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**Perceptions and experiences of the subjective wellbeing of people with a diagnosis of high grade glioma  
a longitudinal phenomenological study**

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**Perceptions and experiences  
of the subjective wellbeing of  
people with a diagnosis of high  
grade glioma: a longitudinal  
phenomenological study**

A thesis submitted in partial  
fulfillment of the Doctorate in  
Healthcare (Nursing)

King's College London

Katie Sutton

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# **Abstract**

## **Aims and Objectives**

The aim of this study was to investigate the lived experiences and perceptions of people with high grade gliomas (HGG) regarding their subjective wellbeing (SWB).

The objectives were:

- To explore the lived experiences and perceptions of people with HGG in terms of their SWB at various points throughout their illness.
- To clarify the meaning of the term 'wellbeing'.
- To investigate the lived experiences and perceptions of people with HGG regarding the assessment tools currently used to monitor their SWB.

## **Method**

Twenty-seven interviews were conducted with 15 patients over a period of two years. The majority of patients were interviewed twice on a face-to-face basis (shortly after surgery, and again following the completion of adjuvant treatment). The study adopted a longitudinal, hermeneutical phenomenology approach. Data were managed using NVivo 10 software and analysed using the Hermeneutic Circle.

## **Findings**

Analysis of the data identified four key domains in relation to the study aims. These were 'daily life', 'experiences of care', 'psychological wellbeing' and 'health'. Each of these domains consisted of multiple themes, which were then critically analysed for their potential to threaten the SWB of people with HGG. Interpretive phenomenological analysis of the data identified a conceptual framework for SWB encompassing three key domains that appeared to be most relevant to participants. These were Hope, Sense of Identity and Sense of Control.

### **Literature Review**

Prior to data collection, a concept analysis of the SWB of people with cancer was conducted as a means of clarifying the general concept of 'wellbeing' before referring to it in discussions with participants. Following analysis of the longitudinal data, a literature review was undertaken to explore the evidence relating to the research question 'What is the impact on wellbeing/quality of life of a diagnosis of high grade glioma?' The evidence reviewed suggests that the Hope, Sense of Identity and Sense of Control domains of SWB identified in the study findings are threatened by a diagnosis of HGG as a result of issues such as loss of independence and normality, social isolation, poor communication and lack of information from health professionals. Strategies for the preservation of SWB were also acknowledged.

### **Conclusion**

Based on the study findings, a unique conceptual model of SWB was developed which represents the key findings. This model demonstrates that SWB consists of three fundamental domains: Hope, Sense of Identity and Sense of Control. The nature of these domains fluctuates over time as they are subjected to a variety of threats resulting from HGG diagnosis and treatment. However, participants identified strategies that helped to preserve a sense of wellbeing despite their diagnosis.

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# **Abbreviations**

CNS	Clinical Nurse Specialist
GBM	Glioblastoma
HGG	High Grade Glioma
HRQOL	Health Related Quality of Life
NSCLC	Non Small Cell Lung Cancer
QoL	Quality of Life
SWB	Subjective Wellbeing
TMZ	Temozolomide
WHO	World Health Organisation

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# **Chapter 1: Introduction**

## **1.1 Introduction**

This introductory chapter provides detail on the background to the study. It includes information on the personal motivations of the researcher, the anatomy and physiology of brain tumours and the clinical setting for the research. It then proceeds to highlight the need to distinguish between the terms wellbeing, subjective wellbeing and quality of life, before concluding with a summary of the structure of the thesis.

## **1.2 Background**

High Grade Glioma (HGG) is a particularly devastating form of brain tumour, with an average life expectancy of less than one year (CRUK, 2010). As a result, most research conducted with this patient group in the past has focused on improving survival duration rather than Quality of Life (QoL) or wellbeing. However, in addition to this poor prognosis, people with a diagnosis of HGG often experience a significant symptom burden resulting from both physical and cognitive deficits, which may have a profound impact on their daily life and SWB (Halkett et. al, 2010). Despite an increased focus on health-related QoL as an outcome of treatment in recent years, the QoL and SWB of people diagnosed with HGG remains a relatively understudied area compared to other cancer groups (Piil et. al, 2018).

## **1.3 Personal motivation for this study**

As a senior cancer nurse at a major London cancer centre, I was for many years involved in the care of patients with malignant brain tumours, particularly those with a diagnosis of HGG. I have cared for people with malignant brain tumours at various stages throughout their disease from diagnosis, during conventional and trial treatments, and during the palliative phase. Prognosis for people with malignant brain tumours depends on several factors. Some low-grade tumours have a relatively high survival rate at five years. Unfortunately, others such as glioblastoma (GBM), have a poorer five-year survival rate of just 4% (Cancer Research UK, 2010). The treatment and monitoring of patients with a poor prognosis often triggered ethical debates amongst healthcare staff at my workplace. There is an

argument for treating people with advanced disease even if the potential for prolonging life is small. Some people with HGG may wish to receive such treatments no matter the cost to their quality of life (QoL) if there is a chance that it may extend their survival. It could be argued that offering treatment preserves hope, which in itself contributes positively to SWB (Sutton, 2012). The importance of enrolling people with brain tumours on trials for which they are eligible so that outcomes may be improved for future generations can also not be ignored. On the other hand, it may be argued that giving treatments with debilitating side effects such as chemotherapy and radiotherapy, which may have a detrimental effect on QoL and SWB for some people is unethical for those who are likely to experience minimal benefits (Neil et. al, 2016).

It was such a discussion that motivated me to propose undertaking this research into the nature of SWB of people with malignant brain tumours. How do we measure it? And should it be health professionals who decide what SWB means to someone with a high-grade malignant brain tumour? Surely it is the personal perceptions and experiences of those with the disease that matters? What is seen as an important element of QoL for one person may not be particularly significant to someone else. A review of the literature revealed very little available investigating the impact of having HGG on SWB from the perspective of those who had been diagnosed with the disease, which consolidated my determination to explore the subject in more depth.

## **1.4 Brain Tumours-anatomy and physiology**

In order to provide context and background for the research project, this section offers a brief overview of the anatomy and physiology of the brain and primary brain tumours, as well as current treatments and recent developments in care.

### **1.4.1 The anatomy of the brain**

The brain is divided into four main parts: The cerebrum, the cerebellum, the cerebral cortex and the brain stem. The cerebrum, the largest part of the



brain, is made up of the right and left cerebral hemispheres. The left hemisphere controls the right side of the body, and the right hemisphere controls the left (Murdoch, 2009).

The cerebrum is responsible for controlling higher-order functions such as thinking and memory and is divided into four lobes, which are summarised in figure 1.1 below.

<b>Lobe name</b>	<b>Function</b>
Frontal Lobe	High levels of cognitive functioning, such as reasoning and judgement.
Parietal lobe	Associated with sensation and touch, and is also involved in the ability to read and write.
Temporal lobe	Responsible for auditory functioning, and the ability to produce and understand meaningful speech.
Occipital lobe	Responsible for vision and the ability to understand what is seen, and to associate it with previous experiences and knowledge.

(Murdoch, 2009)

**Figure 1.1: Functions of the four lobes of the cerebrum**

The cerebellum is located towards the back of the head, at the base of the skull. It is responsible for motor control, co-ordinating voluntary muscle movements, balance and equilibrium. It may also be involved in some cognitive processes such as language function. The cerebral cortex is commonly referred to as 'grey matter'. It takes the form of a layer covering the cerebellum and cerebrum. The area covering the cerebrum is known as the cerebral cortex (Bailey, 2013a). It is folded into numerous layers consisting of nerve cells (neurons) and the non-neuronal, 'glue-like' cells supporting them known as glial cells (Goldman, 2009). The cerebral cortex is responsible for the highest levels of intellectual functioning such as sensation, voluntary movement, thought and reasoning.

The brain stem is the portion of the brain that connects the cerebrum to the spinal cord, consisting of the medulla oblongata, pons and the midbrain. It

has an essential role to play in cardiac and respiratory function. It is also extremely important as neurons pass information through it to and from the upper parts of the brain to the peripheral nerves in the rest of the body. As a result, trauma or disease in the brain stem is often life-threatening (Bailey, 2013b).

#### **1.4.2 Primary malignant brain tumours**

Primary malignant brain tumours develop as a result of the growth of abnormal cells in the tissues of the brain or central nervous system (CNS). The World Health Organisation (WHO, 2016) has identified more than 120 types of CNS tumours classified according to cell origin and behaviour (they may be named after a cell which they share histological features with, but do not necessarily originate from). They may involve either neurons or glial cells. One of the most common types of brain tumour is glioma. Gliomas originate from the glial cells. Classifications of glioma include glioblastoma, astrocytoma, medulloblastoma and oligodendroglioma (National Brain Tumor Society, 2011). Primary malignant brain tumours are graded 1 to 4 depending on how fast they grow and how likely they are to spread. High-grade gliomas are graded 3 or 4 (Brain Tumour UK, 2012). In 2014, there were 16.7 newly-diagnosed brain tumours per 100,000 population in England (Brain Tumour Research, 2016).

#### **1.4.3 Causes**

As with many types of cancer, brain tumours in general have a higher level of incidence in older people. However, some brain tumours (such as medulloblastoma) are more likely to occur in children. Clear causes for brain tumours have not been identified, although people with previous exposure to radiotherapy or certain genetic conditions such as neurofibromatosis seem to be at greater risk (Macmillan, 2012b).

#### **1.4.4 Symptoms, diagnosis and prognosis**

Symptoms often relate to an increase in intracranial pressure resulting from the presence of a tumour in the intracranial space. They may also be caused by the presence of tumours in particular parts of the brain. Examples of

symptoms include nausea and vomiting, headaches, seizures, loss of vision, hearing, speech or co-ordination, numbness, changes in personality or loss of sensation on one side of the body (Macmillan, 2012a).

Diagnosis is confirmed through the use of imaging techniques such as Magnetic Resonance Imaging (MRI), Computerised Tomography (CT), X-ray or Positron Emission Tomography (PET). Biopsies may also be necessary to confirm histology (Cancer Research UK, 2012).

Prognosis for people with brain tumours depends on the type, grade and location of the tumour. Overall, less than 20% of brain tumour patients survive beyond five years of their diagnosis (Brain Tumour Research, 2016). Women and younger people appear to have a slightly better prognosis. People with low grade astrocytomas have a survival rate of 65% at five years. Oligodendrogliomas can be low or high grade (anaplastic) and therefore have a variable five-year survival rate of between 30-78%. More than 50% of people with ependymoma live for at least five years (Cancer Research UK, 2010). However, glioblastoma has a much poorer outlook, with a 4% five year survival, and an average life expectancy of less than a year.

#### **1.4.5 Treatment**

Treatment for malignant brain tumours commonly involves a combination of surgery, chemotherapy and/or radiotherapy depending on the type of tumour and its location within the brain (i.e. whether it is safe to surgically remove it or not). Standard treatment for glioma includes surgery, followed by radiotherapy and/or chemotherapy. Chemotherapy usually consists of Temozolomide (oral chemotherapy) or PCV (Procarbazine, Lomustine (CCNU) and Vincristine - a combination of intravenous and oral chemotherapy). As Temozolomide is given in capsule form, it can be taken as an outpatient. When given as a treatment for HGG, it is generally administered as a course of six cycles of treatment over a few months. Each cycle is 28 days long, with the capsule being taken for the first 5 days only, followed by 23 days without treatment before the cycle is repeated. Each cycle of PCV takes 42 days, with Vincristine and Lomustine administered via

an intravenous infusion on day 1 with a 10-day course of Procarbazine capsules beginning on the same day. The patient then has no more treatment for the remaining 32 days before the cycle begins again (Macmillan, 2017).

Radiotherapy is usually given once a day, 5 days a week for a period of 6 weeks and is given concurrently with chemotherapy.

Numerous clinical trials are currently underway in the UK, which hope to improve the outlook for people with brain tumours. These include the testing of a targeted drug called Olaparib and the vaccine DCVax-L for glioblastoma (Cancer Research UK, 2019)

### **1.5 Care offered at the Cancer Centre**

The brain cancer service at the hospital where this research was conducted has developed significantly over the past few years, particularly in terms of the number of clinical trials offered, and the opening of a dedicated brain tumour unit, which is now internationally recognised as a centre of excellence. As a general rule, in the cancer centre where this research was conducted, people with HGG are diagnosed and have surgical resection of their malignant primary brain tumour within 1-2 months of initial presentation of symptoms. They are then offered first line treatment consisting of Temozolomide chemotherapy in conjunction with a 6-week course of radiotherapy. Following completion of radiotherapy, they are usually given Temozolomide chemotherapy as a form of maintenance treatment. At disease relapse, they undergo further surgery to remove the recurrence of their tumour if appropriate. They are then given second line chemotherapy (such as PCV or Lomustine) or may be enrolled in a clinical trial of a new anti-cancer agent if available. Patients also have the opportunity to enter a clinical trial at any stage during treatment, depending on which trials are open to recruitment. In January 2020, the Centre had seven clinical trials open to recruitment, which were focused on researching treatment options for glioma.

