



The impact on quality of life for people with brain tumours of entering a research trial involving new anti-cancer agents



Katie Sutton*

University College London Hospitals NHS Foundation Trust, T14 North Chemotherapy Office, 235 Euston Road, London NW1 2BU, United Kingdom

A B S T R A C T

Keywords:
Phenomenology
Quality of life
Brain tumour

Purpose: The intention of this study was to offer an alternative perspective to the quantitative findings of larger randomised controlled trials by using a phenomenological approach to explore the impact on Quality of Life (QoL) for people with brain tumours of entering a research trial involving new anti-cancer agents. **Method:** Given the subjective nature of the proposed topic, a phenomenological approach was adopted. Sample size was limited to five participants. A semi-structured interview technique was used. Interviews were digitally audio recorded with permission from those involved. In order to guide data analysis for this study, Colaizzi's framework was utilised.

Results: As a result of data analysis, two major themes were identified. These were 'Hope and optimism' and 'The therapeutic relationship'. Three minor themes were also found. These were 'A complex symptom profile', 'The importance of non-medical coping strategies' and 'Impressions of the QoL tools used'.

Conclusions: This phenomenological study has highlighted key themes relating to QoL which are not addressed in some of the widely used assessment tools such as the EORTC QLQ C30 and BN20. They generally focus on health status, and do not capture issues identified in this study as being of significant importance to the QoL of participants such as hope and optimism, and the importance of the therapeutic relationship. They also omit reference to coping and management strategies.

© 2012 Elsevier Ltd. All rights reserved.

Introduction

Prognosis for people with brain tumours depends on the type, grade and location of the tumour. In the UK, 36% of adults with a brain tumour live for at least a year, 15% have a five-year survival, and fewer than 10% live for more than 10 years after diagnosis (Cancer Research UK, 2010). Treatment for brain tumours commonly involves surgery, chemotherapy and/or radiotherapy. This will depend on the type of tumour and its location within the brain. Chemotherapy usually consists of Temozolomide oral chemotherapy or PCV combination chemotherapy (Procarbazine, Lomustine and Vincristine). A number of clinical trials are currently occurring internationally which hope to improve survival for people with brain tumours. These include the testing of novel therapies such as growth factor inhibitors, angiogenesis inhibitors and vaccines. The Cancer Centre in which this research was conducted is participating in a number of clinical trials involving people with brain tumours. These include those exploring the use of relatively new anti-cancer drugs such as Cediranib, Gefitinib and Cilengitide.

There has been increased awareness over recent years of the importance of assessing quality of life (QoL) as a meaningful outcome for patients participating in clinical trials. The developments of validated tools such as the EORTC Quality of Life Questionnaires are well recognised for offering valuable insights into patient outcomes (Aronson et al., 1993). For patients with malignant brain tumours, the EORTC-QLQ C30, QLQ-BN20 and the FACT-Br are some of the most commonly used assessment tools (Mauer et al., 2008). These multiple choice questionnaires address health-related QoL by asking questions such as 'Do you need help with eating, dressing, washing yourself or using the toilet?' and 'Have you had trouble sleeping?' (Aronson et al., 1993). Whilst these methods are both rigorous and transferable, their quantitative nature poses limitations. They do not allow individuals to make supplementary comments on what they personally feel are the most fundamental factors affecting their QoL. They also do not allow participants to rank issues in order of personal relevance (Gill and Feinstein, 1994). For example, they could state that they are having considerable trouble taking a long walk, but they are not asked how important this is to them. The suggestion that QoL is a personal perception rather than a standardised metric is difficult to take into account when using such quantitative tools. The intention of this study was to offer an alternative perspective to the

* Tel.: +44 08451555000x71482.
E-mail address: katie.sutton@kcl.ac.uk.

quantitative findings of larger randomised controlled trials by using a phenomenological approach to explore the impact on QoL for people with brain tumours of entering a research trial involving new anti-cancer agents.

Aim

- To explore the impact on QoL for people with brain tumours of entering a research study involving new generation, anti-cancer agents.

Objectives

- To investigate the perceptions of people with brain tumours of their QoL whilst on such trials.
- To gain an insight into the patient experience of participating in a research trial.
- To identify which coping strategies people with brain tumours employ as a means of preserving their QoL, including the help they receive from professionals.

