

## How do patients with malignant brain tumors experience general practice care and support? Qualitative analysis of English Cancer Patient Experience Survey (CPES) data

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### Abstract

**Background.** English Cancer Patient Experience Survey (CPES) data show patients with brain cancer report the least-positive experiences of general practice support. We aimed to understand these findings by identifying the issues described in qualitative survey feedback and suggest how care may be improved.

**Methods.** We reviewed 2699 qualitative comments made to open questions about what was good or might be improved about National Health Service care between 2010 and 2014. We identified 84 (3%) specific comments about general practice care and used open coding and framework analysis to develop a thematic framework.

**Results.** We identified 3 key themes and 12 subthemes: first, the experience of initial diagnosis by a general practitioner (GP), including apparent complexity of making the diagnosis, apparent slowness in referral for investigation, referral made by patient or family, delay in receiving scan results, and whether the GP quickly identified the problem and referred to a specialist; second, the experience of care and support from the general practice, including lack of supportive response from the GP, lack of follow-up care from the GP, lack of family involvement by the GP, lack of GP knowledge about management, and whether the GP responded in a supportive way to the diagnosis; and third, the experience of overall coordination in care, including lack of communication between the hospital and general practice and good communication about the care plan.

**Conclusion.** Qualitative responses from patients with brain cancer reveal their needs for better emotional and practical support within primary care. Suggestions include increasing the speed of initial referral for investigation, the depth of discussion about diagnostic difficulties, and developing coordinated care plans with cancer centers.

### Keywords

brain neoplasm | patient experience | primary care

Primary malignant brain tumors (International Classification of Diseases [ICD] 71) are uncommon tumors that occur in England, with an age-standardized incidence rate of 10.5 per 100 000 population for men and 6.5 for women. During 2017 they affected 3602 individuals.<sup>1</sup> Around 85% of malignant brain tumors are classified as gliomas, and despite aggressive treatment by surgical resection,

radiotherapy, and chemotherapy, only 40% of UK patients with brain cancer survive 1 year from diagnosis and only 19% survive 5 years.<sup>2</sup> The profound physical and cognitive effects malignant brain tumors may have on patients' psychological and social functioning, their quality of life, and their needs for supportive care are well documented.<sup>3-5</sup> These consequences are also recognized as raising a

number of challenges for health professionals caring for patients in the community.<sup>6</sup> In 2006 the National Institute for Health and Clinical Excellence (NICE) published guidance for the care of professionals treating individuals with brain and other CNS tumors in England and Wales.<sup>7</sup> Its supportive care guidance covered communication, patient information, psychological and social support, rehabilitation services, and general palliative care, but was largely designed for hospital cancer and palliative care health professionals rather than those working in primary care.<sup>7</sup> Later guidance for the urgent referral of patients with suspected brain and CNS cancers using the 2-week waiting period included a recommendation that general practitioners (GPs) consider an urgent MRI or CT scan “in adults with progressive, sub-acute loss of central neurological function.”<sup>8</sup>

A few early studies analyzed the interview accounts of patients with malignant brain tumors and their relatives and found that the time leading up to the diagnosis may be characterized by a series of nonspecific symptoms that are difficult to diagnose in primary care and that may then be followed by dramatic, disabling, and life-threatening deterioration.<sup>9,10</sup> These findings are reflected in recent large-scale analyses of English cancer data sets. For example, patients with brain cancer are least likely to have been diagnosed by “fast-track” referral routes designed for patients with cancer symptoms, with only 6% of patients going through this route.<sup>11</sup> They are also among the most likely of all cancer patients to be diagnosed during an emergency admission to the hospital at 62% compared with 24% for all others.<sup>12</sup> Quantitative analyses of the English national Cancer Patient Experience Survey (CPES) find that patients with brain and CNS cancers are one of the groups least likely to report that they saw their GP no more than twice before being told to go to the hospital (61% compared with 75% for all other patients).<sup>13</sup> They are also less likely than other patients to report feeling they were seen as soon as necessary in the hospital (78% compared with 83%) or that their health got better or stayed the same while they were waiting to be seen (64% compared with 80%).<sup>13</sup>