## **1.6 Findings from a related study conducted at the cancer centre**

I conducted a related study prior to registering for this PhD programme entitled, 'The impact on quality of life for people with brain tumours of entering a research trial involving new anti-cancer agents.' (Sutton, 2012). This phenomenological study involved interviews with five participants, all of whom were receiving treatment for a brain tumour as part of a research trial. Participants were interviewed about their experiences of entering the research trial, and how they felt it had affected their QoL. Overall, the findings of this small-scale study were extremely positive in terms of participants' perceptions of the impact of entering a research trial involving new generation anti-cancer drugs on their QoL. The two major themes identified in this study focused on the importance of retaining hope and optimism during treatment, and the positive impact of the therapeutic relationship that developed with the health professionals involved in their care. Some participants also talked about the tools used in the trials to assess their QoL. They stated that these tools had the potential to misrepresent the true picture of their wellbeing, as they tend to focus on health status rather than on the personal and subjective issues that participants felt are relevant to their individual lives.

The findings of this study, combined with limited published literature on the topic, reinforced my initial belief that further exploration into the perceptions and experiences of people with brain tumours in terms of their SWB was warranted. I decided to focus the proposed research specifically on people with HGG as they are a group of patients with particularly complex needs and a poorer prognosis. For these reasons, their SWB is likely to be significantly compromised, and so exploring their specific experiences in the hope that it might enhance their care is especially important.

### **Timing of the concept analysis and literature review**

It became clear during this initial phase of the research that there was considerable overlap between the use of the terms 'wellbeing', 'subjective wellbeing' and 'quality of life' despite the fact that these concepts appeared to

have some significant differences in their meaning. It became clear that clarifying the definitions of these concepts before proceeding with more specific research and reviewing the available literature was imperative to ensure a well-informed and coherent study.

As a result, and after consultation with my PhD supervisors, I made the decision to conduct a concept analysis of 'subjective wellbeing' prior to commencing the research rather than a more traditional literature review. This allowed me to undertake an initial review of the literature relating to the subject matter and identify gaps in the knowledge base, whilst at the same time providing a sound theoretical basis for my study. I then undertook a more thorough literature review following analysis of my data. Conducting the literature review at this later stage offered multiple benefits to the study. It allowed me to consider the literature in light of my own findings, which ensured a focus on how the research added to the body of evidence already available and led to a higher level of interpretive and meaningful analysis. It also meant that the themes emerged inductively from the data, rather than being influenced by prior research. Additionally, on a more practical level, it ensured a review of the most up to date evidence relating to my study.

As a part-time student, my PhD study spanned a period of approximately 8 years, including two years maternity leave. Relying on a literature review conducted in the initial stages would therefore have considerably limited the application of recent research to my study. The combined approach of conducting a concept analysis in the first instance and a literature review later on has addressed this potential issue and ensured a more thorough review. Indeed, it was striking to note the increase in reference to the wellbeing of people with cancer during recent years, which would have been missed had I adopted a more traditional approach to my thesis.

As a result of this methodological decision, the chapters of this thesis will be presented in the following order:

- Concept Analysis
- Methodology
- Data Analysis

- Longitudinal Analysis of Participant Data
- Findings
- Literature Review
- Discussion
- Conclusion

## **1.7 Conclusion**

This introductory chapter has provided the background to the study, the personal motivations of the researcher, the anatomy and physiology of brain tumours and the clinical setting for the research. It has highlighted the need to distinguish between the terms wellbeing, subjective wellbeing and quality of life at the start of the project, and the rationale for undertaking the detailed literature review at a later point in the study period. The chapter concludes with a summary of the structure of the thesis.

The next chapter will begin by discussing the theory of undertaking a concept analysis, before providing a thorough description of the process undertaken as a means of justifying the resulting definition of SWB, which was used to inform the basis of this research.

## **Chapter 2: Concept Analysis**



## **2.1 Introduction**

As was previously mentioned, I noticed whilst conducting an initial scoping review of the literature exploring the QoL and wellbeing of people with a diagnosis of cancer or HGG in particular, that the terms were used interchangeably, with little clarity on any differences between the two concepts. On further reading, it appeared that subjective wellbeing was more relevant to this study, which aimed to explore personal perceptions and experiences. It was decided that a concept analysis would be undertaken as a means of identifying an operational definition of subjective wellbeing, which could then be used throughout the research.

This chapter will begin by discussing the theory of undertaking a concept analysis, before providing a thorough description of the process undertaken as a means of justifying the resulting definition of SWB.

## **2.2 What is a concept?**

Before deciding on an approach to concept analysis, it is important to clarify the meaning of the term 'concept' itself. Concepts are mental images of phenomena, which we each hold in our minds to enable us to recognise something. As a result, concepts can differ from person to person (Baldwin and Rose, 2009). An individual's expression of a concept results from an intricate mental formulation of experiences (Chinn and Kramer, 1995). Despite the complexity of defining a concept, it is vital to explore its true meaning, especially as concepts are often referred to as the building blocks of theory (Rodgers, 1993). Additionally, Duncan et al (2009) propose that concepts provide the knowledge required to develop nursing practice and patient care (Duncan et al., 2009).

When a concept first appears in a profession, its meaning may be unclear to those within the discipline, as well as to other members of the multidisciplinary team. For example, the term 'Quality of Life' (QoL) may be viewed from a health perspective in nursing but may also be seen from a social context in sociology. It is crucial to reach a consensus on the meaning

of a concept in healthcare to ensure that it is understood and used in the same way by all. The process of concept analysis helps to address this issue (Baldwin and Rose, 2009).

### **2.3 What is concept analysis?**

Concept analysis is an exercise in defining the characteristics of a concept. It involves careful examination of the use of a word or idea as a way of clarifying meaning. Its purpose is to distinguish between the defining and irrelevant attributes of a concept (Walker and Avant, 1995). Whilst the process of conducting a concept analysis should be both formal and rigorous, it must be emphasised that outcomes will always be tentative. As was previously mentioned, concepts may vary according to context, which is also subject to continuous evolution. Concepts may also be viewed differently between individuals. As a result of variations in context and interpretation, a concept analysis should be viewed as a dynamic, ongoing process rather than as a finished product (Walker and Avant, 1995). An awareness of the pitfalls and limitations of concept analysis is also vital in ensuring that the process is not arbitrary, but is instead a valuable exercise. When approached with insight and caution, it is a method of inquiry that aids communication by clarifying the meaning of terms, is fundamental in increasing the body of knowledge, and consequently acts as a solid basis for theory formation (Baldwin and Rose, 2009).

There are several methodological debates surrounding the use of concept analysis. On the one hand, it is cited by many as the basis for knowledge and theory development in nursing (Rodgers, 1993; Walker and Avant, 1995). However it is not without its critics. Risjord (2009) argues that concepts may be 'theory-formed' rather than 'theory-forming', and that concepts and contexts are mutually dependent. He suggests nursing theorists have made unjustifiable alterations to methods of concept analysis over recent years, without regard for their philosophical foundations, and thus often do not produce meaningful results. Concerns have also been raised regarding uncritical use of these frameworks, which may result in findings based on studies that lack depth and rigour (Beckwith et al., 2008). As a means of

offering clarity on the variety of approaches to concept analysis available, three approaches are summarised below. These were selected for further discussion based on their popularity and frequent use in the nursing literature.

### **2.3.1 Wilson (1963)**

Wilson was a teacher who developed a framework to be used with school children as a means of teaching them to answer questions of a conceptual nature (Avant, 1993). The eleven steps of concept analysis listed by Wilson (1963) can be seen in Figure 2.1 below:

1.	Isolating questions of concept
2.	Finding right answers
3.	Model cases
4.	Contrary cases
5.	Related cases
6.	Borderline cases
7.	Invented cases
8.	Social context
9.	Underlying anxiety
10.	Practical results
11.	Results in language

**Figure 2.1: Wilson’s eleven steps in Concept Analysis (Wilson, 1963)**

Wilson’s approach to concept analyses may be seen as a simple but effective way of defining the essential features of a concept (Risjord, 2009), which may be particularly useful for stimulating group discussion (Avant, 1993).

However, it is worth remembering that this approach sees concepts as inert, and there is little emphasis placed on the impact of evolving context (Beckwith et al., 2008). More recently, nursing theorists have acknowledged that the positivist philosophical approach of Wilson’s method does not fit with the interpretivist foundations of nursing and have sought to adapt

Wilson's approach in an attempt to address contextual issues (Rodgers, 1993; Chinn and Kramer, 1995; Walker and Avant 1995).

### **2.3.2 Walker and Avant (1995)**

Nursing theorists, Walker and Avant (1995) modified Wilson's model so only eight steps are required. These steps are listed in figure 2.2 below:

1.	Select a concept.
2.	Determine the aims or purposes of analysis
3.	Identify all uses of the concept that you can discover
4.	Determine the defining attributes
5.	Construct a model case
6.	Construct borderline, related, contrary, invented and illegitimate cases
7.	Identify antecedents and consequences
8.	Define empirical referents

**Figure 2.2: Walker and Avant's approach to concept analysis (Walker and Avant, 1995)**

Walker and Avant's approach offers a useful framework for nurses looking to undertake a concept analysis and is well-established and supported in the metatheory literature (McCance et al., 1997). However, it is vital to take into account the philosophical foundations of an approach before deciding on the appropriateness of its use. Walker and Avant's method appears to take a positivist stance, presuming that observations lead to the discovery of objective truths (Beckwith et al., 2008). This perspective perhaps oversimplifies the process of concept analysis, particularly in the field of nursing, when the necessity to take into account the personal circumstances of individuals requires a more interpretivist approach.

### **2.3.3 Rodgers' evolutionary method (1993b)**

Whilst the procedure of concept analysis presented by Rodgers (1993) is attributed to Wilson's original work (1963), she acknowledges that the

historical tendency to attempt to produce a finite definition of a concept resulted in findings with limited significance and utility. Her ‘evolutionary’ approach attempts to address this issue by adopting an interpretivist stance, where concepts are recognised as being dynamic rather than static, and context is deliberately considered as a factor rather than attempting to disregard it (Cooley, 1998). The primary activities involved in Rodgers’ method can be seen in Figure 2.3 below.

1.	Identify the concept of interest and associated expressions
2.	Identify and select an appropriate realm
3.	Collect data regarding the defining attributes of a concept, along with surrogate terms, references, antecedents, and consequences
4.	Identify concepts related to the concept of interest
5.	Analyse data regarding the above characteristics of the concept
6.	Conduct interdisciplinary or temporal comparisons, or both, if desired
7.	Identify a model case of the concept, if appropriate
8.	Identify hypotheses and implications for further development

**Figure 2.3: Primary activities of Rodgers’ evolutionary method of concept analysis (Rodgers, 1993b)**

Rodgers’ approach appears to be aligned with the philosophical foundations of contemporary nursing practice and this research project in particular as it recognises the importance of individual differences in experience. The following section explores the key components of Rodgers’ theory in more detail.

### **2.3.3.1 Identify the concept of interest and associated expressions**

The first activity in the concept analysis process is understandably to identify the concept of interest. This usually occurs as a result of reading literature or

experiences in practice that are particularly thought-provoking. Limited guidance on this activity is available in the concept analysis literature. However, Walker and Avant (1995) advised avoiding 'umbrella' terms that may have several meanings. They also emphasise the importance of analysing a concept that will contribute significantly to knowledge development. Rodgers (1993) suggested that at this stage, a broad selection of resources should be considered as a means of identifying expressions associated with the concept of interest. Rodgers offered the example of the concept of 'optimism' being associated with expressions such as 'hope' and 'acceptance'. She also suggests that the evolution of relevant context should be considered at this point. As a result of this exploratory stage at the start of the process, a broader understanding of the concept should be obtained before the more specific analysis begins.

#### **2.3.3.2. Identify and select an appropriate realm**

Rodgers (1993) emphasises the importance of setting an appropriate realm (setting and sample) for data collection. For example, performing an analysis of a concept found in nursing would involve analysis of data relevant to nursing and closely related disciplines, thus acknowledging that the meaning of a concept will depend on its context. Risjord (2009) offers the example of the concept of 'depression' as a means of illustrating this. The term 'depression' has a variety of meanings depending on whether it is being discussed in the field of psychology, meteorology or economics, yet these meanings have no more in common than an ambiguous notion of being 'down'. When conducting a concept analysis, care must be taken to ensure that the domains selected to sample are relevant. Differences in the use of a concept within closely related disciplines should be made explicit to remove ambiguity and enhance validity (Risjord, 2009). Guidance for selecting the setting is limited to the suggestion of making decisions based on initial questions and desired outcomes. Deciding which disciplines to include may be based on familiarity with literature and an awareness of which fields of study regularly refer to the concept of interest (Rodgers, 1993b).

### **2.3.3.3 Collect data regarding the defining attributes of a concept, along with surrogate terms, references, antecedents, and consequences**

In Rodgers' theory, essential components of a concept are known as defining attributes and these constitute a definition. It is this cluster of characteristics that helps to identify the concept of interest. Defining attributes are anything that offer insight into the answer to the question 'what is this idea that we are discussing?' (Rodgers, 1993).

