What do patients with brain metastases from non-small cell lung cancer want from their treatment?

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Brain metastases are a common complication of non-small cell lung cancer (NSCLC). Prognosis is poor and the effectiveness of whole brain radiotherapy (WBRT) is uncertain for patients with moderate performance status. Studies on WBRT effectiveness have thus far used outcome measures, such as survival, performance status and cognitive function. The aim of this study was to study what patients with recently diagnosed brain metastases from NSCLC want from their treatment. We carried out semistructured interviews with nine patients with brain metastases from NSCLC, for whom the benefit of WBRT is uncertain. Interpretative phenomenological analysis was used. Themes identified included quality versus quantity of life, factors contributing to quality of life (including family, mobility and normality), ‘Go for it!’ – the desire to try anything, the desire for a cure or ‘magic wand’, fear and other factors (including family in decision making, information or lack of information, relationship with professionals, experience of steroids and radiotherapy including adverse effects). Quality of life is important to patients, but many are keen to try any treatment which might prolong their life. Understanding patients’ values regarding treatment and goals of treatment can help clinicians discuss these issues with patients and provide appropriate information and can aid selection of appropriate outcome measures.

Key words: brain metastases; interpretative phenomenological analysis; lung neoplasms; patient preference; qualitative research; quality of life

Introduction

Brain metastases from non-small cell lung cancer (NSCLC) carry a poor prognosis. Treatment options include whole brain radiotherapy (WBRT), surgery, radiosurgery, chemotherapy, steroids and supportive care.1,2 The effectiveness of WBRT for most patients with brain metastases from NSCLC is unproven (Pease, et al. 2005), and a Cochrane review highlights the lack of high-quality evidence to determine which subset of patients with multiple brain metastases is likely to benefit from WBRT in addition to supportive care.3 A phase III Medical Research Council (MRC) trial (Quality of Life After Radiotherapy and Steroids [QUARTZ], ISRCTN13826061)4 is underway to determine the benefits and harms of radiotherapy in addition to steroids and optimal supportive care for patients with moderate performance status for whom the oncologist is uncertain as to the benefit of WBRT.5,6

Studies into treatment effectiveness for brain metastases have included outcomes of survival, radiological response, performance status, neurological symptom response7 and cognitive function.8 At the time we planned this research, there were no published studies of what patients themselves want from treatment for brain metastases from NSCLC.

Aim

The aim was to study what patients with recently diagnosed brain metastases from NSCLC want from their treatment.

Methods

The South East Wales Research Ethics Committee granted approval to carry out the study.

Patient selection

Patients with NSCLC and a recent radiological diagnosis of brain metastases (i.e. confirmed on computed tomography or magnetic resonance imaging of brain within the
previous 4 weeks) were identified from oncology clinics. Following discussion of their treatment options (including steroid medication and WBRT), if oncologists were uncertain as to the benefit of WBRT for that individual, patients were invited to take part in an interview in a place of their choosing (home or hospital). Participants were recruited until no new core themes developed from the interviews.

Inclusion criteria were chosen to match those of the QUARTZ trial: adults with radiological evidence of brain metastases within the previous 4 weeks and a histologically or cytologically proven primary NSCLC. Patients for whom there was thought to be a clear indication for surgery or radiotherapy were excluded, as were patients for whom the oncologist thought that radiotherapy would not be beneficial.

Data collection
Semistructured interviews were undertaken after participants and their oncologist had come to a decision about treatment for their brain metastases and participation in the QUARTZ trial. Interviews lasted 30–60 min, and participants were free to stop or pause the interview at any time. Interviews took place within a few days of consenting and were audiotaped and supplemented by field notes.

Data analysis
Interviews were transcribed verbatim and analysed using Interpretative Phenomenological Analysis (IPA). This seeks to ‘make sense of the participant making sense of their world’. It is a qualitative analysis method with similarities to phenomenological analysis. It is ‘committed to the value of attempting to understand the world from the perspective of one’s participants but ‘recognises that this cannot be done without interpretative work by the researcher’.

Transcripts of the interviews were read and reread for emergent themes, which were organised into superordinate themes. Each interview transcript was analysed independently by at least two of the researchers. If disagreement occurred about the presence or nature of a theme, then a consensus was reached through discussion between the researchers.

