Missed opportunities for diagnosing brain tumours in primary care? Findings from a qualitative study

Fiona Walter, Suzanne Scott, Clarissa Penfold, Sarah Curtis, Alexis Joannides

Cancer Research UK Early Diagnosis Research Conference
Birmingham
Use qualitative research methods to understand patient perspectives on:

- appraising their symptoms
- seeking medical help
- routes to diagnosis
Approach
Approach

- Recruited soon after diagnosis with primary brain tumour
- Interviewed, often with family member, before surgery
- Thematic analysis using Model of Pathways to Treatment
- Workshop: confirmation of findings

Walter et al, 2012
Scott et al, 2013
### 39 participants

<table>
<thead>
<tr>
<th>Age at interview</th>
<th>Mean age (range)</th>
<th>53 (22 – 74)</th>
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<tbody>
<tr>
<td></td>
<td>21-40</td>
<td>10</td>
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<tr>
<td></td>
<td>41-60</td>
<td>15</td>
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<td></td>
<td>61 and over</td>
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<table>
<thead>
<tr>
<th>Gender</th>
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<tbody>
<tr>
<td>Male</td>
<td>21</td>
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<tr>
<td>Female</td>
<td>18</td>
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<thead>
<tr>
<th>WHO Grade (2 ungraded)</th>
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<tbody>
<tr>
<td>Low grade: I/II</td>
<td>0, 8</td>
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<tr>
<td>High grade: III/IV</td>
<td>7, 22</td>
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<table>
<thead>
<tr>
<th>Patient Interval (first symptom to first presentation)*</th>
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<tbody>
<tr>
<td>&lt; 7 days</td>
<td>5</td>
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<tr>
<td>1 - 4 weeks</td>
<td>3</td>
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<tr>
<td>1 - 6 months</td>
<td>10</td>
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<tr>
<td>7 - 12 months</td>
<td>11</td>
<td></td>
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<tr>
<td>&gt; 12 months</td>
<td>10</td>
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</table>

<table>
<thead>
<tr>
<th>Diagnostic Interval (first presentation to diagnosis)*</th>
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<tbody>
<tr>
<td>&lt; 7 days</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>1 - 4 weeks</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>1 - 6 months</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>7 - 12 months</td>
<td>4</td>
<td></td>
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<tr>
<td>&gt; 12 months</td>
<td>6</td>
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</tbody>
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* Reported by patient
Key findings

23% presented as emergency, no GP; 47% 2+ GP consultations

- People experience ‘changes’ rather than symptoms, often first noticed by others
  - Headaches, seizures 55%
  - Changes in sleep 58%
  - Changes in cognition 68%

- Multiple subtle changes precede brain tumour diagnosis 97%
- Not all seizures are the same and few come ‘out of the blue’
- Impact of patient-GP communication
"That is not me"  "You weren't quite yourself"

Brain not working properly

Change in ability
Less engagement
Loss of interest

Caring responsibilities

Driving
Errors / crash
Difficulty with directions
Problems changing gear

Eating
Need help
Loss of appetite
Messy

Writing
Takes longer
Messy handwriting
Gobbledygook text messages
Spelling errors

Reading
Wasn't going in
Had to re-read

Walking
Slower

Speaking
No sense
Can't find word
Slurring

Less interest

Spending time

Relationships

Hobbies

Work

Changes in sleep

New or different headache
Longer or continuous
Piercing sharp pain
More intense
Painkillers
Unbearable

Extreem tiredness
Disrupted sleep
Sleep more
Sleep less

Memory: forgetting
Not on the ball
Communication
Comprehension
Concentration
Hard to multitask

Change in balance, sensations & senses

Body parts weak or not working
Vibrating, twitching, shaking
Pins & needles, tingling, numb
Burning, heavy
Can't move, weak
Falling, tripping, leaning, misjudging, stagger

Changes in vision, hearing, taste or smell
Sensitivity to noise and smell
Metallic smell or taste
Blurred, double or reduced vision
Muffled sound

Lethargy "just can't be bothered"
Awkward or stressful interactions
Low mood
More sensitive
Irritated, angry
People experience changes rather than symptoms—often first noticed by others.
Multiple subtle changes precede diagnosis

- Body parts weak or not working
  - Vibrating, twitching, shaking
  - Pins & needles, tingling, numb
  - Burning, heavy
  - Can’t move, weak
  - Falling, tripping, leaning, misjudging, stagger

- Changes in vision, hearing, taste or smell
  - Sensitivity to noise and smell
  - Metallic smell or taste
  - Blurred, double or reduced vision
  - Muffled sound

- Lethargy “just can’t be bothered”
  - Awkward or stressful interactions
  - Low mood
  - More sensitive
  - Irritated, angry

- ‘I wouldn’t say it’s a headache’
  - World of your own
  - Strange, weird
  - Fizzy, foggy, fuzzy
  - Funny spell
  - Dizzy

- New or different headache
  - Longer or continuous
  - Piercing sharp pain
  - More intense
  - Painkillers
  - Unbearable

- Changes in balance, sensations & senses
  - Head feels like...