Surrogate terms are those that have been identified by the researcher as being used interchangeably with the chosen concept. Rodgers offers the example of 'adaption' and 'accommodation' being used as surrogate terms for 'coping'. References offer examples of situations where the concept is applied (Rodgers, 1993).

Antecedents and consequences are situations or phenomena that precede and/or follow an example of the concept. According to Rodgers (1993), these should assist definition of the concept by clarifying its scope and application.

### **2.3.3.4 Identify concepts related to the concept of interest**

According to Rodgers (1993), related concepts are those that bear some resemblance to the concept of interest, but do not share the same set of attributes. Identification of related concepts aids contextual understanding by showing how networks of ideas are linked, and how their differences are identified. Care must be taken not to confuse related concepts with surrogate terms (surrogate terms suggest the variety of ways in which a set of attributes is expressed.)

### **2.3.3.5 Analyse data regarding the above characteristics of the concept**

Rodgers (1993) offers limited guidance on data analysis, however she does recommend delaying data analysis until the end of data collection to avoid jumping to premature conclusions. She advises following a standard procedure of thematic analysis, excluding any related concepts or surrogate terms found (which she suggests usually require little further examination other than stating how frequently they are mentioned).

### **2.3.3.6 Conduct interdisciplinary or temporal comparisons, or both, if desired**

In accordance with the more fluid nature of her evolutionary approach, Rodgers (1993) states analysis should include examination of any differences between disciplines or changes over time noticed in the results.

### **2.3.3.7 Identify a model case of the concept, if appropriate**

Constructing a model case is common to all three models and can be described as offering a 'real life' example of the concept (Walker and Avant, 1995). Wilson (1963) suggests portrayal of a concept through the use of a model case allows for explanation of the essential features of a concept, and that comparison of a number of model cases can determine which elements are essential to the concept and which are not (Avant, 1993). In instances where such model cases cannot be found, both Wilson (1963) and Walker and Avant (1995) suggest cases may be invented to assist in clarification.

Whilst acknowledging that the model case is valuable as a means of offering clarity and encouraging understanding of a concept, Rodgers (1993) advocates identifying rather than constructing a model case. She also warns of the risk of subjectivity and bias associated with the model case. The researcher must be careful to select cases that are as generic as possible, rather than selecting those that suit personal interests (Rodgers, 1993), and if a suitable case cannot be found then it is better to leave the model case out rather than to construct one. It is unrealistic to suggest researcher bias can be completely excluded in this practice. Model cases are identified based on methods of data collection and each researcher may conduct this differently. However, approaching the model case with an awareness of its pitfalls, as well as clear documentation of how cases were identified, enhances rigour. Rodgers (1993) proposes that a constructed model case may imply a clear and well-developed concept, when in fact the reality may be that there is still considerable debate concerning its definition. Even with Rodgers' insistence on the identification of an actual example rather than the construction of one, there are pitfalls associated with the model case. The philosophical basis for the importance of the model case is based on casuistry (Beckwith et. al,



2008). Casuistry involves using an example of the common features of a particular case to dictate a universal rule (Beckwith et. al, 2008). It is an approach often used by the legal profession when a single case is deemed to set a precedent for the outcome of others. Whilst casuistry may be useful to some professions, it is of limited use in concept analyses that are being approached from a nursing perspective. As was previously mentioned in this chapter, there it is acknowledged in nursing that concepts are affected by constantly changing contextual issues, and that people do not always behave in a predictable manner as they are affected by their individual social circumstances and experiences (Rodgers, 1993).

#### **2.3.3.8 Identify conclusions and recommendations for further development**

As concept analysis in nursing is intended as a basis for developing theory, the identification of conclusions and suggestions for further research are perhaps the most important outcomes of the process. If the concept analysis has been conducted in a rigorous manner, then any research conducted based on the findings of a concept analysis should have a sound conceptual foundation (Rodgers, 1993).

### **2.4 Deciding on an approach to concept analysis**

Rodgers' evolutionary method (Rodgers, 1993) was selected for this concept analysis of the SWB of people with cancer for a number of reasons. Firstly, this approach fits with the complex, interpretive nature of nursing by acknowledging that concepts require continual refinement as context and related concepts change, and secondly, that people do not always behave in a predictable manner as they are affected by their individual social circumstances and experiences. This approach accepts that concept analysis is always tentative by nature and may evoke as many questions as it answers (Rodgers, 1993). It is also a method that differs to Wilson's in the sense it adopts a view of concepts as changing over time according to their significance, use, and application (Cooley, 1998). These epistemological foundations appear to fit with the hermeneutic phenomenological approach

used in this research project, thus helping to ensure methodologically sound results.

This chapter will now proceed to describe in detail a concept analysis of SWB in cancer using Rodgers' method. This concept analysis was conducted in 2015.

## **2.5 Concept analysis of the subjective wellbeing of people with cancer using Rodgers' evolutionary approach**

### **2.5.1 Introduction**

The aim of this concept analysis was to produce an operational definition of the SWB of people with cancer to be used in the context of nursing as well as the wider healthcare field. More specifically, it will offer important clarity on the meaning of the term 'subjective wellbeing' when used in this research project exploring the impact of HGG on wellbeing. By making the context explicit in this fashion, evaluation of this concept analysis in terms of its rigour and applicability should be made easier (Risjord, 2009). It was decided that the concept analysis should include all cancer types rather than being limited to HGG at this stage, as the available literature relating specifically to HGG was insufficient to generate a detailed and trustworthy picture. Similarly, the term 'wellbeing' rather than the more specific 'subjective wellbeing' was used in the first instance, as evidence referring to SWB at the time this concept analysis was conducted was scarce.

### **2.5.2 Background**

Even though wellbeing is widely regarded as a fundamental measure of existence, the term is vague and ambiguous. It is a concept that is increasingly referred to on modern political agendas and is now closely monitored by the Office for National Statistics, yet it is often poorly-defined, and used interchangeably with other concepts such as 'health' and 'QoL' (McNaught, 2011). On conducting a preliminary literature search on wellbeing in people with brain tumours, an agreed definition of wellbeing, particularly for people with neurological cancer, was difficult to find. However, in recent years there has been an increase in awareness of the

importance of the wellbeing of people with cancer, particularly as treatments continue to improve, and more people are surviving cancer. The NHS has recently emphasised the importance of safeguarding the wellbeing of people with cancer in the NHS Long Term Plan (NHS, 2019) and Macmillan Cancer Support, the leading UK cancer charity, have stressed their commitment to supporting people to maintain their wellbeing by including it as a central theme in The Recovery Package (Macmillan, 2019).

The idea of wellbeing was introduced as a major international concept in a statement from the Constitution of the World Health Organisation (WHO) (1946: pg 1), which states 'health is not the mere absence of diseases, but a state of wellbeing'. However, the term itself was not defined. This statement also suggests that wellbeing was not something that could be experienced if a person is in ill-health.

In recent years, it has been suggested that wellbeing has two different but inter-related aspects; objective or societal wellbeing, and subjective or individual wellbeing (Tinkler and Hicks, 2011). Objective wellbeing encompasses the more traditionally held belief of wellbeing as the physical, social and psychological welfare of a community. This is the more tangible and measurable idea of the two, incorporating issues such as housing, education, employment, health and crime (Tinkler and Hicks, 2011), and is frequently referred to on contemporary political agendas as a measure of the success of a government and society as a whole (McNaught, 2011). Subjective/individual wellbeing is more difficult to quantify but has nonetheless become a topic of great interest and discussion. The Office for National Statistics introduced subjective wellbeing data alongside objective measures, in recognition of the fact that issues such as a sense of purpose and fulfilment, relationships with family and friends, and a sense of community are crucial to the wellbeing of the nation as a whole (Tinkler and Hicks, 2011). The wellbeing of people with cancer is more closely linked to subjective/individual wellbeing rather than objective/societal wellbeing, as it is concerned with the experiences of individuals, and can therefore only be assessed from an individual perspective. However, it must be acknowledged

that objective components may still have a significant impact on people with cancer.

Attributes such as life satisfaction, independence and relationships raise doubts over the conventional idea of health as the key attribute of wellbeing. There are evidently many more elements to be considered. Wellbeing is an all-encompassing term, which conceptualises an ideal state of existence. It is therefore unsurprising that attempts at establishing an operational definition are fraught with difficulty.

### **2.5.3 Method**

#### **2.5.3.1 Setting and sample**

Rodgers (1993) states that the setting refers to the time period and disciplines to be included in data collection. Guidance for selecting the setting is limited to the suggestion of making decisions based on initial questions and desired outcomes. Deciding which disciplines to include may be based on familiarity with literature and an awareness of which fields of study regularly refer to the concept of interest (Rodgers, 1993). Rodgers does not specify how many domains to include. However, as this concept analysis was approached from a nursing perspective, it was decided that the disciplines to be included would be nursing, medicine, psychology/sociology and health policy as these are disciplines within which the term is commonly used. It was also felt that this cross section of domains would offer a broader perspective on the concept of SWB.

#### **2.5.3.2 Data collection**

Six bibliographic databases were selected for their potential to identify data relevant to all domains. These were Medline, CINAHL (Cumulative Index to Nursing and Allied Health Literature), PsycINFO, ASSIA (Applied Social Sciences Index and Abstracts), Social Policy and Practice and ProQuest.. Using keyword searches on bibliographic databases promotes rigour and credibility, and allows the reader to replicate the search strategy and produce the same results. Initial searches were conducted in each database by combining the keywords 'subjective wellbeing' OR 'subjective well-being',

AND 'cancer' in the title and abstract. Results were restricted to 'English language' and 'humans' wherever databases permitted.

Rodgers (1993) suggests the inclusion of at least 30 resources, or 20% of the total from each discipline is sufficient data to show a consensus within a discipline (Rodgers, 1993). Although the approach to data collection used in this study deviated from Rodgers suggestion by focusing on databases rather than individual disciplines, Rodgers does advocate researchers develop their own unique style of collecting data, as long as all methodological decisions are justified and recorded (Rodgers, 1993). The main reason for modifying Rodgers approach is the issue of overlap between disciplines, particularly in the fields of medicine and nursing. Many databases contain literature pertaining to both. Therefore, performing a search for each individual discipline would be time consuming and unnecessary.

#### **2.5.3.3 Data analysis**

The initial search across all six databases resulted in the identification of 68 articles. On reviewing the abstracts, it was decided that only articles written in the last 20 years would be included, as it appeared that before this time many articles did not differentiate between subjective and objective wellbeing. In recent years, there has been an increasing volume of literature on SWB due to a surge in interest by researchers such as Diener (2005). It was felt that imposing this restriction, would help to ensure that only contemporary interpretations were included in the analysis. At this stage, those articles referring to the wellbeing of carers were also removed, as they were not relevant to the focus of this analysis, which is concerned with the SWB of people with cancer.

In addition to the resources identified in the database search, three additional resources were identified which offered such an important contribution to the concept analysis that they could not be excluded. These were The Constitution of the World Health Organisation (WHO) (2020); a document entitled 'Measuring Subjective Well-being' from the ONS (Tinkler and Hicks, 2011); and the book 'Understanding Wellbeing' (Knight and

McNaught, 2011). Rodgers (1993b) advocated the inclusion of data found in addition to the initial search as long as the researcher deems them to be landmark works, which was the case in this instance given both the status of the authors and the richness of the data offered.

The final number of documents reviewed in depth was 28. Where references to other papers were found within these articles that appeared to offer a valuable insight into the subject, these were also reviewed and included in the analysis.

Each piece of data was read at least once as per Rodger's method (1993) to encourage immersion in the piece of work, and to gain a sense of the author's use of the concept. Each document was analysed for significant statements relating to the antecedents, consequences, defining attributes and related concepts of or to the term subjective wellbeing in cancer as per Rodgers' method (1993). Each piece was also reviewed for its potential to offer an example of a model case. A data table was compiled including details on papers that contributed to the discussion of antecedents, consequences, defining attributes and related concepts (table 2.1). The 'Framework for Assessing Qualitative Evaluations' produced by the National Centre for Social Research (2003) was used as a guide for judging the quality of each article.