Results
Between July 2005 and January 2008, 14 patients were identified as meeting the inclusion criteria, and nine interviews were completed (of the other potential participants, one declined participation, one patient’s daughter requested that the interview did not take place, two deteriorated before the interview took place [within 7 days of consent] and one died before the interview took place [within 2 days of consent]). Four participants were female and five were male. All nine participants had received WBRT, steroids and supportive care.

The following superordinate themes were identified as follows:

- Quality versus quantity of life
- Factors contributing to quality of life
- ‘Go for it!’ … try anything
- Cure or ‘magic wand’
- Fear
- Other factors contributing to decision making

Quality versus quantity of life
This was a common theme, mentioned by all participants. Some participants clearly stated their priority as follows:

- as good as possible for as long as possible (one participant), or
- as long as possible whatever the quality (one participant), or
- living life to the full then rapid deterioration – avoiding prolonged dying phase (three participants).

One participant was content to accept whatever time she had left:

I’m willing to go along with the time the Lord has given me.

(participant 8)

Several participants recognised that individuals have their own priorities:

How can I put it – I think each person has got to weigh up what do they want.

(participant 4)

Prolonging survival
Several participants said that living longer was their main aim:

Interviewer: What are you hoping to gain from the radiotherapy?

Well obviously live longer if I could.

Interviewer: And can you have some idea of how much longer, how many months you would want to gain, or years you would want to gain to make it worthwhile?

I suppose I don’t know, I mean obviously years, anybody would, but even if I got a year out of it I’d be happy.

(participant 2)
Anything that prolongs my life I think that’s probably the only consideration but having said that prolongs my life as you say in what quality. It’s hard to imagine someone saying radiotherapy will extend your life but you might suffer this etc.

(participant 7)

Interviewer: What’s more important to you, quality of life or the length of life?

The length of life obviously. Obviously…I’m young… nobody wants to die young. We all know we’re going to die but you know we want to see grandchildren, you want to see our 60’s 70’s but I mean… I’ve had to accept it; I really do understand what’s going on.

(participant 9)

**Quality of life**

Some participants viewed quality of life as more important than length of survival:

It (quality) is more important than the time, much more important. I would like a long time, wouldn’t we all, but at the end of the day – let’s put it this way, if it’s three months and it’s three months quality time I would rather have that than a year of just plodding – six months of being normal or three months of slowly draining away I’d hate that, I’d rather go quickly.

(participant 4)

Some patients mentioned both length and quality of survival:

Well if it could give me a few months or if not another few years, if it could give me another few years fair enough

(participant 3)

Just to give me a quality of life you know

(participant 3)

**Factors contributing to quality of life**

Participants described several domains which they viewed as important to their quality of life as follows:

- family (six participants),
- mobility/movement (four participants),
- body image or self-image (four participants),
- cognitive function (three participants),
- freedom (three participants),
- normality (two participants), and
- ability to work (one participant).

Examples are shown in Table 1.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Factors contributing to quality of life</th>
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<tbody>
<tr>
<td>(a) Family</td>
<td>Many participants saw their family as central to the meaning of their life:</td>
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<tr>
<td>(participant 7)</td>
<td>I’ve lived my life for my husband and my children.</td>
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<tr>
<td>(participant 8)</td>
<td>Many participants saw their family as central to the meaning of their life:</td>
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<tr>
<td>(participant 8)</td>
<td>I want to spend time with my family and my husband just enjoy myself for as long as I’ve got then hopefully wham damn thank you mam and I’m gone.</td>
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<tr>
<td>(participant 4)</td>
<td>As long as my family are happy. I accept anything, I accept it you know.</td>
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<td>(participant 9)</td>
<td>Some participants felt responsible for looking after their family:</td>
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<td>Just to see them, really more than anything, just to make they’re okay ‘n’ they grow up alright, you know so</td>
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(b) Mobility

Several participants mentioned the importance of being able to mobilise:

Interviewer: What would be good health to you, what would that mean?

Able to get out and have a nice walk around and (4 sec pause) and be a bit more positive in my mind. (participant 1)

Interviewer: …And what would be quality to you?