- Changes in sleep
  - Changes in person: ‘out of character’
  - ‘That is not me’
  - ‘You weren’t quite yourself’

- Extreme tiredness
  - Disrupted sleep
  - Sleep more
  - Sleep less

- Memory: forgetting
  - Not on the ball
  - Communication
  - Comprehension
  - Concentration
  - Hard to multitask

- ‘Brain not working properly’
Commonest changes

Extreme tiredness
Disrupted sleep
Sleep more
Sleep less

Changes in sleep

Memory: forgetting
Not on the ball
Communication
Comprehension
Concentration
Hard to multitask

‘Brain not working properly’

‘I mean, I was just, well, tired, exhausted... I was feeling absolutely totally shattered. [M, 51-60]

‘I could feel myself getting a bit slower in work. I was struggling to do and think of all the things that I’d normally do [...] I just knew I wasn’t as quick and I couldn’t think ahead as much and it just wasn’t the same.’ [F, 31-40]
Also commonly reported changes

‘I wouldn’t say it’s a headache, but you get like a little pain in the front of your head and it goes just like that. It’s almost like a wave.’ [M, 41-50]

‘Very piercing, they would shoot across the back of my head... I could stand there, I hadn’t got a headache. All of a sudden, it was like someone had put a needle in my head.’ [F, 31-40]
Less commonly reported changes

‘I didn’t fall over, I was just a little bit unsteady. I can walk normally but not on a line, you know like when a policeman wants you to walk on a line for being tiddly? I couldn’t do that.’ [M, 71-80]

‘He’s such an easy going man normally, and at home I noticed he’s been a bit snappy with me as well and I just noticed it, odd snaps at me.’ [M, 61-70]
Seizures: not all the same or come ‘out of the blue’

Among the 21 reporting seizures:

- all noticed subtle/vague changes for a time prior to seeking help
- often did not seek help initially, or chose to visit their GP rather than A&E

‘I would feel, ‘Oh, that’s a bit strange,’ I’m just overtired or there’s been a little reaction and it just didn’t seem to make sense... they were so spasmodic then that it was easy to put it down to just being overtired and a bit overwrought at work, really’ [M, 51-60]

‘I thought it was like panic attacks... it started off with little twitches and obviously, you don’t really pay attention but now they’re getting like.. my leg will twitch up that way’ [F, 31-40]
Quality of patient-GP communication

Considerable consequences of subtle differences in discourse during GP consultations:

- Selective / limited disclosure
- Alignment of views
- GP response impacts re-consulting

‘I keep forgetting and every time I [went] I forgot to tell them about my twitches....’ [F, 31-40]

‘We took you to the doctors.. and he told you to go back in a fortnight and he thought it was depression, and I didn’t think it was depression but of course I hadn’t told him about the symptoms with his leg and his hand. I thought he’d had a slight stroke.’ [M, 71-80]
Explanations of changes

Age
Stress, Tiredness
Recent events

Existing illness
Mental health problem
Hormones

New medical condition:
Stroke
Alzheimer’s
Dementia
Eyesight
Missed diagnostic opportunities?

- While some presented with headaches or major seizures, most experienced physical and cognitive changes/symptoms > 6m before seeking help
- Patients are seeking help for (some of) these symptoms, often on multiple occasions
<table>
<thead>
<tr>
<th></th>
<th>Workshop participants’ views on how to improve GP consultations to reduce missed diagnostic opportunities</th>
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<tbody>
<tr>
<td>1</td>
<td>Ten-minute appointments or ‘<strong>one symptom per appointment</strong>’ are not sufficient to share subtle, intermittent changes/symptoms and can lead to selective or limited disclosure.</td>
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<td>2</td>
<td>Vague symptoms need <strong>thorough exploration</strong> by family doctors. Take a good history from family and friends if not forthcoming from the patient as patients may not notice all the symptoms themselves.</td>
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<td>3</td>
<td>Improve how patients present their symptoms in the consultation (e.g. encourage patients to bring <strong>written lists</strong> of symptoms, track multiple symptoms and voice any concerns)</td>
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<td>4</td>
<td>Aim at <strong>continuity of care</strong> so that GPs can have increased awareness of symptom changes over time.</td>
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<td>5</td>
<td>Encourage <strong>follow-up appointments</strong> by making them before a patient leaves the surgery or giving a time limit for symptoms to resolve.</td>
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<td>6</td>
<td><strong>Empower patients to return</strong> if they think something is wrong or if they are unhappy with the plan.</td>
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<td>7</td>
<td>Identify patients with <strong>repeated consultations</strong> with vague symptoms and have lower threshold for referral based on GP intuition.</td>
</tr>
<tr>
<td>8</td>
<td>When ordering investigations, most patients <strong>would rather be told</strong> that cancer is a differential diagnosis</td>
</tr>
</tbody>
</table>
While some presented with headaches or major seizures, most experienced physical and cognitive changes/symptoms > 6m before seeking help

Patients are seeking help for (some of) these symptoms, often on multiple occasions

**PRIMARY CARE APPROACHES**

- Awareness of subtle, intermittent symptoms
- Further investigation- access to brain imaging
- Effective GP- patient communication
- Follow-up as safety-netting
- Triage tool, including cognitive assessment?
• Patients and family members who have so willingly shared their experiences at a very difficult time
• Research team: Suzanne Scott, Alexis Joannides, Clarissa Penfold, Sarah Curtis
• PPI: Joyce Bell, Margaret Johnson
• Recruitment: Rocio Fernandez Mendez, Rebecca Rastall, Will Sage, Carole Hewitt, Andrea Clyne
• Clinical Collaborators: Andrew Brodbelt, Willie Hamilton, Michael Jenkinson, Stephen Price, Colin Watts
• Funder: [Image: The Brain Tumour Charity]

fmw22@medschl.cam.ac.uk