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Symptom experience in patients with primary brain tumours: A longitudinal exploratory study

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ABSTRACT

Purpose: This study was undertaken to further understand the symptom experience and the impact of symptoms in daily life in people treated for brain tumours.

Methods: A qualitative prospective longitudinal design was used with 9 people who were interviewed over 4 time points (soon after diagnosis, 3 months, 6 months and 12-months post-diagnosis), providing 21 interviews in total.

Results: Key issues for these participants were ongoing fatigue, memory loss and inability to drive. Fatalistic views about the outcomes of their disease were the norm. Participants made adjustments to their lives to accommodate their functional limitations. These included making home alterations, introducing regular exercise to their lives and using complementary therapies. Their expectations did not always match with the reality of the situation, which made several participants angry and dissatisfied with health care professionals.

Conclusions: Issues of quality of life are paramount in this group of poor prognosis patients, therefore, health professionals should provide preparatory information to patients on what to expect from the illness and its treatments. Health professionals should also assist patients to manage debilitating symptoms such as fatigue and cognitive impairment.

Introduction

Primary and metastatic brain tumours are a significant cause of morbidity and mortality in cancer patients world wide. In the UK alone, approximately 4500 new primary brain tumours are diagnosed each year (Hamilton & Kernick, 2007). Patients often undergo many treatments, including neurosurgery, systemic chemotherapy and brain radiotherapy, and experience multiple symptoms. Broadly, the symptoms from primary and metastatic brain tumours can be physical (e.g. fatigue, headaches,) emotional (e.g. depression and anxiety) and neuro-cognitive (e.g. decreased attention and concentration, poor short-term memory and speech/language difficulties) (Shaw & Robbins, 2006). While there is information on symptom prevalence in the literature, little is known about how patients experience these symptoms and the impact symptoms have on their daily lives.

The data that is available on the brain tumour population is mainly descriptive in nature (frequencies and intensity of symptoms) (Armstrong et al., 2006; Fox et al., 2007) and does not highlight the meaning behind them from the patients' perspective. In a study of 124 patients with brain tumours it was shown that the most common symptoms experienced were constitutional in nature, including fatigue, sleep disturbance, drowsiness, distress and dry mouth (Armstrong et al., 2009). Six symptoms, including fatigue, uncertainty about the future, motor difficulties, drowsiness, communication difficulties and headaches were reported in >50% in a sample of patients with glioma, impacting on their quality of life (Osoba et al., 2000). Weakness and headaches were the two main symptoms reported at a frequency of >50% (data was obtained from both medical records and from home interviews) in a sample of 92 patients with brain tumour (Davies & Clarke, 2004). Depression has been identified as the single most important symptom predicting quality of life in a cohort of 73 patients with primary brain tumours (Pelletier et al., 2002). In a more recent study, two symptom clusters were identified in a group of newly diagnosed people patients with brain tumours after subjecting symptom data to factor analysis,

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including a language cluster (i.e. difficulty reading or writing and finding the right words), and a mood cluster (sadness, anxiety, depression) (Gleason et al., 2007).

However, the vast majority of the relevant literature is quantitative in nature, using retrospective or cross sectional designs. There is minimal work in this patient population assessing symptom experience with in-depth interviews and exploring the effects of these symptoms on patients' everyday life. Hence, the aim of the current study is to better understand the symptom experience of newly diagnosed patients with brain tumour over time, and to explore the meaning and impact of those symptoms from the patients' perspective. Such work could enhance our understanding of the needs and experiences of this under-researched group of patients, could develop new hypotheses for future research and could identify practice issues that health care professionals need to address in more depth.