To be able to get out and see different things and uh… I should have had reflexology yesterday, just to get out of the house but I just couldn’t do it, I just wasn’t feeling well enough, you know. But it is nice to get out and…. You get so frustrated indoors, you know when there’s something to be done, and you can do it, but you can’t do it but you wait and you say “I…” … (participant 2)

Interviewer: If radiotherapy could only give you one thing, just one thing, what would you prioritise that as?

Movement…. Just want movement that’s all. Just want to walk around town or walk around the front or… around the garden even… (participant 6)

(c) Body image or self-image

Well weight, I look like a demented munchkin for starters – I’ve always been a size 12 but goodness knows what I am now – I look terrible and that’s part of the reason I want to get off them. [steroids] (participant 4)

(d) Cognitive function

Having it on my brain, I’m thinking, will I lose my marbles. You know um that’s a bit worrying. (participant 2)

(e) Freedom

Give me more freedom of movement umm… freedom of breathing… freedom with my legs mainly…. (participant 6)

(f) Normality

It’s been great the last few weeks, obviously I’m breathless, I’m not running anywhere fast, that sense of normality and being able to do normal things has been terrific. (participant 7)

But to me, like I say, it’s keeping the normal things going, cooking food and things like that, that makes you feel normal and it keeps you in the run of things… (participant 4)

(g) Ability to work

One participant continued to work as a writer despite his diagnosis of brain metastases: There are some days where I almost forget that this happened if you can. I haven’t had a treatment now for five to six weeks and I’ve pushed myself back to work pretty much full time. (participant 7)
‘Go for it’ … try anything
Six participants said that they would ‘try anything’, ‘clutch at straws’, ‘go for it’ or ‘take any opportunity’, to try to prolong their life or improve their quality of life by any means possible.

I think, I think I’d try anything if I knew could get rid of it.
(participant 3)

Whatever time I’ve got left I’m going to go for it.
(participant 4)

I would imagine anybody in a similar sort of condition that I am would be clutching at straws wouldn’t they. So you know… Every, any and every opportunity to prolong life for it doesn’t matter how long would be grabbed at by I should imagine, everybody, regardless of personalities or culture or creed would be grabbed at by anybody.
(participant 5)

Cure or ‘magic wand’
Three participants mentioned they were hoping for a cure but also knew this was impossible or unrealistic.

What do we want for goodness sake, a magic wand please
(participant 5)

Well I suppose deep down I wanted a cure. I’m looking for the cure and I’m looking for the ultimate… I want to be that one who goes into remission. I suppose every human being does that.
(participant 9)

Fear
Three participants expressed a fear of loss of dignity, dependence (on others or on oxygen etc.), being a burden, being pitted or being in pain.

And Long John Silver had it right in Treasure Island ‘them that dies will be lucky ones says he’. If you can go zap (interviewee indicates ZAP with a sudden downward movement of his arm) you are very lucky… I have seen people in wheelchairs with oxygen bottles and it is err horrendous, horrendous. I fight hard not to envisage myself in the same condition but inevitably I am going to be.
(participant 5)

I don’t want to become a burden. In a er…. In a nutshell I don’t want people to be looking down at me in a bed, incontinent, having me bum wiped, with pants on, with nappies on… looking down at me saying please die. I do not want that…. How not when?
(participant 5)

If I thought I had to go through that pain again no I wouldn’t wish to carry on I’d wish to call it a day. It sounds silly but I’d say that’s not, that’s not human, I think that’s undignified way of suffering in pain. You know er …. Na I would refuse treatment
(participant 9)

Other factors
In the course of the interviews, it became clear that there were several factors contributing to participants’ experiences, as well as the individual’s perceptions of the importance of quality of life and survival time. These factors included

- Sense of what family would want, avoiding distress; promises to children to try what they could
- Information or a lack of information about treatments (information described as confusing, forgotten and conflicting)
- Relationship with professionals
- Experience of steroids and radiotherapy, including side effects

Family in decision making
Some participants said their decision to have radiotherapy was in part out of a sense of what their family would want and to avoid distress

I promised my children I would try everything so
(participant 2)

Information or a lack of information
Several participants mentioned a lack of understanding about their condition or its treatment (Table 2).

