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Lorraine Webster

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An explorative longitudinal evaluation of prevalence and magnitude of self-reported supportive care needs and distress for people with primary high grade glioma (HGG) following radiotherapy.

Lay summary

This study will examine the met and unmet supportive care needs, and the nature and extent of possible distress post-treatment experienced by people who have received radiotherapy treatment for a primary brain tumour and whether these issues change over time.

People diagnosed with a brain tumour not only experience physical and psychological upset, but may experience further specific problems, as a result of damage to the part of the brain where the cancer has grown or treatment effects. This might include problems with movement, speaking, remembering and understanding. People with brain tumours face significant short and long-term challenges and can experience symptoms such as headache, seizures and insomnia as well as symptoms related to neurological deterioration such as personality changes, motor and cognitive deficits, visual field deficits and difficulties in expressing themselves (aphasia) (Heimans et al. 2002; Osoba et al. 2000; Shaw and Robbins 2006). For many there are also emotional effects such as depression and anxiety which result in burden for patients and their carers (Pelletier et al. 2002; Schubart et al. 2007). Deterioration in quality of life (QoL) appears in physical, social and role functioning (Kvale et al. 2008), particularly the inability to take part in social activities and work (Janda et al. 2008). This research aims to determine the extent of these difficulties in people following the conclusion of their radiotherapy. In particular, it will find out whether people feel their supportive care needs have been met or not and whether these have changed over the six months after finishing radiotherapy treatment. It will also explore whether they feel emotionally distressed and in need of further help during this time. The research will also look at whether peoples' needs (met or unmet) are related to whether they feel distressed anxious or depressed.

a) Aim of the Study

The aims are to evaluate the prevalence and magnitude of needs across five domains (health system and information, psychological, physical and daily living, patient care and support, sexuality) and distress, reported burden and need for help in people who have recently completed radiotherapy for High Grade Glioma. It also aims to explore whether there are any tentative associations between supportive care needs and levels of distress and whether there are any changes in these over time on completion of, and in the six months following, radiotherapy treatment.

b) Primary Research Questions

1. What met and unmet supportive care needs do people with primary high grade glioma report at the end of radiotherapy (T1) and at first 4-6 week follow up (T2), 3 month (T3), 6 month (T4)?
2. What levels of distress, burden and need for help do people with primary high grade glioma report at the end of radiotherapy (T1) and at first 4-6 week follow up (T2), 3 month (T3), 6 month (T4)?
3. Are there any associations between reported met and unmet needs and reported levels of distress, burden and need for help at the end of radiotherapy (T1) and at first 4-6 week follow up (T2), 3 month (T3), 6 month (T4)?

Hypotheses-The following exploratory hypotheses are proposed:

1. Supportive care needs, emotional distress, reported burden and reported need for help will persist beyond completion of radiotherapy treatment.
2. Higher levels of unmet need will be associated with higher levels of emotional distress and greater reported burden and reported need for help.

d) Outcomes

The data will quantify the prevalence and magnitude of supportive care needs and distress and may ascertain if current services are adequate or not and where improvements can be made to aid management of this group of people in the healthcare system.

Outcome Measures

The outcome measure for met and unmet need is the Supportive Care Needs Survey-SF34 (Bonevski et al. 2000; Sanson-Fisher et al. 2000; McElduff et al. 2004; Boyes 2009). Widely used in cancer populations (McDowell et al. 2010), it is a valid and reliable 34-item measure assessing needs across five domains; psychological, health system and information, physical and daily activity, patient care and support and sexuality (Armes et al. 2009; Janda et al. 2008; Sanson-Fisher et al. 2000). It has been shown to be robust and psychometrically sound, (Bonevski et al. 2000; McElduff et al. 2004; Boyes et al. 2009). An additional brain sub-scale developed by Janda et al. (2008) will be used as their study concluded that the 16 Brain tumour items elicited valuable additional information that would not have been forthcoming within the SCNS-SF34. The outcome for distress is the Emotional Thermometer Tool (ET-7) (Mitchell et al. 2010 a). This is a variation of the well known Distress Thermometer (DT) (Roth et al. 1998; NCNN 1999) consisting of a combination of five visual-analogue scales including the original distress scale alongside 3 further predictor domains of anxiety (AnxT), depression (DepT) and anger (AngT). It also includes an outcome domain of 'need for help' (Mitchell et al. 2010 b) and also measurement of impact on daily living and activity to include 'burden', need for help' and 'overall health'. Findings indicate it is more accurate than the DT alone particularly in broader definitions of emotional difficulties in cancer including anxiety, depression and distress. Thus it has the potential to find a greater proportion of people struggling with very "broadly defined emotional complications who would otherwise remain undetected with the application of conventional tools" (Mitchell et al. 2010 a).