An in-depth national audit of the primary care diagnosis of 226 cases of brain tumors found that GPs were more likely to identify avoidable delay when patients had presented with headache alone rather than with other neurological symptoms.<sup>14</sup> In addition, patients with brain tumors are least likely, compared with other cancer patients, to report in CPES that staff at their general practice “did all they could to support them while they were having treatment” (55% compared with 66% for all others) or that different hospital and community staff worked well together (51% compared with 63% for all patients).<sup>13</sup> These findings suggest there may be scope to improve patients’ experiences of primary care support and cancer care. One way of investigating the reasons that may underlie less-positive patient survey results is to make use of more detailed qualitative data in comments from patients collected at the end of the survey.<sup>15,16</sup> Because these data available from patients with brain tumors have not yet been explored or extensively reported, we aimed to 1) understand patients’ experiences of general practice care in more detail by identifying the range of issues described in qualitative written survey comments within the CPES and 2) use these analyses to suggest ways in which care and support may be improved.

## Methods

### Study Setting

This study used national English data collected for the CPES by Quality Health (QH) between 2010 and 2014. The survey was designed in consultation with the Department of Health, patients, staff at National Health Service (NHS) hospital trusts, and researchers to collect information on patients’ experiences of cancer care in England. It has been carried out at 153 acute and specialized NHS hospital trusts in England annually since 2010,<sup>13</sup> and results have been used nationally to monitor the implementation of cancer care policies and to provide feedback on comparative data to individual NHS hospital trusts.<sup>17</sup>

### Selection of Participants

In each of the years 2009 to 2013, NHS hospital trusts reviewed data for their adult patients to identify those admitted with a diagnosis of cancer between September and November who were eligible for the survey. The names of those aged 18 years or older were identified from patient lists, checked against the Patient Administration System within hospitals, and sent to QH by research nurses and administrative staff. After further checks that each patient was still alive, QH sent a survey directly to each person at home between January and June the following year. This study considered only surveys returned from patients coded by hospitals as having been diagnosed with primary malignant brain tumors (ICD 71).<sup>18</sup>

### Data Collection

During the study period 2010, 2011 to 2012, 2013, and 2014, CPES asked patients 68 questions about their experiences of NHS care, including their diagnosis and hospital treatment, clinical nurse specialist contact, the information they received about support available, home care and support, and care from their general practice. Two of the 68 survey questions asked specifically about general practice care. At the very end of the survey 3 open questions asked 1) “Was there anything particularly good about your NHS cancer care?” 2) “Was there anything that could have been improved?” and 3) “Do you have any other comments?” Of 2739 patients with brain cancer (ICD code 71) who completed the survey, 2699 made comments about their cancer care or added further comments about the questionnaire itself. These comments, which covered a wide range of NHS care issues identified by patients as important, were transcribed verbatim by QH staff from the returned questionnaires. Names of staff or hospitals were omitted, and QH supplied these comments to the researchers with personal identifiers such as name, age, postal code, or NHS number removed.

### Research Design

This study sought to identify, describe, and understand essential features, issues, or themes relating to patients’

reported experiences of general practice support and care. Our focus was on making use of and understanding the more detailed qualitative comments initiated by patients about this aspect of their care to understand or make sense of the quantitative results.<sup>15,16</sup> A qualitative inductive approach is an appropriate way to identify and analyze potential themes emerging from free responses to such open questions. This approach allows categories or dimensions of analysis to emerge without presupposing what these will be, or by specifying an a priori hypotheses or conceptual framework. We used framework analysis, which is a commonly used method in health policy research for identifying a thematic framework of issues relevant to patients and staff.<sup>19</sup> It has also recently been used to analyze the open comments made by patients completing the CPES to try to understand why patients in London report less-positive survey responses than those in the rest of England.<sup>16</sup> The purpose of developing such a framework is to identify issues of salience or concern for a study population and to try to understand their interrelationships or perceived consequences. The method is designed to work with a sample that represents a range of responses rather than a representative one and does not presume that the final framework is representative of all possible responses. All analyses for the study were performed on anonymized data, and separate ethical approval was therefore not required.