Relationship with professionals
Several participants clearly appreciated the staff involved in their care:

The staff are brilliant, they make you feel very comfortable.
(participant 9)

Experience of steroids and radiotherapy, including side effects
Steroids were mentioned both as extremely helpful in improving symptoms, but also associated with troublesome side effects. Some participants felt that radiotherapy had been straightforward, with fewer side effects than they had expected (see Table 3 for examples).
Table 2  Information or a lack of information

| The books are really confusing because it is like this non-cancer cells, I don’t understand these non cancer cells, small non cancer cells, they confuse me. (participant 2) | I didn’t think two (treatments) would be enough, I don’t know anything about it. (participant 1) | I know I am going to lose my hair, they said I’d lose my hair, but I mean what’s worrying me now is, do they shave my hair, I should have asked questions, I don’t know, I haven’t really been told what they are going to do. (participant 3) | I think it was five (treatments), well five lots were mentioned. I am still a bit hazed over that I think because… When I went in, I didn’t concentrate because my husband was in such a state… actually it doesn’t all sink in… I don’t know whether it’s every day, I don’t know yet until I go. I haven’t been told anything like that. (participant 2) |
| I don’t know what information is there really do I (participant 8) | Like I say I don’t understand the medicines going on. I haven’t a clue what’s going on behind me, what’s going on in that machine…. (participant 8) | I would like to understand a bit more about it. (participant 9) | I’m non-medical my love, I’m a man of small intellect. For goodness sake how can I make a decision about what I want? (participant 5) |
| One participant appreciated information being given at an appropriate pace: He (the doctor) seemed quite keen not to get bogged down in all possibilities until we needed to really, which I kind of appreciated. (participant 7) | | | |

Discussion

Strengths and limitations of the study

Research following the diagnosis of brain metastases is a potentially sensitive area. A qualitative approach using semistructured interviews best suited addressing the research question. This format enabled us to pose ques-

Table 3 Experience of steroids and radiotherapy, including side effects

| Oh yes the steroids in the beginning helped lots ... but they’ve been cutting them down… the steroids have been very good, they’ve kept me going… (participant 3) | The steroids got rid of my symptoms which was wonderful (participant 4) | It’s just that my eyes won’t close, and my brain won’t turn off, like you know, I just got to keep… I can’t sit still for long, I’m up and down, up and down. (participant 2) | The main thing is get rid of the symptoms if you have steroids like me they give you terrible symptoms, try to get rid of them. The radiotherapy is nothing, well touch wood it has been nothing with me anyway doesn’t bother me. (participant 4) |
| Hair loss, doesn’t bother me. (participant 4) | I got told about the headaches which touch wood haven’t come… uhm the hair loss, the nauseous and the tiredness… I do feel tired at the moment, very tired. (participant 9) | I said I was expecting monsters, like a kid, like Halloween init... expecting machines, naa… it was absolutely brilliant. It’s not daunting and it’s so quick. That’s the thing about it, you expect to go in there for hours but it’s so quick and before you know it you’re back home. (participant 9) | I would strongly recommend to anybody who’s been diagnosed with brain secondaries and who’s been suggested treatment, err…. radio… radiotherapy treatment, to grab it with both hands. It is a doddle. It is a doddle. (participant 5) |

Discussion of emergent themes in the context of current literature

Survival and quality of life

Some patients valued survival time above other factors, but many patients valued quality of life. Patients identified time with their family, normality and mobility as important in determining quality of life. Some patients were fearful of loss of dignity or independence. These factors are consistent with themes found in studies of patients with other conditions. A semistructured interview study of patients with newly diagnosed brain metastases (from various primaries) and caregivers, using content and thematic analysis concluded that there are four major factors influencing decision making in palliative radiotherapy: hope, knowledge, expectations of radiation therapy and current symptoms. Sze, et al. commented on the blurring of the boundaries between hope and expectation and that is relevant to the current study: ‘what patients want’ could be interpreted as ‘what patients expect’ or ‘what patients hope for (even if unrealistically).’ Therefore, patients may talk of wanting a cure, even though they know that this is not realistic.

