that overlap but specialist palliative care has well-defined areas of expertise to respond to unresolved symptoms, as well as complex psychosocial, end-of-life and bereavement issues for patients with advanced disease [4]. Limited empirical knowledge exists to describe the needs of those directly affected by PMG, notably patients and their carers [5], thus the provision of supportive and palliative care services are ill-defined [6], and frequently ad hoc [5].

A recent review of psychosocial and supportive care needs of PMG patients conducted by Catt et al. confirmed the gaps in evidence available and highlighted the need for further

* Corresponding author at: Centre for Palliative Care, St Vincent's Hospital, PO Box 2900, Melbourne, Fitzroy, VIC 3065, Australia. Tel.: +61 3 9416 0000; fax: +61 3 9416 3919.

E-mail address: anna.collins@svhm.org.au (A. Collins).

investigation particularly around end-of-life management [6]. Qualitative approaches are well placed to provide direct patient and carer narrative reports of experience and need, thereby confirming or negating the anecdotal reports of clinicians [7]. The challenge is ensuring that such qualitative studies have been conducted with adequate rigour to inform practice, by utilising an established means of appraisal [8].

To date there has been no systematic evaluation of the current qualitative research in this area. This review has developed a novel approach combining two methods to select, report on and appraise the level of quality for qualitative research. This review therefore seeks to bring together previously disparate viewpoints from patients, current carers and bereaved carers, to assess the quality of current evidence, and by doing so, to set a research agenda for a future model of care. The aims of this review are to: (1) document the supportive and palliative care needs of patients with PMG and their carers and (2) undertake a clearly defined appraisal process to evaluate the quality of the current literature.

2. Methods

2.1. Research question

What is the quality of evidence regarding the supportive and palliative care needs of patients with PMG and their carers, what are the key areas of our current knowledge, and what gaps exist?

2.2. Design

The descriptive nature of the research question required knowledge that was rich, contextual and without any pre-conceived boundaries. Narrative synthesis described by Rogers et al. [9] was therefore selected as a well-defined methodology to underpin this review. The steps included (1) theory development which is articulated in the aim, research question, and search strategy undertaken; (2) preliminary synthesis and data extraction through tabulation of findings; (3) exploration of relationships by a thematic analysis; and (4) assessment of the robustness of the synthesis and evaluation of the studies according to previously defined methods of qualitative appraisal including the Critical Appraisal Skills Program (CASP) [10], and hierarchy of evidence-for-practice (HEP) [11].

2.3. Search strategy

An exploratory hand search was first conducted to examine terminology commonly used in the literature to inform the search strategy. Data sources were selected to be sufficiently sensitive to identify all aspects of need across the illness trajectory, yet specific to the target population (i.e. those with high-grade disease) [12].

Electronic databases (Medline, CINAHL, PsychINFO, and EMBASE) were systematically searched to identify studies which included a term relating to (1) glioma, (2) high-grade disease, and (3) some aspect of palliative or supportive care need (palliative care, supportive care, information, communication, quality of life (QOL), psychosocial function, patient or carer need, functional status, end-of-life, and symptom management). All search terms were applied to 'key word', 'title' and 'abstract' and were chosen individually for each database to ensure the terminology corresponded to the databases' system of indexing.

The results of this search were compared with studies from the exploratory hand search to ensure the current search strategy had successfully identified relevant papers. It was noted that some valuable literature had been omitted because it referred primarily to 'brain tumour', not glioma. Therefore the above search strategy

was repeated, searching 'brain tumour' in substitution of glioma, and eliminating any duplicates from the previous search.

The search was limited to literature on adult and human populations, published in English from January 2000 to December 2010. The results were imported into Endnote software program to remove duplicates and monitor selection process. Searches were carried out in January 2011. The full strategy including search terms used for each database is available and may be requested by contacting the corresponding author.

2.4. Inclusion criteria

- *Types of participants*: Patients with PMG at any stage across the illness trajectory or their carers (current and bereaved).
- *Study designs*: Qualitative studies were included which detailed participants' direct reports of their supportive and palliative care needs. Reviews and case reviews in these areas of study were identified and referenced, but excluded from analysis since they were not a direct report of patient or carer need.
- *Types of outcome measures*: Palliative and supportive care needs (including communication, information, support and service provision outcomes) as expressed by PMG patients or their caregivers. Studies were excluded if the focus of the article was medical/clinical treatment, biochemistry or cell-biology, or prognostication.
- *Publication language*: English studies.
- *Methodological quality*: Only studies with sufficient methodological quality were included as described below in Section 2.5.

2.5. Selection of the literature

Fig. 1 illustrates the study selection process. The title and abstract of 933 studies were initially screened according to inclusion criteria (including 5 review articles [6,13–16] and 8 case reviews [5,17–23]), leaving 100 studies for full text review. Seventy-nine studies were excluded because they were not specifically aiming to investigate some aspect of patient and/or carer palliative and supportive care need or not did meet the minimum criteria for rigour [10], leaving 21 studies for appraisal.

2.6. Data appraisal

The recognition of qualitative research and its contribution to the understanding of complex questions and experiences is enhanced by the development of methods of appraisal of rigour [7,8]. This review utilised a two-phase method of appraisal to assess studies (see Fig. 1). (1) Studies selected for full text review were screened according to The Critical Appraisal Skills Program (CASP) [10] to assess study rigour, credibility and relevance for inclusion in the review. Included studies were required to satisfy at least the minimum criteria for rigour: 'Was there a clear statement of the aims?' and 'Is a qualitative methodology appropriate?' These studies were independently assessed by two reviewers and, in the case of discrepancies, agreement was reached by discussion.

(2) The 21 studies which met all inclusion criteria were independently appraised by two reviewers and HEP [11] was used to categorise studies according to their strength of evidence (1 = generalisable, 2 = conceptual, 3 = descriptive and 4 = single case studies) (see Fig. 1). In the case of discrepancies, a third independent review was conducted.

2.7. Data synthesis

Preliminary synthesis was conducted by tabulating the specific details of included studies and outlining the service setting, sample, methodology and key findings (see Table 1). Thematic

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