## Data Analysis

The comments that mentioned an aspect of general practice care were initially identified and extracted from all others by the first researcher (IF). There were 101 comments mentioning general practice care, but 17 appeared to have been made by relatives or carers rather than patients themselves. We concentrated on the 84 comments that had clearly been made by patients, and these amounted to 3% of the 2699 comments about all aspects of NHS care. Eleven were responses to the question "Was there anything particularly good about your NHS care?" Forty-five were responses to the question "Was there anything that could have been improved?" Twenty-six were responses to the question "Do you have any other comments?" One researcher (IF) first used a process of open coding to assess the focus and meaning of each comment about general practice care. The codes were then compared and the data clustered together to develop an initial set of categories and themes within a potential framework. This was discussed with the second researcher (ED), who reviewed all these comments and coded, categorized, and sorted them to develop a similar though slightly different second framework. Together we reviewed and discussed the 2 frameworks, identifying which comments fitted within each, which did not, and where they agreed or disagreed. A number of comments appeared to fall into different or several framework categories, or it appeared unclear whether the patient was conveying a positive or negative point. We identified and discussed these differences to agree on the final framework. This included 3 key themes: 1) experience of initial diagnosis by the GP, 2) experience of care and support in general practice, and 3) experience of overall coordination

in care. Five separate subthemes were identified within themes 1 and 2 and 2 within theme 3 (Box 1).

## Results

Overall the 84 comments analyzed suggested some variation in patients' experiences. Most (68/84, 81%) described a negative aspect of care across either the initial diagnostic phase or through treatment and into follow-up care. These comments focused on the need to establish a clear initial diagnosis and avoid delays (n = 39), lack of support or a disappointing response from their general practice (n = 17), and overall issues in coordination of care between their cancer center and general practice (n = 12). The remainder reported positive comments about the diagnosis or supportive care (n = 16). Three fundamental aspects influencing patients' experiences of support from their general practice were identified in the analysis framework (Box 1). These are considered in turn together with the subthemes within each, and illustrated using specific examples.

### Experience of Initial Diagnosis by General Practitioner

The most common issue patients commented on was an apparent complexity of making the diagnosis, which had often left them overwhelmed by what they now interpreted as a misreading of the initial symptoms and a consequent

#### Box 1. Thematic Framework Developed to Understand the Experience of General Practice Support for Patients With Brain Tumors

1. Experience of initial diagnosis by general practitioner (GP)
  - a. Apparent complexity of making the diagnosis
  - b. Apparent slowness in referral for investigation
  - c. Referral made by patient or family
  - d. Delay in receiving scan results
  - e. GP quickly identified problem and referred to specialist
2. Experience of care and support from GP
  - a. Lack of supportive response from GP
  - b. Lack of follow-up care by GP
  - c. Lack of family involvement by GP
  - d. Lack of GP knowledge about symptom management
  - e. GP responded in a supportive way to diagnosis
3. Experience of overall coordination in care
  - a. Lack of communication between hospital and general practice
  - b. Good communication of care plan

later diagnosis. Patients commented that their GP had not appeared to recognize unusual symptoms or behavior. For example, they recalled the initial diagnoses as “sinusitis for weeks,” “suspected meningitis,” “epilepsy symptoms,” “vertigo,” or “carpal tunnel syndrome.” Other patients suffered further symptoms from their tumors, for example, “headache for months” or “changed practices because my original doctor told me to go for long walks and cut out caffeine to stop my headaches.” Many of these patients felt they had needed to present themselves several times, often with the same symptoms or issues, until they were referred for investigation or admitted as an emergency: for example, “saw 2 GPs in 2 weeks” or “my illness was confirmed at hospital within one hour, but missed by 2 GPs.” One other observed that the diagnosis was found incidentally by another specialist “6 months” later.