**Table 2.1: Concept Analysis data**

Reference	Contribution to Concept Analysis
<p>Carver, C. S., Smith, R. G., Antoni, M. H. et al (2005) Optimistic personality and psychosocial well-being during treatment predict psychosocial well-being among long-term survivors of breast cancer. <i>Health Psychology</i>. 24 (5) 508-516.</p>	<p>Antecedents:            positive impact on SWB:           <ul style="list-style-type: none"> <li>• Having a partner</li> <li>• Confidence in being cancer-free</li> <li>• Trait optimism</li> </ul>           negative impact on SWB:           <ul style="list-style-type: none"> <li>• Chemotherapy</li> <li>• Low Socio-Economic Status</li> </ul> </p>
<p>Clavarino, A. M., Najman, J. M., Beadle, G. (2003) The impact of will to live and belief in curability on the subjective well-being of patients with advanced cancer. <i>Mortality</i>. 8 (1) 3-19.</p>	<p>Antecedents:            Sense of purpose associated with positive impact on SWB</p>
<p>Courneya, K.S., Bobick, T.M., Rhodes, R.E. et al (2000) Personality Correlates of Patients' Subjective Well-Being After Surgery for Colorectal Cancer. An Application of the Five-Factor Model. <i>Journal of Psychosocial Oncology</i>. 18 (4) 61-72.</p>	<p>Antecedents:            positive impact on SWB:           <ul style="list-style-type: none"> <li>• Extroversion</li> <li>• Conscientiousness</li> <li>• Positive affect</li> </ul>           negative impact on SWB:           <ul style="list-style-type: none"> <li>• Neuroticism</li> </ul>           Defining attributes:           <ul style="list-style-type: none"> <li>• Similar to general population</li> </ul> </p>
<p>Deiner, E. (1996) Traits can be powerful, but are not powerful enough: Lessons from subjective well-being. <i>Journal of Research in Personality</i>. 30:389-399.</p>	<p>Defining attributes:            Both cognitive and emotional elements play a role</p>
<p>DeNeve, K.M., and Cooper, H. (1998) The happy personality: A meta-analysis of 137 personality traits and subjective well-being. <i>Psychological Bulletin</i> 124:197-229.</p>	<p>Defining attributes:           <ul style="list-style-type: none"> <li>• Life satisfaction</li> <li>• Happiness</li> <li>• Positive affect</li> </ul> </p>

Reference	Contribution to Concept Analysis
Edmondson, D., Park, C. L., Blank, T. O. et al (2008). Deconstructing spiritual well-being: existential well-being and HRQOL in cancer survivors. <i>Psycho-Oncology</i> , 17, 2, 161–9.	Consequences: Maintaining wellbeing associated with lower incidence of depression
Ganz, P. A., Desmond, K. A., Leedham, B. et al (2002). Quality of life in long-term, disease-free survivors of breast cancer: A follow-up study. <i>Journal of the National Cancer Institute</i> . 94, 39–49	Antecedents: Chemotherapy leads to reduced SWB
Gilbert, E., Ussher, J. M., Perz, J. (2011) Sexuality after gynaecological cancer: a review of the material, intrapsychic, and discursive aspects of treatment on women's sexual-wellbeing. <i>Maturitas</i> 70 (1) 42-57	Consequences: Negative impact on sexuality and sexual function
Hou, W and Lam, J. (2014) Resilience in the year after cancer diagnosis: a cross-lagged panel analysis of the reciprocity between psychological distress and well-being. <i>Journal of Behavioral Medicine</i> ; 37 (3): 391-401.	Defining attributes: SWB is a unique and individual evaluation of life. Being calm Feeling happy  Related concepts: <ul style="list-style-type: none"> <li>• Suffering</li> <li>• Distress</li> </ul>
Kedde, H; van de Wiel, H B; M; Weijmar Schultz, W C; M; Wijzen, C. (2013) Subjective sexual well-being and sexual behavior in young women with breast cancer. <i>Supportive Care in Cancer</i> 21(7) 1993-2005.	Antecedents: Younger people=greater impact of diagnosis on SWB  Consequences: Reduced SWB associated with negative impact on sexuality and sexual function  Related Concepts: QoL
Lo, C; Lin, J, Gagliese, L.,Zimmermann, C; Mikulincer, M; Rodin, G. Lo, Christopher (2010) Age and depression in patients with metastatic cancer: The protective effects of attachment security and spiritual wellbeing. <i>Ageing &amp; Society</i> 30 (2) 325-336.	Consequences: Safeguarding SWB leads to increased acceptance of disease and emotional stability



Reference	Contribution to Concept Analysis
McDonough, M. H., Sabiston, C. M., and Wrosch, C. (2014). Predicting changes in posttraumatic growth and subjective well-being among breast cancer survivors: the role of social support and stress. <i>Psycho-Oncology</i> . 23 (1) 114-120.	<p>Antecedents:</p> <p>positive impact on SWB:</p> <ul style="list-style-type: none"> <li>• having a partner</li> </ul> <p>negative impact on SWB:</p> <ul style="list-style-type: none"> <li>• being younger</li> <li>• greater disease and treatment burden</li> </ul>
Mount, B.M., Boston, P.H. and Cohen, S.R. (2007) Healing Connections: On Moving from Suffering to a Sense of Well-Being. <i>Journal of Pain and Symptom Management</i> 33(4) 372-388.	<ul style="list-style-type: none"> <li>• Related concepts: QoL</li> <li>• Distress</li> <li>• Suffering</li> </ul>
Palgi, Y; Ben-Ezra, M; Hamama-Raz, Y. et al (2014) The Effect of Age on Illness Cognition, Subjective Well-being and Psychological Distress among Gastric Cancer Patients. <i>Stress &amp; Health: Journal of the International Society for the Investigation of Stress</i> 30 (4): 280-6.	<p>Defining attributes:</p> <ul style="list-style-type: none"> <li>• Unique, individual evaluation of life satisfaction</li> </ul> <p>Related concepts:</p> <p>QoL</p>
Persoskie, A., Ferrer, R., Nelson, W. L., Klein, W. M. P., (2014) Precancer Risk Perceptions Predict Postcancer Subjective Well-Being. <i>Health Psychology</i> 33 (9) 1023-1032.	<p>Defining attributes:</p> <ul style="list-style-type: none"> <li>• Peace</li> <li>• Joy</li> <li>• Excitement</li> </ul> <p>Antecedents:</p> <ul style="list-style-type: none"> <li>• Perceiving self to have a low risk of cancer-protective effect on SWB</li> <li>• Optimism</li> </ul>
Pinquart, M. and Frohlich, C. (2009) Psychosocial resources and subjective well-being of cancer patients. <i>Psychology &amp; Health</i> . 24 (4) 407-421.	<p>Antecedents:</p> <ul style="list-style-type: none"> <li>• Will to live</li> <li>• Perceived support network and improved SWB</li> </ul> <p>Defining attributes:</p> <ul style="list-style-type: none"> <li>• Functional status and disease stage not relevant</li> </ul>

Reference	Contribution to Concept Analysis
Reimer, Y. and Gerber, B. (2010) Quality-of-life considerations in the treatment of early-stage breast cancer in the elderly. <i>Drugs &amp; Ageing</i> 27 (10): 791-100.	Antecedents: <ul style="list-style-type: none"> <li>• Younger= greater impact of diagnosis on SWB</li> </ul>
Schickler, P. (2005) Achieving health or achieving wellbeing? Learning in Health and Social Care.4 (4) 217–227.	Defining attributes: <ul style="list-style-type: none"> <li>• Health status not important</li> </ul>
Simon, A. E.; Wardle, J. (2008) Socioeconomic disparities in psychosocial wellbeing in cancer patients. <i>European Journal of Cancer</i> . 44 (4) 572-8.	Antecedents: <ul style="list-style-type: none"> <li>• evidence of potential negative impact on SWB of low socioeconomic status</li> </ul>
Tinkler, L. and Hicks, S. (2011) Measuring Subjective Well-being. Newport: Office for National Statistics.	Defining attributes: <ul style="list-style-type: none"> <li>• Individual experience</li> </ul>
VanderZee, K. I.; Buunk, B. P.; DeRuiter, J. H. et al. (1996) Social comparison and the subjective well-being of cancer patients. <i>Basic and Applied Social Psychology</i> 18 (4): 453-468.	Antecedents: Personality factors <ul style="list-style-type: none"> <li>• Coping strategies (Social comparison)</li> <li>• Optimism</li> </ul>
World Health Organisation (WHO) (2020) <i>Constitution (49<sup>th</sup> edition)</i> . Geneva: WHO. Available at: <a href="http://apps.who.int/gb/bd/pdf_files/BD_49th-en.pdf#page=7">http://apps.who.int/gb/bd/pdf_files/BD_49th-en.pdf#page=7</a>	Related Concepts: <ul style="list-style-type: none"> <li>• QoL</li> </ul>

## **2.5.4 Findings**

Findings from this concept analysis are presented as per Rodgers approach (1993) in terms of antecedents, consequences, defining attributes, surrogate terms and related concepts.

### **2.5.4.1 Antecedents**

Rodgers (1993) describes antecedents as situations or phenomena that precede an example of the concept. It became clear whilst reviewing the data that there were a number of antecedents that appeared to have a strong impact on the SWB of people with cancer. These included: personality factors, will to live, sense of control, support networks, distress, the nature of cancer and its treatment and demographics.

#### ***2.5.4.1.1 Personality factors***

There is a growing body of evidence suggesting that trait optimism (a general tendency to “expect the best”) is positively correlated to the SWB of people with cancer (Vanderzee, 1996., Persoskie et al., 2014). For example, a study conducted by Carver et al. (2005) recruited participants retrospectively from studies conducted up to 13 years previously who had been asked about their levels of generalized optimism, their confidence about remaining free of cancer and various aspects of emotional and psychosocial well-being. Participants were asked the same questions again many years post-treatment to allow longitudinal comparisons to be made. Carver et al (2005) found that reports of optimism and life satisfaction had a significant relationship with SWB at the time of diagnosis, and that this appeared to be maintained through to long-term follow-up. They concluded that identifying those who had a generally optimistic outlook at diagnosis would assist health professionals in predicting who would appear to have adjusted well to their diagnosis many years later.

The work of Courneya et al. (2000) also supported the suggestion that optimistic personality traits have a positive impact on the SWB of people with cancer. They applied the five-factor model as a general personality framework to the understanding of SWB in people with colorectal cancer.

The five-factor model, developed by Costa and McCrae (1992) cites the five domains of personality to be neuroticism, extroversion, openness to experience, agreeableness, and conscientiousness. Courneya et al. (2000) found that those who displayed the personality traits of extroversion and conscientiousness were likely to have a positive affect and thus maintain a 'good' level of SWB following surgery for colorectal cancer. They were also more likely to adapt fairly quickly to major life events and regain their baseline level of happiness.

There is evidence to suggest that people who have developed cognitive and behavioural coping styles to use during stressful periods, and who apply these following their cancer diagnosis are more able to preserve their SWB (Carver et al, 2005). One of the most widely acknowledged coping strategies is that of social comparison (where one copes with the threat posed by a cancer diagnosis to their wellbeing by comparing their situation, their feelings, and their responses with those of others). Vanderzee, (1996) conducted a study in the Netherlands comparing the use of social comparison as a coping strategy between people with cancer and healthy individuals. Participants were asked questions such as 'How often do you realise that you are in many respects better off as compared to other cancer patients?', and 'How often do you compare yourself with other cancer patients who are worse off?'. They found that people with cancer made downward comparisons more frequently than the general population, and as they experienced increasing psychological stress they used this strategy as a means of coping. Selecting people whom they felt were in a worse position than them helped them to feel better off and resulted in a more positive evaluation of their SWB. Whilst Vanderzee's study (1996) produced some interesting findings, it is important to note some limitations. Only people who were told that they had at least 12 months to live were recruited, thus we cannot take this as an accurate representation of the cancer population as a whole. It is likely the results are more positive as they excluded those with less favourable prognoses. The authors also acknowledge that the reliability and validity of the social comparison measures used has been questioned (Vanderzee, 1996). Despite these shortcomings, this study offers a thought-

provoking insight into the psychological coping strategies employed by people with cancer.

Less literature could be found identifying antecedents with a negative impact on the SWB of people with cancer than on those with a positive impact. However, there is some evidence that personality traits resulting in negative affect (such as neuroticism) may relate significantly to lower levels of satisfaction with SWB. Indeed, in Courneya et. al's (2000) research into correlations between personality dimensions and SWB in people with colorectal cancer, neuroticism was the dimension of personality most negatively associated with subjective well-being, leading the authors to suggest that clinicians should identify patients with neurotic personality traits at an early stage in their treatment and offer them additional support to help alleviate negative affective experiences.

#### ***2.5.4.1.2 Will to live***

There is some evidence to suggest that having a sense of purpose in life, and feeling that life is worth living, is positively associated with SWB in people with cancer (Pinquart and Frohlich, 2009). Clavarino et al. (2003) analysed a subset of data from a study of patients diagnosed with metastatic, incurable cancer in Queensland, Australia. Data were analysed at three points in time: within two weeks of diagnosis of metastatic, incurable cancer; approximately three months after enrolment in the study; and within eight weeks of death. Those who exhibited a strong will to live and belief in curability reported higher levels of satisfaction in terms of SWB, and tended to remain optimistic throughout the course of their disease. This study consisted of a relatively small cohort of 46 patients, however its findings are supported by a number of other studies. For example, Pinquart and Frohlich (2009) collected longitudinal data from 163 patients and found that not only did a sense of purpose in life and will to live at the diagnosis predict a positive long-term effect on SWB, but also that this effect seemed to become stronger as cancer treatment progressed. Perhaps having something to live for proved to be even more important when coping with the severe side effects and symptoms that the patients in the study were experiencing.