Theoretical framework

Given the subjective nature of the proposed topic, a phenomenological approach was adopted. Phenomenology is a qualitative, inductive method of research that is concerned with understanding the way people exist in the world, and the lived experience of everyday events (Stephenson and Corben, 1997). As healthcare has shifted away from the scientific, positivist paradigm towards a more holistic approach, requirements in healthcare research have also changed. Phenomenology suits the drive to discover more about the patient experience of the treatment they receive, when often the data is rich, but challenging to document and has therefore been under-researched. Complex concepts such as emotions and attitudes are difficult to quantify, however adopting a phenomenological approach permits closer examination of everyday experiences from the patient's perspective. It also allows for recognition that the world does not remain static (Van der Zalm and Bergum, 2000), and that multiple realities will always exist.

Many of the core values of healthcare such as empathy, active listening and the development of a therapeutic relationship are held in high regard by phenomenologists. The use of such a research approach therefore seems appropriate for qualitative healthcare studies, including this particular study of the experiences of people with brain tumours of entering a research trial. Involving patients in research to such a degree should result in findings portraying what the patients themselves feel about the impact on their QoL of entering a research trial, rather than what the researcher expects to discover. The crucial findings are those that detail the patient perspective of the experience (Munhall, 1994).

Sampling

It is believed that a sample size of five patients is sufficient to gain a new and varied insight into the experience of participants, whilst at the same time being small enough to allow in depth analysis in accordance with a phenomenological approach (Sandelowski, 1995). It was also a non-probability, purposive sample limited to those who have experienced the phenomenon, in this case those people with brain tumours who have experienced entering a research trial involving new anti-cancer agents.

For the purposes of this project, the population was defined as any adult with a brain tumour who had been entered on to a research trial involving new generation, anti-cancer drugs at the Clinical Research Facility of a large Cancer Centre in London. Exclusion criteria included

those under the age of 18, and those whose disease had progressed to the stage that they did not have the mental capacity to give informed consent (Mental Capacity Act, 2005).

Data collection

A semi-structured interview technique was used. Semi-structured interviews cover a specified list of topics and follow a predetermined interview guide whilst permitting some degree of flexibility. Thus the researcher can ensure that all subjects relevant to the research question are covered whilst at the same time allowing scope to develop an unexpected train of thought if it is deemed to be of particular interest. The inclusion of 'prompting' questions such as 'Could you tell me about the experience?' and 'how did it make you feel?' is a useful technique for encouraging the participant to explore their thoughts and feelings further (Holloway and Wheeler, 2002). Kvale (1996) states that interviews are the main method of collecting data in phenomenology as they allow for descriptions to be explored and illuminated. He also suggests that interviews should be 'in-depth', with no predetermined structure. However, if there is no structure at all then the researcher may be tempted to develop questions based on what previous participants have discussed, which could be interpreted as more of a grounded theory method. It was also felt that a certain amount of structure will act as a reminder to discuss particular issues that are relevant to the project (Wimpenny and Gass, 2000).

All interviews were conducted in a private clinic room within the Clinical Research Facility and lasted no longer than 1 hour. This time limit was felt to be appropriate as it allowed sufficient time to explore the subject matter without over-burdening participants who were also attending the hospital for treatment. Interviews were digitally audio-recorded with permission from those involved. Box 1 provides a summary of questions included in the interview guide which was followed for each participant.

Questions included in interview guide.

1. Can you tell me about your experience of Entering this Research Trial?
2. How do you think that entering this trial has affected your quality of life?
 - For example were you able to carry on with your daily activities just as before?
 - Were there any physical activities which you required more help with?
 - Were there any physical activities which you required less help with?
3. Do you feel that being on this trial has affected your ability to communicate with other people?
 - Has it affected your relationship with your family?
 - Do you feel that being on this trial has affected your social life?
4. Were there any particular periods when you felt mentally or emotionally worse than before?
 - What do you think made it worse?
5. Were there any occasions when you felt mentally or emotionally better than before?
 - What do you think helped?
6. Have you sought advice from any health professionals regarding symptoms you have experienced during this trial?
 - What type of health professional was this?
 - Did you feel you knew who to turn to?
 - Do you feel their advice was useful?

دانلود مقاله



<http://daneshyari.com/article/2649469>



- ✓ امکان دانلود نسخه تمام متن مقالات انگلیسی
- ✓ امکان دانلود نسخه ترجمه شده مقالات
- ✓ پذیرش سفارش ترجمه تخصصی
- ✓ امکان جستجو در آرشیو جامعی از صدها موضوع و هزاران مقاله
- ✓ امکان پرداخت اینترنتی با کلیه کارت های عضو شتاب
- ✓ دانلود فوری مقاله پس از پرداخت آنلاین
- ✓ پشتیبانی کامل خرید با بهره مندی از سیستم هوشمند رهگیری سفارشات