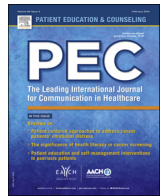




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Patient Perspectives and Characteristics

# Don't need help, don't want help, can't get help: How patients with brain tumors account for not using rehabilitation, psychosocial and community services

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### ABSTRACT

**Objective:** To understand why some adults with primary brain tumors do not use support services despite indications of a need for help.

**Methods:** Nineteen adults recently diagnosed with primary brain tumors participated in semi-structured interviews. Thematic analysis was used to identify recurrent ways participants explained their non-use of support services.

**Results:** Some patients indicated that they did not use support services as they did not need help, in particular reporting positive experiences relative to their expectations or to others, that their needs were met, or difficulties recognizing their needs. Some patients reported not wanting help, citing preferences to self-manage, other priorities, or negative perceptions of the services available. Many patients identified barriers to support service utilization, particularly problems recognizing that services could address their needs and that their needs were valid concerns.

**Conclusion:** The gap between patients' needs and their service use may result from patients' expectations from the medical system, shifting of standards for well-being, cognitive changes, and access issues.

**Practice implications:** Addressing knowledge barriers and perceptions relating to help-seeking, as well as recognizing the challenges specific to this patient group in terms of need recognition and access issues, may assist in improving patients' physical, psychological and social well-being.

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## 1. Introduction

Primary brain tumors are associated with numerous physical, cognitive and neurological impairments, and psychosocial sequelae to the tumor and its treatment [1,2]. Patients often experience functional, occupational, family and social changes, and high levels of unmet supportive care needs [3–5]. Clinical guidelines for glioma, the most common primary brain tumor, recommend offering patients multidisciplinary rehabilitation to address any residual deficits during and following treatment [6,7]. Assessment of patients' needs and referral to information, support and counseling services, and sources of practical assistance, are also recommended [8,9].

Although a clear pathway including assessment of unmet needs, appropriate clinician referral, patient use of services, and subsequent resolution of unmet needs would be ideal, few people affected by brain tumors experience such care. We recently conducted a population-based study in the Australian state of Queensland to assess the supportive care needs and use of multidisciplinary rehabilitation, community and psychosocial services, collectively referred to hereafter as 'support services', among adults recently diagnosed with a primary brain tumor [10]. Participants reported high levels of unmet needs; forty to seventy percent of patients had a moderate to high level of need for help with each of the five most prevalent supportive care needs at each time point. Patient awareness of support services was high, with all or almost all participants being aware of at least one support service in each category of information, health professionals, support and counseling, and practical assistance. Clinician referral to services varied across categories, but the proportion of patients referred to at least one service in each category ranged from 47% to 81%. However, use of support services was low relative to need,

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particularly for support and counseling services and practical assistance.

Our results add to growing evidence that a gap between patients' needs and their use of supports or support services exists [2–4,11–13]. The gap may be partly due to factors relating to the availability of appropriate services, particularly in regional or rural areas [14]. Low clinician rates of referral of people with brain tumors to support services have been demonstrated in the US [15], the UK [16], and Australia [17]. Even if support services are available and accessible, however, patients must choose to use them.

A number of studies have qualitatively explored the reasons why patients with brain tumors use support services of various kinds. These studies suggest that patients want support services to help address their needs for information, navigate through bureaucratic processes, and to return to pre-treatment responsibilities or prepare for long term care [18]. Patients with brain tumors found brain tumor-specific support services valuable for understanding their illness and receiving emotional support [19], and brain tumor support groups helpful to maintain morale [20]. Health professionals were seen as able to provide expert opinion, treatment and support, which was valued as patients grappled with uncertainty over their prognoses and how their diagnoses would affect their quality of life [21]. Cognitive and physical rehabilitation services were used to help patients to understand their impairments and develop strategies to manage them [19], and to 'get back to normal', gain independence, maintain hope, and connect with everyday life [22]. To the best of our knowledge, no study has specifically investigated why patients with brain tumors do not use support services, although Hackman suggested that some patients may not understand the purpose of rehabilitation in light of a poor prognosis [22].