e) Review of the literature and identification of current gap in knowledge

There is an increasing focus on survivorship within the oncology arena and the need to develop supportive care services for the period immediately following treatment. The short- to-medium term survivorship period, which Richardson et al. (2009) deemed as less than two years, maps on to what is referred to as the acute and sub acute phases of survivorship (Feurestein 2007). Over the past two decades, interest has increased in finding strategies and approaches to improve cancer patients' and survivors wellbeing (Ross et al. 2002). The concept of cancer survivorship has grown over the last 25 years out of perceived neglect of the issues that may be important to these patients and in response to the increasing cancer survival rates seen both nationally and internationally. This has been acknowledged across the devolved nations in the UK, in the Cancer Reform Strategy for England (2007), and in Scotland in Better Cancer Care: An Aid to Planning Cancer Services. Cancer Scenarios Scotland (2008), and Better Cancer Care, an Action Plan (2008). Although there is a substantial body of knowledge on the immediate psychological impact of a cancer diagnosis, less is known about the impact in relation to peoples' supportive care needs and emotional distress as they move beyond the completion of treatment and try to resume their lives.

One of the drivers to improve patient assessment of need stems from the National Institute for Clinical Excellence (NICE) Guidance on Improving Supportive and Palliative Care for Adults with Cancer (2004). They identified potential barriers to needs not being met as under-recognition by healthcare

professionals or indeed patients themselves, thus resulting in services not being available. They called for improved assessment of needs across the domains of physical, psychological, social and spiritual care. In 2006, NICE made recommendations designed to provide all brain tumour patients with a high standard of treatment, support and care (NICE 2006). This proposal is timely as it addresses a need for research focussing on people with HGG, a gap previously highlighted in the literature (Salander et al, 1996; Davies and Higgenson, 2003; Corner, 2008). In addition, a review by Catt et al.(2008) claimed that despite the NICE clinical guidelines (2006) there has been slow progress in supportive care research and called for empirical “support initiatives that will help patients, their families and health-care professionals to deal with this disease on a daily basis”.

Survivorship and issues for people with HGG

HGG are incurable and until very recently effective therapies for improving control of disease and improving survival remained elusive (Heigi et al 2005; Cairncross et al. 2006). The literature on survivorship in people with brain tumours largely consists of small non-controlled studies (Bosma 2009). It is also mainly descriptive in nature focusing on the intensity and frequencies of symptomatic issues,(Armstrong et al. 2006) with few considering the impact these have on daily living (Molassiotis et al. 2010). Large scale studies have demonstrated a high prevalence of distress in people diagnosed with cancer,(Pascoe et al. 2000; Zabora et al. 2001; Fallowfield et al. 2001) although this often goes largely unreported and thus under treated,(Carlson et al. 2004) and often occurs when multiple needs are unmet. The cognitive and neuropsychological sequelae of brain tumours put people at a particular risk of elevated distress (Keir et al. 2006; Keir et al. 2007). However there is little information concerning specific needs in relation to supportive care, distress and disease burden following their primary treatment in the acute setting, and often they find that they cannot access services(Catt et al. 2008; NICE 2006). Brain tumour patients have a range of physical, emotional, practical, social, spiritual and financial needs as they make the transition from end of radiotherapy treatment into the sub-acute phase of cancer survivorship. Needs vary throughout illness therefore “needs assessment is a vital component of managing patient care” (NHS Quality Improvement Scotland 2008).

There is a substantial body of evidence illustrating the efficacy of providing information and support, in particular about diagnosis and treatment. Research has demonstrated that people with cancer have high level of unmet needs with perceptions of need clustering around the provision of information (Girgis et al. 2000; Sanson-Fischer et al. 2000; Tamburini et al. 2000); psychological and emotional support (Sanson-Fischer et al. 2000; Clavarino et al. 2002; Lintz et al. 2003); managing daily life (Soothill et al. 2001; Davis et al. 2003); and sexuality issues (Steginga et al. 2001; Lintz et al 2003). In addition, it is acknowledged that with the right information, advice and support “most people are able to manage their own conditions” (Scottish Government 2009). However in order to provide that appropriately, it is important to establish what people with HGG themselves report as needs and explore how this relates to their perceived levels of distress. This directly aligns to research priorities with the National Cancer Research Initiative identifying research is required in realms of survivorship, emotional distress, depression, anxiety and social needs and associated incidence, prevalence and severity (NCRI 2010). Therefore while there is emerging research into unmet needs in cancer patients, there is little empirical evidence about those needs and distress specifically at the completion of radiotherapy treatment, particularly in those with HGG. This research will provide quantifiable evidence of prevalence and magnitude in these domains which may prove significant to warrant changes to existing services.