Persoskie et al. (2014) used longitudinal data to explore whether SWB in cancer survivors was related to their individual predictions, made prior to diagnosis, of their likelihood of getting cancer. They concluded that for those participants who predicted themselves to be at high risk, a cancer diagnosis had a modest but significant negative impact on affect and life satisfaction, whereas no negative impact emerged for those perceiving themselves to be at low risk. The mechanisms of this relationship are not clearly understood, although the authors suggest that perhaps those with low perceived cancer risk tend to have higher preventability beliefs and greater perceived control over cancer. Such beliefs may offer a protective effect on SWB following diagnosis and treatment as a means of managing anxiety regarding the potential for cancer recurrence or progression. Carver et al. (2005) support the assertions of Persoskie et al. (2014) in their study findings which suggested that confidence in remaining cancer-free was related to less distress (and thus SWB) in both the short and long-term.

#### ***2.5.4.1.3 Support networks***

A number of studies have suggested that those who feel that they have a good level of social and emotional support experience better outcomes in terms of their SWB as their cancer treatment progresses (Pinquart and Frohlich, 2009). The important factor to be highlighted from these studies is that it is the perception of support that is important, rather than the actual level of support received (Bloom et. al, 2001). Those who receive extensive support have been known to report lower levels of SWB (Pinquart and Frohlich, 2009). However, this could be related to the likelihood that it is the patients who have the most complex needs and cancer-related impairments who are given the greatest amount of support (Pinquart et. al, 2007). More specifically, it has been suggested that having a partner at the time of diagnosis and treatment has a significant positive impact on longstanding SWB (McDonough, Sabiston & Wrosch 2014). This finding is supported by Carver et. al (2005), who recruited 163 participants from three studies conducted between 1988 and 1995 to complete questionnaires relating to their quality of life many years after treatment for cancer had finished, and found that having a partner was a strong indicator for higher reported levels of SWB in the long-term.

#### ***2.5.4.1.4 The nature of cancer and its treatment***

There is evidence that those who experience significant consequences of cancer and its treatment on body image and functioning will be more likely to report lower levels of satisfaction with their SWB. This is particularly apparent in the breast cancer population, although this may be a result of the high volume of research into cancer wellbeing being conducted in this group. Lymphoedema, numbness and reduced upper-body function are significantly associated with reductions in SWB, as functioning may be substantially affected for many years following treatment (McDonough, Sabiston & Wrosch, 2014; Kornblith et al., 2003). Receiving chemotherapy also appears to result in higher levels of distress and reduced SWB in the years following diagnosis (Carver et al, 2005; Ganz et al., 2002). However, it is not clear which element of having chemotherapy may have caused this effect. It could be speculated that this may be related to long-term side effects of treatment, but it could also be a consequence of the disease burden of those receiving chemotherapy. Therefore, these findings should be regarded with caution until further research is undertaken in this area.

#### ***2.5.4.1.5 Demographic characteristics***

Pinquart and Frohlich (2009) observed lower levels of psychological wellbeing in women than men with cancer. However, they acknowledged that this might have been a consequence of women being more likely to admit negative experiences and feelings. No further research was identified to support this suggestion. More evidence was found on the impact of age on SWB, with four studies concluding that being younger at the time of diagnosis is associated with a significant negative impact on SWB (Reimer, 2010; Kedde et. al, 2013; McDonough et. al, 2014). Lo et al. (2010) collected data from 342 adult patients in Canada to explore why lower levels of distress and the maintenance of SWB are inversely related to age in people with advanced, metastatic cancer. They found that older people were more likely to have developed adaptive strategies such as attachment security (feeling others will be available and supportive when needed) and spirituality (feeling life has meaning, purpose and value), which allowed them to cope better with their diagnosis. This relationship between age and SWB may also reflect the fact that younger people are more likely to be facing significant life

changes relating to their career, fertility and family life as a result of their diagnosis (Lo et al., 2010). Again, these results should be regarded with caution. We do not know for certain if older people genuinely experience less of an impact on their SWB when diagnosed with cancer, or if they are less likely to communicate their concerns and feelings.

A number of studies have examined the impact of socioeconomic status (SES) on the wellbeing of people with cancer (Carver et al., 2005). It has been suggested that those from lower SES groups are more likely to experience stress related to finances and domestic responsibility, which leads to a more significant impact on their SWB once they are diagnosed with cancer (Simon and Wardle, 2008). However, many of the findings on this subject are conflicting. In Simon and Wardle's study (2008), data on psychosocial wellbeing were collected longitudinally over a two-year period and measured using four different questionnaires. They found that whilst those patients from a lower SES group experienced a more significant impact on their wellbeing around the time of diagnosis, by the time they were approximately one year out of treatment the gap in SWB reports between the higher and lower SES groups had diminished to an insignificant level. As a result of the inconsistencies of these findings, it is not possible to confidently assume that being in a lower SES group will have a negative impact on the SWB of people with cancer.

### **2.5.5 Consequences**

According to Rodgers (1993), consequences are situations or phenomena that follow an example of the concept, which should assist definition by clarifying its scope and application. As was mentioned earlier in this chapter, care must be taken to ensure that misleading assumptions are not made, particularly in terms of identifying causal relationships. For example, does social isolation lead to reduced SWB, or does reduced SWB result in social isolation? This difficulty in identifying direct effects of either the preservation or impairment of SWB in people with cancer will be discussed in greater detail in the 'discussion' section of this concept analysis. Despite these methodological challenges, there is some evidence of the consequences of



either the preservation or impairment of SWB in people with cancer found in the literature that is worth highlighting.

#### **2.5.5.1 Reduced likelihood of depression**

There is some indication in the literature that preserving spiritual wellbeing in people with cancer leads to a reduced likelihood of depression. The term spiritual wellbeing has been used to define a sense of purpose and value in life (Edmondson et al., 2008) and is an important component of SWB. It has been suggested that maintaining spiritual wellbeing following a diagnosis of cancer encourages acceptance and emotional stability, and reduces the likelihood of depression (Lo et al., 2010). However, this study focused on people with advanced, metastatic cancer, and the findings relating to the impact of maintaining SWB on the incidence of depression refers particularly to older people. As was previously discussed, older people are more likely to have developed adaptive strategies, such as attachment security, than the younger population (Lo et. al, 2010). Therefore, it cannot be assumed that these findings are relevant to the wider population of people with cancer, and unfortunately no further literature was identified to reliably confirm this assumption.

#### **2.5.5.2 Impact on sexual function and sexuality**

Two studies were found which had considered the issue of the impact of sexual function and sexuality on SWB. Kedde et al. (2013) considered the impact of factors affecting the SWB of people with breast cancer on sexuality. Data were collected via questionnaires from Dutch women under the age of 45 who had been diagnosed with breast cancer. They found that side effects of the disease and its' treatment, such as fatigue, pain following surgery or radiotherapy and changes in body image, had a significant impact on SWB. As a consequence, many women reported a more negative experience of sexuality and found it harder to enjoy sex. Whilst these consequences were significant for women undergoing treatment, the study did find that sexual activity and satisfaction with their sex life returned to levels comparable with the general population of Dutch women once treatment had finished.

Further evidence of the impact of impaired SWB on sexuality was highlighted by Gilbert, Ussher and Perz (2011), who conducted a systematic review of the literature relating to sexuality after gynaecological cancer. They concluded that gynaecological cancer and its' treatment had a significant impact on the SWB of women, both physically and emotionally, and that this had a detrimental effect on their sexuality. They also found that many women felt unprepared for this change in their sexual wellbeing, suggesting that healthcare professionals need to do more to address this unmet need. The authors also identified a knowledge gap in the sense that most of the research involved white heterosexual women. Further research on the sexuality of women from different cultures and sexual orientations is recommended.

It is important to note that all of the research that could be identified on the impact of reduced SWB on the sexuality of people with cancer relates to women and cancers in the areas of the body most associated with sexual function and expression. Further research is also required into the impact on the sexuality of men to make assumptions that reflect the general population.

### **2.5.6 Defining attributes**

According to Rodgers' theory, defining attributes are the essential components that combine to produce a definition of the concept (Rodgers, 1993). There was a consensus in the literature that SWB is a uniquely individual evaluation of life satisfaction (Palgi et al, 2014; Hou and Lam, 2013) involving both cognitive and emotional elements (Deiner, 1996). It is also generally accepted that SWB consists of life satisfaction, happiness and positive affect (DeNeve and Cooper, 1998). Positive affect relates to optimistic factors such as feeling calm, happy and full of life, as well as having a sense of peace, joy and excitement (Hou and Lam, 2013; Persoskie et al., 2014).

It is important to consider how the defining attributes of SWB might change following a cancer diagnosis. Courneya et al., (2000) propose that the elements of SWB that are most important to people with cancer are similar to those important to the general population, where socioeconomic and health

factors seem to play a limited role. It could be assumed that health in particular would be considered a fundamental element of SWB for people with cancer, but Schickler (2005), found that a sense of wellbeing could be achieved in a state of either health or disease, as people defined it as achieving all that they were capable of doing within the context of a certain time in their life. Pinqart and Frohlich (2009) also support this assertion in their findings, which did not identify any significant variation in the reported SWB of people with cancer as a result of functional status or stage of disease (although they did admit that very few patients with severe functional impairment took part in the study).

### **2.5.7 Surrogate terms and related concepts**

Rodgers (1993) state that related concepts are those that bear some resemblance to the concept of interest, but do not share the same set of attributes. She warns that care must be taken not to confuse related concepts with surrogate terms (surrogate terms suggest the variety of ways in which a set of attributes is expressed). On reviewing the data collected for this concept analysis, it became clear that the term 'Quality of Life' (QoL) is closely related to SWB in terms of its definition and use. It is a term that is conceptually similar to SWB to the extent that the two are sometimes used interchangeably in the literature. Although there was evidence in the papers of the term QoL being used as a surrogate term for SWB (Mount et. al, 2007; Kedde et. al, 2013) it appears that SWB is only one aspect of QoL (Palgi et al, 2014). It should therefore be considered a related concept rather than a surrogate term.

The related concepts of 'suffering' and 'distress' are referred to in two papers to describe the antithesis of SWB in people with cancer (Mount, Boston and Cohen, 2007; Hou and Lam, 2014). One study conducted in Hong Kong examined the reciprocal relationship between distress and SWB in the year following diagnosis of colorectal cancer, where distress was defined as negative affect including tension, anger and depression (Hou and Lam, 2014). Their cross-lagged panel analysis suggests a significant reciprocal relationship between distress and SWB, with higher levels of depression and

anxiety resulting in a loss of positive affect, and a subsequent negative impact on SWB.

Mount, Boston and Cohen (2007) described suffering as being at one end of a continuum, with an experience of integrity and wholeness (and thus SWB) at the other. They suggest that both SWB and suffering are influenced by physical, psychological and social elements. As with wellbeing, the meaning of suffering to each individual is unique and cannot be presumed based on objective factors.

### **2.5.8 The model case**

A model case could not be identified within the data. However, as Rodgers (1993) stated that if a suitable case cannot be found then it is better to leave the model case out rather than to construct one to suit the personal interest of the researcher, this should not be viewed as a failing of the concept analysis process.

## **2.6 Discussion**

The concept of SWB is referred to on an increasingly prevalent basis both on national social and political agendas and within healthcare. However, the term is poorly-defined and often confused with related concepts such as Quality of Life. This concept analysis has sought to develop a meaningful definition of the SWB of people with cancer. Given the subjective nature of the concept, this was a challenging task. However, the following definition has been developed based on the definitions, attributes, antecedents and consequences found in this concept analysis:

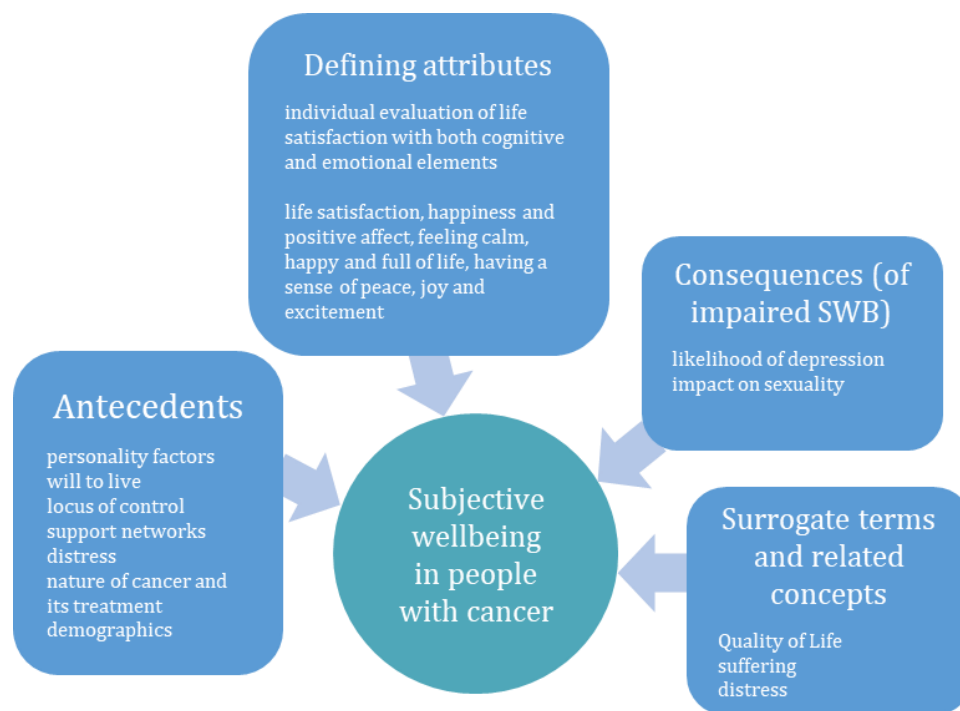
*“Wellbeing is an all-encompassing term which conceptualises an ideal state of existence. The idea of wellbeing during illness is more closely linked to subjective/individual wellbeing rather than objective/societal wellbeing. It is concerned with the experiences of individuals and can only be assessed from a person’s own perspective. During periods of illness, subjective aspects of wellbeing may take precedence for the individual. These aspects are wide-*

*ranging, but can be grouped into the themes of 'sense of self', 'relationships' and 'daily living'.*

*Aspects of SWB relating to sense of self include life satisfaction, having control and independence when making life choices, a sense of purpose and fulfilment, being happy and calm, not being defined by illness, altruism and feeling capable and having positivity and hope for the future. Aspects of SWB relating to relationships are: positive relationships with family and friends, having faith and a relationship with God and reciprocating care. Finally, aspects of SWB relating to daily living include engagement in leisure activities, being free from pain, the ability to sleep and setting and achieving challenges and goals.*

*The importance placed on objective elements of wellbeing during illness may vary from person to person, but may include issues such as housing, education, crime, leisure time, job satisfaction and income, sense of community, social life, lifestyle measures such as diet and alternative medicine, and the environment."*

A conceptual framework of SWB, based on this definition, is offered in Figure 2.4.