The reasons why patients with primary brain tumors do not access support services is unclear. This paper reports a qualitative study designed to explore the experiences of adults with primary brain tumors who have unmet needs. Our purpose here is to explore the reasons reported by patients with brain tumors when explaining their non-use of support services to address their unmet needs.

## 2. Methods

Research ethics approval was obtained from Queensland University of Technology Human Research Ethics Committee and the Queensland Cancer Registry (QCR). Methods are described in full elsewhere [10]. Briefly, potential participants were identified through the QCR, a population-based cancer registry which records all brain tumor diagnoses in Queensland, Australia. Eligible participants were adults aged eighteen years and over who had been diagnosed with a malignant or benign primary brain tumor. Patients were approached for participation at approximately three months post-diagnosis, to allow the completion of primary surgical and radiotherapy treatment, and after confirmation of eligibility and permission to contact was provided by their treating doctors. After written informed consent was provided, participants completed structured quantitative questionnaires, administered via telephone interview, to ascertain their unmet supportive care needs and secondary outcomes. Approximately three months later, participants were administered the same questionnaire, plus a questionnaire assessing their awareness of, referral to, and use of psychosocial, rehabilitation or community services.

### 2.1. Qualitative interview procedure and schedule

Semi-structured interviews were conducted at the end of the follow-up quantitative telephone interview and aimed to identify

barriers and facilitators to utilization of support services. Interview content was informed by the concepts identified in the literature as possible influences on decisions to use health services. Concepts included self-efficacy, social support and constraints, attitudes to help-seeking, subjective norms, distress, outcome expectations, awareness of services, and clinician referral. Although participants were encouraged to speak spontaneously, prompts were used to assess topics which had not been introduced from the concept list. As many patients had identified significant unmet supportive care needs and low utilization of support services in the quantitative questionnaires, many interviews focused on participants' reasoning for not using support services despite reporting unmet needs, and thus is the focus of the analysis reported here. The qualitative component of the interviews took between 15 and 30 min. Interviews were audio recorded and transcribed verbatim.

### 2.2. Participants and setting

Of the forty persons who participated at baseline, 32 participated at follow-up, and 27 of those participants completed a qualitative interview (Fig. 1). In eight cases, a family member participated on the patient's behalf at follow-up with their consent, as the patient was not well enough to participate. To ensure that data reported reflected patients' perspectives, analysis was undertaken of data from the 19 interviews conducted with patients only. Although the exclusion of data collected from family member proxies may limit the sample to those with better health status, some studies suggest that partners are typically more dissatisfied with patients' psychosocial care than patients themselves [23,24]. Family members may also experience barriers to having their own psychosocial needs met, which may influence their perceptions of the psychosocial services available to the patient, and their reasons for using or declining support services [25]. Although data collection was undertaken with all available participants rather than until theoretical saturation, the rich data and recurrence of themes allows empirical confidence in the theoretical propositions generated [26], in a novel and understudied area.

Interview participants were ten women and nine men, half of whom lived in a major city. Eight had received a diagnosis of a malignant brain tumor, nine had a diagnosis of a benign brain tumor, and two reported being unaware of the malignancy of their tumor. Participants reported a median of nine (range 1–21) moderate or high level unmet supportive care needs at baseline, and one (range 0–26) moderate or high level unmet needs at follow-up. The most common unmet needs were *concerns about the worries of those close to you* at baseline and *lack of energy or tiredness* at follow-up.

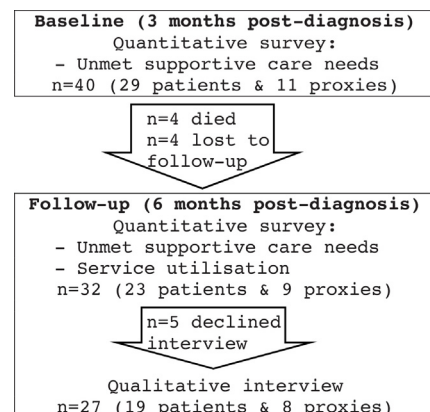


Fig. 1. Study design and participation across study activities.

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