Study design considerations

There are few research studies into the unmet needs and associated distress of people with brain tumours in the early survivorship period and those that exist have largely been qualitative in nature (Janda et al. 2006). Studies on cancer survivorship have largely been carried out in Australia and the USA, questioning their cultural and contextual relevance to a UK population, particularly the West of Scotland. Others have been conducted in mixed populations, making it difficult to ascertain the needs of specific groups such as those with brain tumours (Armes et al. 2009). In addition, although studies of distress in survivors exist, many of these are qualitative in design or have used different measures and outcomes, making cross comparison of studies and generalisability challenging. Few studies have been conducted longitudinally, making it difficult to understand how prevalence and magnitude of needs and associated distress changes over time. Whilst qualitative research can offer a valuable and in-depth understanding of the rich individual issues and needs encountered by this patient group, it does little to aid understanding of prevalence and magnitude of need and its association with factors such as emotional distress. Cross sectional research in people with brain tumour by Janda et al. (2008) gave important insights into their needs but did not explore change over time. For these reasons, the proposed research will be conducted in people who have completed primary radiotherapy for brain tumour in the West of Scotland, using a quantitative, longitudinal design. However, one of the major challenges of this longitudinal study is population attrition. Small population numbers with a disease that can rapidly progress from diagnosis to death, in people who

have physical and mental disability and decline means attrition issues are acknowledged as a challenge and a potential limitation. However the study is justified due to the lack of current evidence in this area and as previously discussed, the increasing number of survivors with this tumour type who have longer term supportive care needs. Whilst in the timescale set for the project it may not produce statistically secure evidence, it will however be successful as a feasibility study and provide the evidence needed to design a larger and statistically valid study over a longer time period.

f) Methodology: In contextualising research in health, a researcher's paradigmatic positioning relates to their "understanding of the nature of knowledge (their epistemological standpoint) and of reality (their ontological standpoint)" (Broom & Willis 2007). Whilst a paradigmatic difference exists between qualitative and quantitative research methods, the important distinction in this study is the "assumptive base that underpins the research design and thus data collection (Broom and Willis 2007)". This quantitative study design takes the positivist paradigm that reality is fixed and objective knowledge is ascertained through rigorous methodology. This investigator is therefore operating from a deductive standpoint by hypothesising that supportive care needs and distress exist as issues of concern for people with HGG following radiotherapy and that their prevalence and magnitude can be measured. Some of the supportive care needs and distress for people with HGG and their impact on quality of life are to some extent already known about, and are as Bowling (2009) described amenable to valid and reliable measurement (Osoba et al. 2000). Thus the quantitative methodology described is the appropriate method of investigation for the aims of the study and the specific research questions.

Study Design

This research is a prospective, quantitative, longitudinal study using a survey questionnaire method of Patient Reported Outcome Measure (PROM) to investigate supportive care needs (SCNS-SF34, and Brain Tumour Subscale) accompanied by a measure to screen for levels of distress, burden and need for help (Emotion Thermometer 7). PROMS needs assessment spans both quality of life and quality of care issues (Bonevski 2000) by providing evidence from the patient point of view and should have a greater role in the NHS (Richardson et al. 2007; Darzi 2007; Davies et al. 2009).

