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Finding the right kind of support: A study of carers of those with a primary malignant brain tumour

Anne Arber[a,*], Nicky Hutson[a], Kay de Vries[b], Douglas Guerrero[c]

[a] Faculty of Health and Medical Sciences, Duke of Kent Building, University of Surrey, Guildford GU2 7TE, UK
[b] Victoria University of Wellington, Wellington Hospital Clinical Services, Newtown Campus, New Zealand
[c] Royal Marsden Hospital, Sutton, Surrey, UK

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ABSTRACT

Purpose: Caring for someone with a primary malignant brain tumour is very demanding due to the dynamic situation involving changes to personality, short term memory loss and changes in family relationships. The purpose of this qualitative study is to examine the support needs of carers of those with a primary malignant brain tumour.

Methods & sample: 22 Carers who were currently caring for someone with a primary malignant brain tumour were recruited from one specialist cancer centre in the south east of England. The study took a grounded theory approach and data were analysed using the constant comparative method generating categories and themes that are grounded in the data.

Key results: A key concept that emerged from the data was: 'Connecting on the caring journey'. The themes that emerged from the key concept were: building helpful relationships; safe places and comfort zones; and threats to connecting.

Conclusions: Many carers do find a great deal of support within the family and from their relationships with friends as well as from cancer and carer support groups. However this is by no means universal and many carers experience a lack of timely access to good quality supportive care services. For some carers supportive care services do not meet their expectations so they spend valuable time searching for the connections they need to continue to care combined with feeling frustrated and under pressure.

Introduction

Primary malignant brain tumours are rare and in the UK there are around 4700 new cases diagnosed each year (Cancer Research UK, 2011). For all types of malignant brain tumour about a third of people diagnosed (36%) live for about one year (Cancer Research UK, 2011). Therefore the prognosis for this condition is generally poor. However there is evidence that for some groups of patients particularly those with glioblastoma multiforme having combined treatment (including radiotherapy and chemotherapy) is leading to better outcomes in terms of survival (Mirimanoff et al., 2006). The needs of those with a malignant brain tumour differ from those with other cancers as there is more responsibility on the carer due to the changes in the patients short term memory and the reduction in cognitive skills and decision making ability (Halkett et al., 2010). Carers of people with a malignant brain tumour face a unique set of circumstances that place many demands on them in relation to physical and emotional care and reduces their quality of life (Janda et al., 2007). This article is concerned with the support needs of carers of those with a primary malignant brain tumour. The terms carer, informal carer and caregiver are used interchangeably in the article to identify those who give unpaid care in the home to a person with a primary malignant brain tumour.

Background

Patients with a malignant brain tumour experience many complex symptoms and problems including fatigue, falls associated with seizures, neuro-psychiatric symptoms as well as personality changes (Molassiotis et al., 2010; Braine, 2010; Fox et al., 2006; Sherwood et al., 2004). The many physical, social and emotional problems experienced by patients means that the supportive care needs of those with a malignant brain tumour and their carers are massive (Spetz et al., 2005; Lidstone et al., 2003). Furthermore those with this condition find it difficult to get access to supportive care services such as rehabilitation services (Hackman, 2011). There is also evidence that health care professionals view patients with malignant brain tumour as not suitable for rehabilitation services

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[*] Corresponding author. Tel.: +44 1483 686768.
E-mail address: a.arber@surrey.ac.uk (A. Arber).

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because of the poor prognosis and the personality and cognitive changes that occur (McCartney, 2011). Frequently carers find themselves in a rapidly changing situation associated with diagnosis and treatment, coupled with the distress associated with the sudden onset of the illness and its palliative course (McConigley et al., 2010). Carers find many practical and emotional challenges when caring and this may limit their abilities to see beyond the present challenges (Williams et al., 2009) and they may operate using an approach dealing with problems as they arise, a reactive approach, rather than seeking a longer term solution (Lowit and van Teijlingen, 2005). Carers are reported to have many unmet needs and a proactive approach to carers by health care professionals is not necessarily practised leading to many gaps in service provision (Docherty et al., 2008; Hudson, 2004). There is evidence that the emotional needs of carers may not be addressed by health professionals (Boston and Mount, 2006). Several studies identify that carers have little time to talk to health care professionals about their situation as they do not want to take time away from the needs of their loved one and they feel ambiguous about the benefits of drawing attention to their own needs (Madsen and Poulsen, 2011; Eriksson et al., 2006).