Although most patients appeared to have relied on their GP to assess their symptoms, in a few cases the referral was made by patients or their family. Several patients reported that their relatives had not been certain that the initial diagnosis was correct and had taken them directly to the hospital for a second opinion: for example, “on the Saturday (next day) my wife felt I was getting worse so took it upon herself to take me to hospital” or “my wife insisted I go to hospital.” Others described making “many appointments to the GP” before receiving a diagnosis, and some remained dissatisfied with this: for example, “GPs I saw would (of) listened to me earlier on and arranged a scan,” or “my GP they should listen to me straight away” or “GP should have shown more care and understanding.” Associated therefore with this apparent complexity of making the diagnosis was an apparent slowness in referral for investigation: for example, “should have taken my symptoms more seriously, earlier.” Other patients described problems with administrative processes and repeated cancellations of appointments leading to delays in receiving scan results. By contrast, some participants reported a very good experience in that their GP had quickly identified their problem and referred them to a specialist: for example, “quick admission to the hospital,” “speed of referral”, or prompt investigation after reporting symptoms to their GP “within a week, I was diagnosed with a brain tumour.”

### Experience of Care and Support From General Practice

Some patients described negative experiences of care from their general practice in the period following brain surgery or treatment or felt disappointed and alone during this time. These patients identified a lack of a supportive response from their GP, with ongoing physical and psychological issues including their need to talk, ask questions, and regain their self-confidence. There was also a sense of a lack of follow up care: for example, “I have not had any follow up care or had any contact to them to check progress and wellbeing,” or “following my operation there was no communication from the GP regarding the surgery.” Some patients also reported experiencing a lack of family involvement by their GP: for example, one patient reported, “family should have been involved when the

GP was giving results.” Another described a lack of a supportive response for themselves and their carers during their appointment: “GPs were insensitive and very unprofessional towards my family,” “GP care could be better,” “GP care was very poor,” and “I am not happy with the level of service with my GP” Some patients expressed dissatisfaction with a lack of GP knowledge about symptom management: for example, “I wish my GP had altered my epilepsy medication before I lost my job. This took months to sort out and was simply a case of changing medicines,” or “More input from my GP and district nurses for side effects, seizures, swollen feet.”

By contrast, several patients praised how their GP responded in a supportive way to their diagnosis: for example, “It took a month to sort out diagnosis but my GP group practice remains supportive in every way,” or “fantastic support from GP throughout. After diagnosis very quick admission into hospital at operation for removal of tumour,” “GP was very supportive and provided the best care,” and “GP very well in all care throughout and excellent.”

### Experience of Overall Coordination in Care

Another important issue was the challenge for the care system to provide coordinated care. The majority of the patients who commented on this mentioned a lack of communication between the hospital and the general practice as a key theme. Examples included “GPs and hospitals do not communicate” or “more co-ordination care between GP and hospital and district nurses.” Some patients reported that new information did not always reach their GP: for example, “No copies of my details yet from recent contact sent out” or “GP didn’t receive discharge letter as never posted from the N” or “no information was given to my GP—he had to write a letter asking for advice on future care.” Transitions from one care setting another appeared to be times of heightened stress and uncertainty. A few patients described their GP receiving misleading information: for example, “stating my tumour was benign when in fact it was malign” or “not told enough about my side-effects and difficulty in needing to go to my GP” Some patients recognized that negative experiences of coordination were due to the system of care rather than their general practice itself. A slow communication of routine information between different hospital departments and the GP was often mentioned. For example, “info from hospital too slow in getting to GP,” “medication—I was given (it) 10-14 days after my return home,” “No information about the health status of the patient at all” and “(GP) did not know I’d had a 2nd biopsy.” Patients suggested improvements such as “more coordinated care between GP and hospital and district nurses,” “better access to test results, scans etc,” “GPs could have more easily accessed information, eg, results of scans.” One observed the role they had to play themselves—“on occasion I have had to coordinate receipt of blood test results from local A&E [accident and emergency], district nurse, specialist unit and keep all parties updated.”