Knops, et al. described three domains of relevance to patients with severe or terminal disease in determining preferences for care: patients’ feelings about disease, about suffering and about the circumstances of their death. These themes are apparent for some of the participants of the
current study – particularly fear of dependence and loss of dignity and for some participants the desire to avoid a prolonged dying phase. A ‘quick death’ has previously been identified as preferable for some patients with lung cancer, in a study of 100 patients.13

Several participants expressed their priority in terms of quality of life or length of survival, or a combination of the two. However, it is unrealistic to suggest that the patient’s choice lies between living for as long as possible (whatever the quality) or with maximal quality of life (for however long). It is feasible that for patients responding well to WBRT, life may be prolonged and quality of life improved. For those who respond poorly, survival may be shortened and quality of life impaired. Neither the patient themselves nor their doctor can choose whether the individual patient responds well or poorly to the treatment.

Individual perspectives
It is clear from the interviews that although there are common themes, patients make individual judgements about what is important to them, and this must be taken into consideration when discussing treatment options. Previous studies have also reported a considerable range in the attitudes of patients with lung cancer toward treatment, and the potential treatment-associated toxicity they would be prepared to endure for the possibility of prolongation of their life.14–16

Information and understanding
Several patients did not seem to have a clear understanding of what palliative radiotherapy to the brain would entail on a practical level, raising important questions about the validity of ‘informed consent’ for treatment. Chow, et al. studied 60 patients receiving radiotherapy for symptomatic metastases and found that 78% reported they had not been given information about radiotherapy and 87% were not familiar with the concept of radiation therapy.17 In that study, 35% believed that their cancer was curable and 20% reported a belief that palliative radiotherapy would cure their cancer. A more recent study by Audrey, et al. suggested that patients with advanced cancer are not always fully informed about the likely effects of palliative chemotherapy and are, therefore, not in a position to make informed decisions.18

Although one participant appreciated that the clinician gave him information at the appropriate time (rather than getting ‘bogged down’ in too much information at an early stage), many participants said that they would like to understand their illness and treatment better. The lack of patients’ understanding or recall does not necessarily reflect any inadequacy or inaccuracy in the information given to them, but it may signify the difficulty of absorbing and retaining new information at the time of a devastating diagnosis, particularly a diagnosis which can affect cognitive ability.

Side effects and burden of treatment
No participant mentioned the burden of travelling to and from hospital for WBRT and few immediate side effects of radiotherapy were mentioned. This should be interpreted with caution, as noted above: Kondziolka, et al. showed that 88% patients reported hair loss after WBRT for brain metastases and 95% reported excess fatigue compared with only 5% after radiosurgery alone.19 Short-term memory problems were reported in 72% of patients, concentration problems in 61% of patients and long-term memory problems in 33% of patients following WBRT. Davidson, et al. reported that most patients with lung cancer rated the following information as ‘essential’ in arriving at treatment decisions: details of treatment regimen, early and late side effects, survival and effects of treatments on disease symptoms.20

Implications for clinical practice
Identifying areas of importance for individual patients can help clinicians ensure they give appropriate information about what can be achieved with treatment and thereby establish realistic goals.

Clinicians should ensure that information is given to patients in a way that they can understand. It may be helpful to offer written information, perhaps with illustrations and audiotapes of consultations. Some participants were frightened of receiving radiotherapy until they had actually experienced it; videos or digital video discs showing the treatment process, or being shown round the radiotherapy department, may help patients to understand what they should expect.

Given the uncertainty of the effectiveness of treatment for brain metastases, we suggest the clinical focus should include the following:

- Establishing the patient’s understanding of their condition and treatment and the extent to which the patient wishes to be involved in decision making
- Finding out what the patient’s priorities are in terms of quality or quantity of life and specific goals, as well as specific fears or concerns
- Giving information about potential treatments and their possible effects in a way which the patient can understand, retain and weigh up to make decisions about their treatment
- Supporting the patient and their family in dealing with uncertainty as well improving symptom control and optimising health

Implications for research
Knowledge and understanding of the issues that are important to patients can help guide the choice of appropriate outcome measures in clinical trials. Specifically, we
suggest that outcomes should include survival and a quality of life measure including the domains of mobility, family, normality and possibly work, independence, cognition and body image. Quality of life measures in which participants themselves can select domains of importance are attractive, although the data can be problematic to analyse.

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References