Sampling Strategy and Size

In a quantitative study it is vital to consider bias and maximise validity in the study population. However, there are limitations because HGG is a rare cancer and thus, consists of relatively smaller numbers of people diagnosed and completing radiotherapy treatment. This coupled with the potential for attrition, (owing to the nature of possible deterioration from this particular tumour type) means that a convenience, consecutive sampling strategy will be employed to approach all potentially eligible people with Grade III and IV primary HGG receiving and completing radiotherapy. In 2009 there were 118 registries for people attending for radiotherapy for tumours of the central nervous system. There are on average 6 to 8 HGG (Grade III & IV) patients each calendar month. Therefore over a 10 month period of recruitment at the end of radiotherapy, there may be 60-80 people eligible for study participation, for whom it will be potentially possible to follow through for a subsequent 6 month period. It is impossible to estimate numbers not meeting inclusion criteria, nor those lost to attrition due to progressive disease over the longitudinal follow-up, however, this information will be gathered during the course of the study. The following criteria apply:

Inclusion: Adults diagnosed with Stage 3 or 4 HGG receiving radiotherapy in accordance with the BWoSCC Management Guidance. They must have WHO performance status 1 or 2 (ranging at least to; up and about more than half the day, able to look after self but not capable of work) and or Karnofsky Performance Status (KPS) ≥ 70 (ranging to; at least able to care for self but not able to carry on with all normal activity or work). Person should be able to understand the questions, however in some instances where motor or cognitive ability is limited, a carer or the researcher may be required to simply read the questions and mark the preferred response option on behalf of the patient

Exclusion: Children < 16 years. Adults with cognitive and physical impairment that would prevent completion of survey tools. Those with WHO Performance status 3 and 4 and or KPS < 70 or who are unable to read or complete survey tools in English or give informed consent.

Statistical Analysis

Descriptive statistics such as frequencies and proportions will be used to describe the diagnostic and demographic variables of the study population. Summary data for each of the 5 domains of the SCNS-SF34, brain tumour scale and the ET-7 scores will be presented numerically and graphically. Levels of scores over time will be compared using repeated measures ANOVA models. However, a clinical statistician has cautioned that the ET scores may cause some eventual problems if the parametric ANOVA model assumptions are not acceptable. If that were the case then nonparametric Friedman ANOVA may have to be employed. Further advice and support from a clinical statistician will be sought as required.

Any relationship between SCNS-SF34 domain scores and levels of distress will be assessed using correlational analysis, either Product Moment or Spearman's Rank depending on the symmetry of the

data scores. Statistical analyses will be conducted using the Statistical Package for Social Science (SPSS V18 for Windows) with all tests performed at the 5% level of significance. The SCNS-SF34 Guide to Administration, Scoring and Analysis will be used to guide data collection for that scale as well as the brain sub-scale. (McElduff et al. 2004, Janda et al. 2008). The ET will score distress according to the levels of clinical cut-offs described by the tool developers (Mitchell A. <http://www.psychoncology.info/ET.htm>).

Ethical issues

The study will be conducted in accordance with NHS and University ethical approval and this will be sought prior to the study commencing. There are some ethical issues which require consideration. The study population are a potentially vulnerable group with ongoing needs for care, treatment and support. However it is not anticipated that the questionnaires will be particularly upsetting nature. Levels of distress are being measured, and the researcher will report any individual experiencing severe levels of distress (8-10), with their permission to their consultant and/or medical care team. This will then be dealt with on advice and consideration of the clinical team. Additional support/counselling/psychology services are available if deemed appropriate by the medical staff. Additional Consultant Clinical Psychology support has been sought and agreed. The researcher will emphasise the statement within the Patient Information Sheets, that people can decline to take part in the study or choose to withdraw at any time without affecting their standard routine on-going care.

g) Potential impact of the study: The NCSI's focus is on support and care given to "patients and their families from the end of primary treatment onwards" with an emphasis on measuring concerns and outcomes (Richardson et al. for NCSI 2009; Dept. of Health 2010). Their depiction of the phases of survivorship included the period immediately following treatment. Richardson et al. (2007) highlighted that patient-centred care cannot occur without sufficient understanding of patient needs and their associated influencing factors. Thus, this research, in assessing needs and distress will add to the evidence base and may prove a critical step in achieving improvements to service planning and patient-centred care for people with HGG, particularly about when most are vulnerable and when service needs are greatest. (Harrison et al. 2009).

h) Dissemination strategy: Priority to neuro-oncology colleagues and Senior Management Team BWoSCC and Board of NHSGGC. Apply for oral presentations at appropriate conferences e.g. CoR Annual Radiotherapy Conference, UK Radiation Oncology Conference, ESTRO, British Neuro-Oncology Annual Conference, Scottish Adult Neuro-oncology Conference. Journal submissions to College of Radiographers Journals, Journal of Cancer Survivorship, Psycho-oncology, Supportive Care in Cancer, Radiotherapy in Practice; European Journal of Cancer Care and appropriate Oncology Nursing Journals..

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