In addition, some patients emphasized the supportive and generally positive collaboration between the different

professionals throughout their diagnosis and overall treatment: for example, “GP delivered this news sensitively and had ensured that the consultant, surgeon and team were ready for me before I arrived at A&E,” and “I had the best care and treatment from start to finish and brilliant after-care from hospital and my GP”

## Discussion

### Summary of Main Findings

This study used qualitative data from 84 patients with malignant brain tumors collected by the English national CPES between 2010 and 2014 to better understand their experiences of general practice care. Framework analysis found that most patients (68/84, 81%) identified negative aspects of care and that these could be categorized into 3 distinct themes. These were first, experience of the initial diagnosis by their GP, second, ongoing support and care from their general practice, and third, overall coordination in care. The aspects patients identified for improvement related to their perceptions that it had taken longer than necessary to make the diagnosis, their needs for emotional support in adapting to the diagnosis and managing symptoms after treatment were not met, and that care was not always well coordinated between the hospital and their general practice.

### Comparison of Findings to Previous Research

There is little previous qualitative research on the experiences of patients with brain tumors with primary care or general practice support with which to compare these findings. However, one early interview study found that 60% (36/64) of patients questioned were highly satisfied with their GP,<sup>20</sup> reporting that they had been quick to see them, organized referral, and showed concern. A significant proportion (20%, 13/64), however, were very dissatisfied, and the principal reasons given were feeling that their GP had not acted quickly enough on their early symptoms or shown little interest in them after the diagnosis.<sup>20</sup> Likewise, a Danish study has shown that patients referred by specific cancer referral pathways are more likely to report overall positive experiences of the prediagnosis phase compared to others.<sup>21</sup>

As already noted, the national CPES data for 2010 to 2014 show that patients with brain cancer consistently report more negative experiences of support from staff at their general practice than other patients with cancer,<sup>13</sup> and these findings persist in the more recent survey results for 2015 and 2016.<sup>22,23</sup> The consistency of the new qualitative findings with the earlier explanations elicited at interviews suggests that a combination of diagnostic, follow-up, and coordination factors may explain the less-positive overall CPES findings of support from their general practice reported by these patients. The qualitative findings on the perceived need from patients for better supportive follow-up care and coordination are also consistent with findings from early interview studies and subsequent systematic reviews.<sup>3,4,9,24</sup> Good communication is recognized as an important element of supportive

care, particularly because psychological distress and mood changes are common in patients with malignant brain tumors.<sup>4</sup> Coherent information is also very important for those relatives and carers at home with these patients.<sup>25</sup> The problems patients describe with the overall coordination between hospital and primary care services are also consistent with an early small survey of 24 GPs who had looked after patients with malignant brain tumors. One-half (12/24) were dissatisfied with at least one aspect of information or care from the treatment center.<sup>20</sup>

### Strengths and Limitations of the Study

This is the first qualitative study of comments from a substantial number (84) patients with malignant brain tumors about primary care support. Its strengths are that it draws on a national survey of English patients carried out in 4 consecutive years. The issues identified are therefore likely to be representative of patients responding to CPES and for whom some aspect of general practice care was particularly salient. It seems unlikely that these comments would be specific to general practices or neuro-oncology centers in particular geographical areas. The number of comments made about primary care support also seemed to reflect the proportion of questions in the survey about general practice support. However, patients returning the CPES are already a selected group in that they have survived into the sampling frame period of 3 months following discharge from the hospital and are well enough to focus on, complete, and write additional comments in the survey.<sup>26</sup> This means that those with a poorer prognosis including older patients are very likely to be underrepresented. Indeed Abel and colleagues estimated that 16.5% of the initial hospital sample of these patients had died before the survey could be sent to them.<sup>26</sup> The survey is also completed in English only, and non-English-speaking citizens may have chosen not to seek translation services. In addition, the CPES survey was quite long, including 83 demographic and care questions over 12 pages and may therefore have been too time-consuming or complex for ill patients with cognitive problems to complete. This is suggested by a proportion of surveys in which relatives appeared to have written in comments about general practice care for the patient (17/101, 17%). The large number of comments patients made about their NHS care were outside the study focus on primary care support but it would be useful to study whether patients with brain cancer make particular comments about their care more frequently or in different ways from patients with other types of cancer. Finally, though national data are useful for identifying issues that need to be addressed at a policy level, the sample size does not provide sufficient information for local quality improvement purposes. A larger and more specific survey would be needed to provide more detailed information on general practice care around different treatment centers, and face-to-face qualitative interviews could have obtained a multifaceted picture of the different themes identified. Finally, though we took steps to ensure a systematic approach to the development of the framework, it is possible that our attitudes and previous clinical and research experience with these patients influenced the study design and analysis.