Methods

Design

The study used data from qualitative interviews and field notes, and its design was prospective longitudinal. This was part of a larger programme of research in cancer patient symptom experience, involving eight cancer diagnostic groups; people with brain tumours being one of them. Originally all interviews were planned to be analysed together. However, during analysis, the data from participants with brain tumours seemed quite distinct from the other cancer diagnostic groups, meriting report separately from the other groups. Hence, some methodological issues, that may seem ambitious in nature for this particular small group of typically poor prognosis patients, reflect the larger programme of work rather than a design specific to patients with brain tumours. This is a key limitation of the current report. Examples of the output of the larger study include our work with people diagnosed with lymphoma (Johansson et al., in press), myeloma (Potrata et al., in press; Molassiotis et al., in press-a), experiences of diagnostic delays (Molassiotis et al., 2010) and the quantitative analysis of the programme (Molassiotis et al., in press-b), with several others being in the process of being published. The interviews were designed to give participants the opportunity to discuss their experiences around symptoms in their own terms and to give the opportunity for the interview to assess the meaning and significance of the symptoms. Leventhal's self-regulation theory (Leventhal & Johnson, 1983) has served as the study's theoretical framework, which suggests that symptoms activate a cognitive search process, resulting in the construction or elaboration of illness representations. These representations then serve as standards against which new information is matched and evaluated.

The interviews were conducted by experienced qualitative researchers using a narrative format. This provided a relaxed and casual atmosphere that encouraged patients to discuss their experiences of symptoms and allowed patients to naturally convey their reflections on the symptoms and how they interpreted them. The interviews were conducted prospectively over the first year from the initial diagnosis, namely soon after diagnosis (1st interview), around 3 months (2nd interview), 6 months (3rd interview) and 12-months (4th interview) post-diagnosis. This was the design of the larger study (not specific to the current sample) and reflected the beginning of treatment, time during treatments, end of treatments and survivorship/long-term outcomes, respectively. While a specific qualitative paradigm for data collection, interviewing and analysis was not used as such, a common sequence of steps for the data collection, interpretation and analysis as described by Miles & Huberman (1994) were followed. This included noting the researcher's reflections, devising and affixing codes to field notes from interviews, conducting a more focused investigation in observed commonalities and differences in the next wave of data collection and so forth.

Sample

Participants were recruited from a specialist oncology centre in the UK which receives referrals from around the country. While 24 people with brain tumours were approached to participate in the study, 11 people provided consent, with the remaining patients being too ill to participate or not wanting to take part. Previous experience suggests that this sample size is adequate to tap the range of patient experiences and understandings, while ensuring that the data analysis does not become unmanageable and allowing a deep, case-oriented analysis to take place. The sampling method was broad to include maximum variation in perspectives and views. The sample included patients with any disease stage, left- and right-sided brain tumours, and those receiving chemotherapy or radiotherapy (with or without radiosurgery). People with cognitive impairment at recruitment, life expectancy of less than 6 months at recruitment, or unable to carry out the interview, were excluded from the study.

Procedures

The study was approved by the local Research & Ethics committee and the Ethics committee of the University of Manchester. Patients were recruited shortly after diagnosis when they arrived at the hospital to receive their first treatment. They were subsequently provided with information about the study and written consent was obtained. The first interview was conducted towards the end of the first month post-diagnosis. Subsequent interviews were held at 3 months, 6 months and 12-months post-diagnosis. The interviews were semi-structured and an interview topic guide was also developed to aid in the fluency of the interview and subsequent analysis. The interview started with the researcher asking the patient ‘How have you been feeling physically this past week?’. Other questions included ‘How have you been feeling emotionally this past week?’; ‘What were the most distressing symptoms you experienced and why?’, ‘How did you attempt to manage your symptoms?’, ‘What is it like living with the (reported) symptoms?’. New issues identified in the early interviews were incorporated into the interview guide for subsequent interviews. All interviews were tape-recorded (subject to respondents' consent) and subsequently transcribed verbatim. Interviews were carried out by two experienced qualitative researchers (BW, LB) who also received training in interviewing and supervision from a senior researcher (AM). Regular meetings took place between the team members to discuss progress and any issues deriving from the study thus far. The average interview duration was approximately between 45 and 60 min. The interview location was at a convenient place for patients (often their home).

Information about socio-demographic characteristics including age, gender, education, and marital status, as well as disease and treatment-related information (diagnosis, treatment received, stage of cancer), were retrieved from the patients or the patients' records as appropriate.

Data analysis

The participants' descriptions of their post-diagnostic symptoms were primarily read and then analysed using content/framework analysis (based on Leventhal's theory), and were compared with the field notes. Key themes were inductively deduced and derived from the transcripts in line with the overarching aims and objectives of the project. Then, key summaries were made of the patterns within those themes and master copies were produced to compare themes