**Figure 2.4: Proposed conceptual framework of subjective wellbeing of people with cancer**

It is critical to emphasise that the epistemological foundations of Rodgers approach to concept analysis limit both the resulting definition of SWB and the conceptual framework. They must be regarded as a reflection of the data analysed on this occasion, and therefore may need to be revisited and refined as context changes within the continuously evolving field of healthcare.

One of the most interesting observations made during this concept analysis is the volume of data suggesting strong similarities between the reported SWB of people with cancer and that of the general population (Rijken et. al, 1995; Courneya et. al, 2008; Reimer and Gerber, 2010). Courneya et. al (2008) found that the relationships between personality and SWB in people with colorectal cancer were similar to those in the population as a whole. They also reflected that although the SWB of people with cancer was significantly affected around the time of diagnosis, individuals appeared to employ adaptive strategies to help them to cope with managing the stress and trauma of their diagnosis and returned to their baseline level of wellbeing relatively quickly. As previously mentioned, people with cancer have been identified as using downward comparison as a means of preserving their own SWB. Vanderzee et. al (1996) also found that the healthy control group

in their study employed the same tactics when undergoing a period of trauma, suggesting that this is not specific to the cancer population and is a coping strategy widely used by people in times of stress. This similarity in the meaning of SWB to both people with cancer and the general population may be initially surprising. However, it is worth remembering that this concept analysis has identified the key components of SWB to include purpose in life, support networks and feelings of calm and peace, all of which may be attainable (and indeed become more pertinent) as health status declines.

It is interesting at this point to consider the extensive work of the Office of National Statistics (ONS) in relation to measuring the SWB of the nation. Since 2011, the ONS has undertaken a Programme called 'Measuring National Well-being' (ONS, 2018) which includes data collection on SWB. This data is collected via the inclusion of the following four questions in the Annual Population Survey, and is the source of published National Statistics estimates of wellbeing across the UK (ONS,2018):

- 1. Overall, how satisfied are you with your life nowadays?*
- 2. Overall, to what extent do you feel the things you do in your life are worthwhile?*
- 3. Overall, how happy did you feel yesterday?*
- 4. Overall, how anxious did you feel yesterday?*

People rate their answers on a scale of 0 to 10, where 0 is "not at all" and 10 is "completely".

There is growing recognition that monitoring SWB more simply through these four questions has significant benefits. Since the introduction of this national data collection, the questions have been introduced in over twenty other surveys across government and numerous surveys in the academic, private and third sector (ONS, 2015). As these questions appear to reflect the findings of this concept analysis, it is suggested that further research into the relevance and validity of using these questions to monitor the wellbeing of people with cancer would be an interesting and worthwhile exercise, as it would allow comparisons to be made both with other specific groups and

with the population at large. This would allow further testing of the conclusion reached in this concept analysis that the SWB of people with cancer is subject to the same influences as the SWB of people in general, and would allow further development of a conceptual framework for the SWB of people with cancer. One note of caution might be to highlight the potential flaw of asking people how they felt yesterday. As the ONS itself emphasises, 'yesterday' may not have been a typical day for an individual. It is therefore important to ensure that any potential sample would be large enough to reduce the impact of any individual experiences (ONS, 2015).

## **2.7 Limitations**

This concept analysis is not without its limitations. Documents included in the analysis were identified from a limited number of databases, which means the findings can never truly represent the entire volume of data available on the SWB of people with cancer. For example, it would be interesting to expand this study to include popular media sources, so that the perspectives of the general public could be explored and compared to the understanding of healthcare professionals. However, this restriction was necessary and appropriate given the constraints on both time and resources.

The theory that one action can be identified as an antecedent or consequence of another is known as causality (Beckwith et al., 2008). When a causal inference is made, it is presumed that all relevant insights into the events are known. Whilst conducting this concept analysis, it became apparent that distinguishing between antecedents and consequences of the SWB of people with cancer is problematic. Although identifying significant relationships between SWB and elements such as personality and support networks was relatively obvious and well-supported by robust data, deciphering a causal relationship was more challenging as a result of both lack of evidence and the multifactorial nature of the concept. For example, in the case of positive affect it was difficult to decipher whether being happy and optimistic led to greater SWB, or that maintaining SWB resulted in feeling more positive. In Courneya et. al's study (2008), significant correlations were identified between personality and the SWB of people with cancer. However, as the



authors admit, there were selection biases limiting the generalisability of the findings. Participants were younger, had better performance status and were more likely to be receiving adjuvant therapy (and thus had a better prognosis) than the general cancer population. Had the research included those with more advanced disease and impaired SWB, the findings may have been very different.

On reflection, this difficulty in confidently assuming causal relationships is a limitation of using Rodgers' approach to concept analysis approach in defining SWB in people with cancer, and perhaps assessing the data for significant relationships rather than antecedents and consequences specifically would have been less ambiguous.

## **2.8 Conclusion**

The concept analysis process described in this chapter has resulted in the generation of a definition of SWB that portrays its multifactorial nature. Aspects of SWB are wide-ranging, but can be grouped into the themes of 'sense of self', 'relationships' and 'daily living'. This definition has provided a meaningful basis for the study exploring the experiences and perceptions of people with HGG in terms of their SWB, and has been used to further inform the design and methodology of the research. The next chapter will proceed to discuss this methodology, as well as the detailed design and conduct of the study.

## **Chapter 3: Methodology**

### **3.1 Introduction**

This chapter begins by stating the aims and objectives of the research. It then proceeds to discuss the reasons for implementing a hermeneutic phenomenological approach to this study, and also considers issues specific to phenomenology such as reflexivity, bracketing and ensuring quality. It then proceeds to explain in detail the design and conduct of the study, including the consideration of ethical issues.

### **3.2 Aims of the study**

The aim of this study was to investigate the lived experiences and perceptions of people with high grade gliomas (HGG) regarding their own sense of SWB.

The specific aims were:

- To explore the lived experiences and perceptions of people with high grade gliomas in terms of their SWB at various points throughout their illness.
- To clarify the meaning of the term 'wellbeing'.
- To investigate the lived experiences and perceptions of people with high grade gliomas regarding the assessment tools used to monitor their SWB.

### **3.3 Deciding on a methodological approach**

The aims of this research involved exploring the experiences and perceptions of people with HGG. Given the exploratory nature of this study, adopting a qualitative approach is more appropriate than a quantitative method, which would attempt to measure numerical data. Qualitative research encourages the researcher to explore the subjective experiences of participants by interacting and connecting with them at a human level, and is therefore most likely to address the aims and objectives of the study in a meaningful manner (Corbin and Strauss, 2008).

Several qualitative methodologies exist for researchers to consider. These include Grounded Theory, Phenomenology, Ethnography, Case Studies and Narrative approaches (Chen and Teherani, 2016). It is essential that researcher contemplates which approach is most closely associated with the philosophical underpinnings of their study aims to ensure high quality outcomes based on methodological accuracy. On reviewing possible methodological approaches for this enquiry, it was decided that both phenomenology and grounded theory appeared to be methodologically aligned to this research. There are a number of similarities between these two approaches, particularly in terms of their philosophical foundations. Both phenomenology and grounded theory are rooted in the philosophical paradigm of interpretivism, which is based on the premise that reality is mentally constructed, and that multiple realities will always exist (Harper and Hartman, 1997). The focus of this paradigm is on the way people interpret and make sense of their experiences and the world in which they live (Holloway and Wheeler, 2002). This interpretive approach to research also acknowledges that individuals do not exist in a vacuum and so need to be viewed in the context of their surroundings.

### **3.4. Grounded Theory or Phenomenology?**

Grounded theory was originally developed by Glaser and Strauss in the 1960s and was underpinned by the idea of developing theories grounded in research data rather than by testing hypotheses (Charmaz, 2006). Its roots are in the sociological school of symbolic interactionism (the meaning of events to people), and its fundamental focus is on the development of meaning through experiences and interactions. I aimed to understand the world from the participant's perspective by learning as much as possible about their world, and why they might interpret events in a certain way (Baker, Wuest and Stern, 1992). Grounded theorists also adopt a process of 'theoretical sampling', where recruitment of participants continues until theoretical data saturation is reached (Corbin and Strauss, 2008).

The philosophy of phenomenology is anchored in experience rather than theory and is concerned with the way people exist in the world and the

significance of everyday phenomena (Stephenson and Corben, 1997). It aims to explore experiences from the perspectives of individuals who have lived through them, and to develop meaning and understanding from these experiences (Harper and Hartman, 1997). This interpretive approach to research also acknowledges that individuals do not exist in a vacuum and must be viewed in the context of their surroundings.

As phenomenologists are concerned with describing the essence of the lived experience of an individual in its purest form as a means of improving understanding and challenging preconceived assumptions (Starks and Trinidad, 2007), they are most likely to use interviews alone to gain an insight into the patient experience. Alternatively, grounded theorists seek to understand social processes involved in the situation being explored. They may also use interviews, but can draw on other sources such as diaries, observations and reading relevant literature as a means of data collection (Baker, Wuest and Stern, 1992).

Reflecting on these two research methodologies, a phenomenological approach was deemed most appropriate for the proposed research project, as it appeared to fit more closely with the aims and objectives of exploring the individual perceptions and lived experiences of people with HGG.

### **3.5 Phenomenological schools of thought**

Phenomenology is a methodological approach that has been refined and reinterpreted over the years to the extent that it now includes a number of related schools of thought. Navigating the complexity of these various approaches is a difficult task given that their use is often blurred in the literature (Lopez and Willis, 2004; Mackey, 2004). However, clarity on the various types of phenomenology is vital to ensure a sound methodological basis for this research study.

Phenomenology is fundamentally divided into the two main schools: 1) Husserlian- descriptive phenomenology and 2) Heideggerian - interpretive or hermeneutic phenomenology (Koch, 1994; Lopez and Willis, 2004). Husserl

is widely regarded as the originator of the phenomenological movement. A critic of the positivist paradigm, he sought to investigate the experience of consciousness (Baker et al 1992). His approach to phenomenology was transcendental and descriptive, observing phenomena in their most innocent form (Stephenson and Corben, 1997). It sought to uncover the essences of consciousness that transcend human experience (Koch, 1995). Findings derive from descriptions of phenomena and experiences portrayed in their purest form (Dowling, 2007).

Descriptive phenomenology attempts to understand the essential nature of a phenomenon free from context and preconceived ideas. Husserl specified that the researcher must actively ignore their prior expert knowledge and opinion when conducting phenomenological research (a practice known as 'bracketing'), as this can jeopardise the integrity of any outcomes (Crotty, 1996). The neutrality of the researcher must be constantly reassessed throughout the research process to ensure objectivity is maintained (Lopez and Willis, 2004).

Heidegger, once a student of Husserl, went on to develop a phenomenological approach that went beyond description towards interpretation of the lived experience of a phenomenon. Underpinned by existentialism, that is the way one views the world in the 'here and now' (Holloway and Wheeler, 2002), it promotes an appreciation that the holistic background and everyday surroundings of a person must be taken into consideration. Heidegger summarised the principle that Human and World are inextricably linked in the term 'Dasein', or 'Being-in-the-World' (Heidegger, 1962). This more pragmatic approach (known as hermeneutic or interpretive phenomenology) offers the researcher the advantage of exploring not only the participant's perceptions of a phenomenon, but also of interpreting what other factors may have influenced their experience and response to it. It is based not on the descriptive question of 'what is being?', but on the ontological question of 'what does it mean to be?' (Mackey, 2004). Hermeneutical phenomenology, therefore, is a process of inquiry that not only describes a phenomenon, but also attempts to reveal meaning that is normally hidden in human

experience, and accepts that realities for individuals and the life choices they make are invariably influenced by the world in which they live (Lopez and Willis, 2004).