## Implications for Policy, Practice, and Research

These findings shed light on patients' perspectives on a cancer that is often very difficult to diagnose at an early stage in general practice. They suggest ways in which policy makers may consider how care may be centered around the needs that patients identify as important in this situation. Recent NICE guidance has not explicitly reconsidered aspects of support and follow-up in primary care or the overall coordination between hospitals and general practice care, but has concentrated instead on identifying symptoms that are most likely to signify brain tumors. Policy makers can ensure that consistent and less-positive CPES findings are highlighted in annual reports, that national guidance and local improvement plans consider these, and that research is commissioned nationally to develop interventions to improve these elements. New guidance may be necessary to support GPs in diagnosing these patients and to care and support them with a complex range of symptoms and problems that they and their families face. For example, a recently published interview study of 39 patients and their relatives or carers identified a range of nonspecific initial changes in function that had been noticed and taken to their GP. It also revealed that the perceived quality of GP communication played a role in patients' decisions to reconsult regarding these issues.<sup>27</sup>

From the perspective of general practice it could be argued that it is inevitable these patients will report less-positive experiences than other cancer patients because any single GP will see very few patients develop brain tumors during their careers. One approach to this situation is that taken by neurological charities that have focused on developing training on the assessment and referral of key neurological symptoms.<sup>28</sup> A recent national audit of the diagnosis of 226 patients with brain tumors found that in around one-third of cases the GP involved considered or was not sure whether there had been avoidable delays in diagnosis. In around 20% of the cases reviewed the GPs felt that rapid investigations would have been helpful, and the authors suggested that GPs test patients with headache for cognitive problems.<sup>14</sup>

Another approach is to recognize that once the diagnosis has been made in the hospital, the primary care focus should be on discussing perceived delays in diagnosis with patients and their family, providing support, and becoming involved in developing an overall care plan. Up to the point of diagnosis the GP is the health care professional who is likely to have known the patient and his or her family the best. During treatment and beyond the GP remains geographically closest to them and is most likely to be involved in palliative care when this takes place in the community. Improving support locally therefore means treatment centers understanding the significance of quickly providing information about the diagnosis to the GP together with a package of information to help resolve lingering doubts the patient and family have about the influence of any delay on the prognosis. Much of the information needed is available to national brain tumor charities but may need to be repackaged via the internet for busy GPs.<sup>28</sup> Indeed, signposting to such information may help GPs repair any damage the diagnostic period has made to their relationship with the patient.

In terms of research, more qualitative studies are needed to understand patient and family help-seeking behavior and professional responses to symptoms. Mood and behavioral changes due to the tumor are relatively common, and future studies might explore whether these influence consultations in general practice and in turn influence patients' experiences with them.

## Conclusions

Patients with brain tumors may present in primary care with symptoms that are often initially difficult to diagnose. After diagnosis these patients face a poor prognosis, and their disease may cause a wide range of physical, cognitive, and social problems. This first study using qualitative CPES data to identify patients' specific experiences of GP or family doctor care revealed the most common themes were about establishing the diagnosis, apparent delays in referral, lack of supportive responses, and poor coordination in care between their treatment center and general practice. These findings may explain the overall less-positive CPES survey results for general practice care and suggest that GPs could be more involved in discussing perceived delays in diagnosis, developing care plans, and in research designing supportive interventions in primary care.

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