There is an extensive literature showing that caring for a person with cognitive and behavioural changes such as those with malignant brain tumours and dementia can have a negative effects on a caregiver's physical, and emotional health as well as their social life (Andrén and Elmsta, 2008; Annerstedt et al., 2000; Thompson and Briggs, 2000). In a study by Janda et al. (2007) of those with a brain tumour similarities were found between carer's and patient's overall quality of life, with those in the same household reporting similar reductions in emotional and social well-being. When comparing the experiences of those with cancer and those with dementia and their principal carers it was found that they both shared common experiences related to loss of identity (Gillies and Johnson, 2004). The loss of identity means that relationships suffer and there is a profound effect on the family unit and in particular the primary caregiver (Madsen and Poulsen, 2011).

The study aim

The aim of the study is to explore the experience of family caregivers when caring for a person with a primary malignant brain tumour.

Participants

Participants were recruited to the study if they were aged over 18 years and were currently caring for a person with a primary malignant brain tumour (i.e those with a diagnosis of glioblastoma multiforme, ependymoma, oligodendroglioma and astrocytoma). They also needed to be identified by the patient as their primary caregiver. This was a purposive sample of 22 carers recruited by the clinical nurse specialist at one cancer centre in the South East of the England during 2006–2007. None of the carers approached declined to be interviewed. Although 24 carers were approached and agreed to participate 2 could not be contacted for interview due to holiday and other commitments. The sample included 12 female partners, 5 male partners, 2 daughters, 1 son, 1 mother and 1 father. The majority of carers ($n = 17$) were aged under 60 years and 15 were female. Most carers ($n = 14$) had been caring for under 1 year with 8 people caring for between 2–5years.

Data collection

The task of the grounded theorist is to collect data and develop theoretical analysis from the start of the study and the purpose of grounded theory is to discover what is going on (Glazer and Strauss, 1967). This study takes a constructivist grounded theory approach (Charmaz and Bryant, 2011). Constructivist grounded theory is concerned with participants definitions, meanings and experiences. In the constructivist approach it is the participant's definitions that are the focus. This approach goes into the emergent phenomena (being a carer) and defines their properties (connecting and forming helpful relationships). By exploring the phenomenon of caring the researcher can build in what and how questions into data collection; for example how the processes of support and information work and what they consist of (Gubrium and Holstein, 2008). According to Charmaz (2006) interview data fits grounded theory well as researchers can refine their concepts and analyses as they gain experience in the field.

During the interviews conducted for this study an open-ended approach was taken asking few rather than many questions, which allowed the participants to tell her story without the researcher preconceiving the content, or the direction the interview will take. Following the first two interviews an initial analysis of the transcribed data were undertaken by two researchers to guide further interviews. In these first two interviews the issue of support, connections and information about becoming a carer were key constructs identified by the participants and this became an area of focus for subsequent interviews. The interviewer created a relaxed atmosphere using open questions, careful listening skills and probes to enable the participant to tell their story and express themselves. The opening question was worded in the following way: 'can you tell me about how you've been managing as a carer?' It was noted in the researcher's journal that 'none of the participants questioned the use of the term 'carer' to describe them'. The carers had a lot to say and conveyed a great urgency in speaking about matters that were important to them. Another observation noted in the research journal was the 'time pressure' that the carers were under; they had so many things to organise it was difficult for them to fit in the time for the interview. Yet they felt it important to be involved in the research and have the opportunity to talk about their situation and experience.

The initial sample was determined by the subject area and by the carers proximity to caring and included those caring for people who were seriously ill and potentially dying with a malignant brain tumour. This group were interviewed first. Further theoretical sampling was directed by emerging concepts related to being a carer and at this point a decision was made to include more male carers ($n = 7$) (as they were an unrepresented group in comparison to female carers $n = 15$) and those caring for over one year were also included, as some patients were found to be surviving well beyond their predicted prognosis of one year. Therefore theoretical sampling was used to gather further data to check hunches about caring and support and to fill out the emerging categories of connecting. Recruitment of carers stopped once theoretical saturation was reached and no new insights emerged from the data (Glazer and Strauss, 1967; Charmaz, 2006).

Data analysis

Data analysis was undertaken using the steps of open coding using line-by-line analysis and codes attached to words and sentences. Data were entered into the computer package (NVivo) and coded and retrieved enabling a comprehensive analysis of all the data. Memo writing enabled the researcher to consider codes and distil interpretations and explicate emerging concepts. Emerging codes were compared with existing codes through a process of constant comparison which helped identify persistent patterns and differences within and across the data and enabled the identification of the features that constitute categories and sub