After careful consideration, the hermeneutic phenomenological approach was adopted for this study. The rationale being, as is often the case in nursing research, this study aimed to reflect the holistic approach of the profession by seeking to understand more about human experiences of illness. Hermeneutic phenomenology is preferable to Husserlian phenomenology in this instance as it goes beyond description and allows for interpretation of the lived experience and exploration into why a person felt and responded as they did. This interpretive approach fits well with the aims of this study which were focused on exploring the perceptions and lived experiences of the participants and should, therefore, have resulted in richer data and improved transferability of any findings (Harper and Hartman, 1997).

### **3.6 Bracketing and reflexivity**

An important methodological issue to consider when undertaking phenomenological interviews is that of bracketing. It is understandable that researchers may have preconceptions and opinions on the subject that is being studied, as it is often a field in which they have experience. In an attempt to reduce the risk of prior experience influencing any findings, Husserl introduced the idea of 'bracketing', which involves the researcher acknowledging their assumptions and beliefs and setting them aside, thus the findings are untainted by the researchers experiences and the integrity of any findings is maintained (Crotty, 1996). However, it could be argued that it is impossible to guarantee a researcher will not be influenced at all by their past knowledge and experiences, even if it happens subconsciously. Hermeneutic phenomenologists believe that not only is bracketing impossible to achieve, it is also undesirable. To attempt to suspend one's own beliefs denies the fact that the researcher will have used their prior knowledge and experience to arrive at the idea of conducting the research in the first place. In fact, hermeneutical phenomenologists actively encourage engagement with the participant and reflection on the context of the

experience in order to develop interpretive findings. Thus they deem the personal knowledge of the researcher to be both useful and necessary to ensure the research results in original findings (Dowling, 2007).

An alternative to the controversial approach of bracketing is reflexivity. It is widely agreed that reflexivity is an essential component of qualitative research, and is defined as '*the process of critically reflecting on the knowledge we produce, and our role in producing that knowledge.*' (Braun and Clarke, 2013: page 37). This includes evaluating the impact of functional elements of the research process on the findings, for example, by considering issues such as the method of data collection (where and how were interviews conducted? How were participants recruited?). It also involves a more personal reflection on the influence of the researcher on the research. This may include considering the background, values and assumptions of the researcher, and the effect these may have on how data is interpreted. Walsh and Downe (2006) suggest it is imperative to address reflexivity to ensure the integrity of any qualitative research. Having said this, it is important to note that being a reflexive researcher is not always easy. Braun and Clarke (2013) caution that reflexivity should be undertaken in a meaningful way, rather than as a flippant, 'box-ticking' exercise. For example, stating that the researcher is a white, female cancer nurse is only useful if an explanation is also given of how this might impact on any findings. On a more analytical level, it is also important to take into consideration any cultural or political standpoints that may influence interpretation of the data (Clancy, 2013). For example, as an employee of the hospital where the research was conducted, I was already aware of organisational issues such as long waiting times, and the negative impact this had on people's experience of the service. I also reflected on the possibility that as a nurse who had previously worked as a CNS, I was more likely to value the importance of this role, and have an underlying desire to communicate this through my research. Developing and maintaining an awareness of such issues rather than attempting to deny them throughout the research process allows for more trustworthy and credible interpretations to be made (Clancy, 2013).



### 3.7 Ensuring quality in hermeneutic phenomenology

As the volume of qualitative research methodologies such as hermeneutic phenomenology has increased in healthcare over recent years, there has been considerable debate over the issue of how to judge the quality of a study (Dixon-Woods et. al, 2004). Terms traditionally used when assessing the quality of research conducted from a positivist stand point such as reliability and objectivity are based on the epistemological principle that there is only one true, objective reality and it cannot easily be transferred to a qualitative paradigm (Walsh and Downe, 2006). Instead, qualitative researchers acknowledge and value the subjective nature of the research process. Rather than attempting to eliminate an issue that is human nature, a high-quality hermeneutic phenomenological study will acknowledge preconceptions and biases from the outset and reflect on them continuously to assess their impact on the research findings (Braun and Clarke, 2013). Numerous attempts have been made by qualitative researchers to define a set of criteria for judging the quality of qualitative research. However, there is considerable debate over the ability of one set of criteria to address the rich and complex plethora of qualitative research designs (Sin, 2010), and the terms used to define quality vary significantly across the literature. Lincoln and Guba (1986) originally proposed the four terms of credibility, dependability, transferability and confirmability as key criteria for establishing the rigour of qualitative research. Trustworthiness and applicability are also often associated with evaluating quality in qualitative research (Holloway and Wheeler, 2002; Noble and Smith, 2015; Sin, 2010). More details regarding the significance of these terms to evaluating qualitative research are summarised in table 3.1 below.

**Table 3.1 Commonly used terms for appraising qualitative research**

<b>Term</b>	<b>Definition and significance</b>
Trustworthiness	Methodologically accurate, recognises that multiple realities exist
Credibility	Researchers findings reflect perceptions of participants

Dependability	Consistent and accurate findings. Context of research is described, decision-making is explicit
Confirmability	Intellectual honesty, reflexivity and transparency Recognises that methods and findings are intrinsically linked to the researchers' philosophical position, experiences and perspectives.
Applicability	Consideration is given to whether findings can be applied to other contexts, settings or groups

(Holloway and Wheeler, 2002; Sin, 2010; Noble and Smith, 2015).

Rather than being too concerned with 'criteria', some researchers such as Dixon-Woods et. al (2004) suggest applying a more generalised set of prompts (see figure 3.1). This more fluid approach to judging the quality of a study allows for a degree of subjectivity, which it could argued is more closely aligned with the interpretivist nature of the phenomenological paradigm than undertaking a 'tick box' assessment.

- Are the research questions clear? Are the research questions suited to qualitative inquiry?  
Are the following clearly described?
  1. sampling
  2. data collection
  3. analysis
- Are the following appropriate to the research question?
  1. sampling
  2. data collection
  3. analysis
- Are the claims made supported by sufficient evidence?
- Are the data, interpretations, and conclusions clearly integrated?
- Does the paper make a useful contribution?

(Dixon-Woods et. al, 2004)

**Figure 3.1: Prompts for appraising qualitative research**

Despite these methodological complexities, the ability to ensure the quality of a piece of research is essential both for the reader and for the integrity of the qualitative research community as a whole. Consideration of the issues involved in ensuring and evaluating quality in qualitative research will be discussed further in both the data analysis and the literature review chapters of this thesis.

### **3.7.1 Support for the use of hermeneutic phenomenology in the study on the experiences of people with cancer**

A considerable precedent now exists for the use of hermeneutic phenomenology in nursing research and in cancer nursing in particular (Charalambous, 2010). This is not surprising given that this method is concerned with understanding and interpreting personal experiences. These objectives are compatible with the philosophical foundations of nursing, which views people as holistic beings, constantly influenced by their surroundings. Indeed, it has been suggested that hermeneutic phenomenology is at its most valuable when it is embedded in the subjective exploration of emotive issues such as the personal experiences of people with cancer (Charalambous, 2010). Conducting a search of the Medline database using the keywords 'hermeneutic phenomenology' and 'cancer' revealed 40 studies that have used hermeneutic phenomenology to explore the experiences of people with cancer. These include papers discussing topics such as experiences of women with endometrial cancer following laparoscopic surgery (Hughes et. al, 2010), lived experience of receiving a cancer diagnosis (Tobin and Begley, 2008), experiences of receiving bone marrow transplants (Jones and Chapman, 2000) and living with the uncertainty of a breast cancer diagnosis (Nelson, 1996). Given the volume of evidence supporting the use of hermeneutic phenomenology in the study of the experience of people with cancer, it seems appropriate to implement this methodological approach for this research, which is concerned with exploring the perceptions and experiences of SWB in people with HGG.

## **3.8 Study Design**

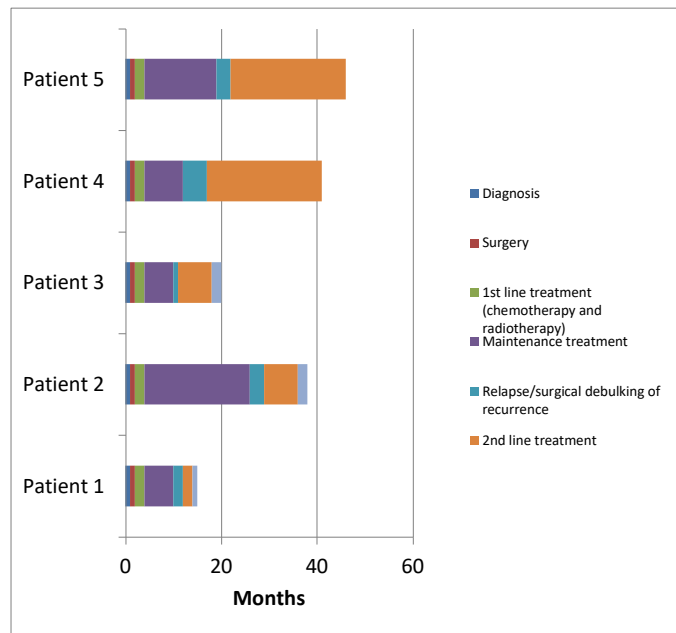
### **3.8.1 Population, setting and sample**

For the purposes of this research, the population was defined as any adult with a diagnosis of HGG receiving treatment at a large cancer centre in London. The Brain Tumour Unit at this cancer centre receives tertiary referrals from both GPs and hospitals across the south of England, and offers a comprehensive range of investigations, treatment and support for patients with brain and spinal tumours. The Brain Tumour Unit participates in both national and international research trials investigating diagnostic and treatment options for brain tumours. As a result, the centre has a diverse patient profile including people from a variety of backgrounds.

Excluded from the study were those under the age of 18, and those whose disease had progressed to a stage whereby they did not have the mental capacity to give informed consent. Those who could not speak English fluently were also excluded, as it was felt that the essence of meaning, which is so important in this type of research, may have been lost if a translator was involved. These exclusion criteria were selected as a means of limit ethical risks related to informed consent and causing unnecessary distress to participants.

### **3.8.2 Sample**

In order to accurately evaluate the size of the population available for this research, a mapping exercise was undertaken looking at the medical histories since diagnosis of the five patients involved in the study which I conducted at the cancer centre prior to commencing my PhD (Sutton, 2012). The aim was to specifically map the intervals between and duration of treatment at various stages throughout their disease as a means of determining the number of participants required, and how many interviews could be conducted with each person in order to acquire sufficient longitudinal data. The findings of this exercise are shown in Figure 3.2 below.



**Figure 3.2: Diagnosis and treatment time (in months) for studied group of patients with HGG in 2012 (Sutton, 2012)**

As can be seen from Figure 3.2, the time spent receiving second line/trial treatment varied dramatically between individuals. Some experienced disease progression after only a few weeks and progressed to palliative care, whereas others still had stable disease at 24 months.

It was decided that a sample size of fifteen participants, with each being interviewed on three occasions was sufficient to gain a new and varied insight into the experience of people with high grade glioma and to allow for attrition, whilst at the same time being small enough to allow in depth analysis in accordance with a hermeneutic phenomenological approach (Sandelowski, 1995). A non-probability, purposive sampling technique was used, limited to those who had experienced the phenomenon, which in this case was adults with a diagnosis of high grade glioma receiving treatment at a large cancer centre in London. As the aim of a phenomenological study is to

explore experience rather than theoretical knowledge of a phenomenon, Colaizzi (1978) states that experience of the topic and the ability to articulate this experience is sufficient as a means for defining criteria for selecting a sample. As previously mentioned, phenomenologists keep their sample size deliberately small with the aim of revealing the richness of individual experience (Baker et al, 1992).

### **3.8.3 Sample recruitment**

The principal researcher attended the neuro-oncology multidisciplinary team meeting to explain the aims and objectives of the research and discuss the practicalities of recruiting and interviewing participants. At this meeting, it was agreed that the Clinical Nurse Specialist (CNS) would identify patients who met the inclusion criteria and briefly explain to them the purpose of the research and extent of their involvement should they agree to participate.

After three weeks it became clear that the CNS did not have time to prioritise this discussion as a result of their work schedule. Consultants and Clinical Nurse Specialists were again approached to discuss alternative options for participant identification. It was decided that the researcher would attend the neuro-oncology clinic weekly, as a means of identifying appropriate patients. The clinical team would then discuss the study with potential participants at the end of the clinic appointment if they felt it was appropriate. This proved to be a far more successful approach, with an average of two new patients per month identified and recruited over the ensuing 6 months.

It is important to highlight that the principal researcher did not approach potential participants at the identification stage, in case this placed undue pressure on them to take part. Once they agreed with their clinician to discuss participation with the researcher, they were offered both verbal and written information (see Appendices 2 and 3) outlining the study. This included information on the risks and consequences of being involved in the research to enable them to make an autonomous, informed decision as to whether or not they wished to take part (Lyon and Walker, 1997). They were

then given a minimum of 24 hours to consider their involvement in the research. In practice, this tended to involve patients and carers taking the information sheets home to read with the agreement that I would phone them prior to their next clinic appointment to answer any questions and to confirm their willingness to participate. On their next attendance at clinic they were asked to sign a consent form (see Appendices 4 and 5) agreeing to participate. This consent form highlighted the patient's right to withdraw from the study at any time, and emphasised the fact that this withdrawal in no way affected their ongoing treatment. The consent form also requested permission from the participant for the researcher to view their medical records to gain information relating specifically to this research project only (e.g. gender, age, diagnosis, treatment history).

Participants were invited to involve a family member and/or carer in the interview if they wished. Subject to the wishes of the participant, it is considered appropriate to have companions present during qualitative interviews involving participants who are vulnerable or who have palliative conditions (Sivell et. al, 2019). The decision to allow significant others to be present was made following discussion with the clinical team, as it was felt that it would offer reassurance and reduce anxiety for those who may have had difficulty communicating as a result of cognitive changes brought about by their diagnosis. Whilst this decision was made in the best interests of the participants, it was important that any findings were considered within the context of their family member/carer being present, and the impact this may have had on the conversation (Sivell et. al, 2019). This issue will be reflected on in more detail in the discussion chapter.

### **3.8.4 Interviews**

Participant interviews are the most commonly used form of data collection in phenomenological research, and are seen to generate rich descriptions of the phenomenon. The success of research aims in phenomenology depends on how they are used to gain insight into how a person experiences a phenomenon as opposed to their theoretical knowledge of it (Colaizzi, 1978). As phenomenologists are concerned with finding out more about everyday

events and how these are experienced from an individual's point of view, it is important to establish interviews in a way that feels comfortable for participants to talk naturally rather than feeling restricted by abstract research language (Benner, 1994). As such, phenomenology is fundamentally at odds with adopting a structured approach to interview questions. However, some element of interview structure is required to ensure transferability of the research (Wimpenny and Gass, 2000). Stephenson and Corben (1997: page 121) describe such interviews as 'conversations with a purpose'. A successful phenomenological interview technique allows relevant topics to be covered, whilst offering the flexibility to follow a particular subject of interest (Baker et. al, 1992). Hence, an interview guide was developed based on my knowledge of the field and the relevant literature. This was used to establish context and assist in developing a description of the participants' perceptions and experiences, but was kept deliberately broad to avoid influencing respondents' answers, in accordance with phenomenological theory (Baker et al, 1992). A copy of the interview guide can be found in appendix 6.

Perhaps the most fundamental skill of the researcher is being able to adapt the language and style of interview depending on the participant. For example, some participants in this study liked to discuss the more theoretical and ideological aspects of cancer and its impact on SWB, whilst others preferred to focus on practicalities and impact on their daily activities. Some needed very little prompting to discuss their thoughts and feelings, whilst others answered briefly and required more encouragement from the researcher. On reflection, I realised that I often approached the interviews as if they were a clinical nurse and patient interaction. I had a tendency to focus initially on questions about surgery, symptoms and side effects, as these were topics I felt knowledgeable about, and was comfortable discussing. Whilst this generally proved to be an effective ice-breaker, which led on to wide-ranging and insightful discussions, it is important to consider how my framing of the interviews may have impacted upon the findings. A considerable volume of data collected was focused on symptoms and side-effects, and whilst these may well have been extremely important issues for



the SWB of participants, it cannot be ignored that it may also have resulted from my initial approach to the dialogue. However, once the researcher-participant rapport was better established by the time of interview two, my tendency to focus on such clinical issues lessened and a broader range of topics were discussed.

One of the benefits of keeping the interview fluid was that it allowed for the reality that all interviews proceeded in a slightly different manner, and that an interaction can never be identically repeated. Although this adaptability had clear benefits in terms of personalising the interaction to the individual, it presented certain challenges, such as ensuring the conversation remained focused on the theme being explored in order to produce meaningful outcomes. It also required excellent communication skills on the part of the researcher, who must use their professional intuition and expertise to ensure the interview remained focused, whilst at the same time remaining sensitive to the fact that many of the discussions were highly emotive. I found that my advanced communications training and previous experience of conducting interviews in phenomenological research provided an excellent grounding for undertaking the interviews. The use of prompting words such as 'yes', 'right' and 'ok' were often enough to encourage participants to continue talking about a particular subject, as was knowing when to remain silent. When participants started to discuss an experience or train of thought which appeared to potentially offer a valuable insight into their perceptions and experiences relating to the impact of HGG on their SWB, they were encouraged to explore this further by asking questions such as 'could you tell me a bit more about that?', 'how did that make you feel?' and 'what do you mean by that?'

An 'active listening' approach (Benner, 1994) was adopted by regularly confirming understanding (e.g. by saying 'let me check that I understand what you are saying') and repeating back statements to the participants. Conveying a genuine interest in what the participant is saying in this way empowers individuals to continue to communicate (Benner, 1994). This

approach appeared successful in generating richer, more detailed responses (Braun and Clarke, 2013).

#### **3.8.4.1 Why adopt a longitudinal approach?**

Collecting longitudinal data offers a number of significant advantages over cross-sectional studies. The primary purposes for collecting longitudinal data are to capture the depth and breadth of participants' life experiences through continuing immersion in the field, and to observe change through long-term comparative observations of their perceptions and actions (Saldaña, 2003). A longitudinal approach recognises that 'private' accounts are more likely to be elicited from participants through multiple interviews, and allows the researcher to revisit issues and discuss new areas that have emerged from the data. It also allows participants to discuss areas they may have forgotten or may have decided to withhold during the previous interview (Cornwell 1994).

Despite these advantages, there are some potential drawbacks to a longitudinal approach, most obviously linked to the fact that, by its very nature, longitudinal data collection takes longer to perform (Lynn, 2009). Sample attrition is a major risk, particularly in this group of participants whose health and consequent ability to participate in the research may be compromised. This factor was taken into account when deciding the sample size for this project, to ensure that the risk of collecting insufficient data, particularly at the later stages, was mitigated.

Saldaña (2003) highlighted particular issues in conducting longitudinal qualitative research that are helpful to bear in mind when designing such a project. For example, keeping an accurate chronological archive of data is of paramount importance when a high volume of data is being collected and it may be months or years before the data is formally analysed. He also recommends these chronological records are divided into categories and subcategories of emerging themes, which can then be analysed according to time points in the first instance, and then by themes emerging along the longitudinal spectrum (this approach will be discussed in more depth in the data analysis chapter).

An important practical consideration of longitudinal research is storage of data over a prolonged period of time. The longer data is stored for, the higher the risk of it getting lost. Saldaña (2003) emphasises the importance of storing data in multiple locations to mitigate this risk. For the purposes of this study, data was stored on my password-protected personal areas of both the NHS and university shared drives. Hard copies were also stored in a locked filing cabinet at my place of work (with all identifiable data removed).

#### **3.8.4.2 Longitudinal scheduling of interviews**

Based on the treatment mapping exercise shown in figure 1, it was decided to collect over a maximum period of 24 months. This time frame covered the majority of significant changes in the disease and treatment journey of participants. On a more pragmatic level, it was felt that this period was long enough to collect a significant volume of insightful longitudinal data, whilst at the same time acknowledging that due to practical time constraints the data collection period would need a realistic endpoint.

Three interviews were planned with each participant at key points in their disease and treatment. This schedule was determined by the notion that any temporal changes in perception and experience would be most significant at these times, and that conducting the interviews at these moments would capture the accounts of participants whilst they were still in recent memory. The interviews were scheduled as follows:

1. Shortly after diagnosis and initial surgery
2. During or shortly after first line treatment
3. During or shortly after any subsequent treatments

It was decided not to attempt an interview at the palliative care stage for two key reasons. Firstly, because data from the mapping exercise suggested that the amount of time spent receiving palliative care is often short. Patients may also have progressed to the stage that participating in an interview would have placed an increased psychological burden on them. In addition

participants may be too physically unwell and possibly unable to communicate at this point as a result of the impact of their advanced HGG (Mauer et al, 2008). Secondly, the findings of the mapping exercise (figure 1) suggested some patients continue on second line treatment for at least two years before progressing to palliative care, which unfortunately was an unrealistic time frame due to practical limitations on the research project. This interview schedule is endorsed by Taphoorn et al (2010), who recommend researching patients at key points in their disease trajectory as a means of comparing their SWB over time.

Attendance at three interviews was only achieved with one participant (Yulia). The others were unable to participate for a variety of reasons, including transfer of care to a different area, disease progression to the extent to which they could no longer participate, or death.

Of 15 participants, only four did not manage a second interview: two because of time restraints on completing data collection, one (Mateo) returned to his home country (Spain) and another (Tom) experienced significant disease progression which meant that approaching him to participate in a second interview would have been ethically inappropriate.

#### **3.8.4.3 Interview structure**

All interviews were conducted in a private clinical room within the cancer centre at a time convenient for the participant and were audio-recorded. Most participants chose to attend the interview after their appointment with the Consultant. As these appointments were generally 'on-treatment reviews', they tended to have a practical focus on treatment and side-effects and were less concerned with discussions about diagnosis and prognosis. It would be ethically inappropriate to the researcher and the clinical team to suggest conducting interviews on the same day as receiving MRI results for example, as this may have placed an increased emotional burden on patients. It was agreed with participants beforehand that the interview would not last longer than 1 hour. It was decided that this was a sufficient amount of time to explore their perceptions and experiences, and that any longer than this may

risk over-burdening them. Fortunately a private clinic room was regularly available in which to hold the interviews. This was beneficial in the sense that conducting a confidential discussion was easier. It was also hoped that this would limit distractions and background noise. However, in reality most participants were waiting for their chemotherapy tablets to be dispensed during interviews one and two. As a result, the interviews were subject to interruptions (such as members of the clinical team wishing to discuss practical matters regarding treatment with participants). Whilst this was unfortunate in some ways, the fact that the interviews were done at a time when participants were waiting for treatment anyway reduced the burden on their time. This was important to them as many were spending long periods of time at the hospital and might perhaps have been less likely to participate if it involved making extra visits.

Throughout the research process, the impact of conducting interviews in a clinical environment rather than in participants' homes, and the impact this decision may have had on the findings was reflected upon. It has been proposed that conducting interviews in participants' homes results in a more equal relationship between researcher and participant, and may also encourage participants to feel safer and more relaxed whilst discussing their experiences (Gagnon et. al, 2015). In this project it was not possible to attend participants homes due to an extremely large geographical catchment area. However, every attempt was made to ensure that the interviews were as convenient and comfortable for the participants as possible. Confidentiality was also paramount, as I was aware of the importance of participants feeling secure when talking about their experiences relating to the care they received when their healthcare team was so close by, and the potential impact this might have on what they chose to disclose.

Braun and Clarke (2013) suggest that a potential disadvantage of conducting interviews in a formal office or clinic room is that it may have a more intimidating and sterile atmosphere than they would experience in their own homes. They argue this may affect the interviewer-participant relationship, and hence the quality and richness of the data. To mitigate this risk,

participants were generally met in the communal areas of the clinic in the first instance to have an informal introductory chat as a means of encouraging people to feel at ease. Comfortable seating was also ensured, positioned at an angle rather than directly opposite each other, and at the same height to encourage a sense of equality in the relationship and a relaxed conversational atmosphere (Braun and Clarke, 2013). Drinks of water were offered to all patients and carers during the interviews.

### **3.8.5 Ethical issues**

Developing a trusting rapport is particularly important in phenomenological interviews in order that participants feel able to reveal their personal perceptions without fear of recrimination or consequences (Colaizzi, 1978). Participants may be discussing feelings and experiences about emotionally-charged events, and it is crucial that the researcher remains aware of this. This was particularly pertinent in this study, as it focused on the perceptions of people with a terminal disease. In order to foster and maintain a trusting relationship, a number of ethical issues were considered prior to conducting this research.

Despite being the researcher for this study, as a nurse, my professional responsibility for the health of participants remained paramount at all times. If a situation arose where involvement in the research could potentially impact on the SWB of the patient, then the participant's needs always took priority over the research (Lyon and Walker, 1997). For example, a second interview was arranged with one participant only to be informed by his clinical team that he was awaiting results of an MRI scan which may or may not reveal disease progression. Proceeding with the interview at such an anxious time could have been upsetting for the participant as it could bring up discussions involving how they felt about their disease and treatment. In such scenarios, my responsibility to protect the participant from psychological harm, known as non-maleficence, always took priority over the research project (Lyon and Walker, 1997) and interviews were rescheduled to suit the participant's needs.

### **3.8.5.1 The risk of 'role blurring'**

It was anticipated that some participants would find discussing their diagnosis and treatment upsetting, and that this must be treated with the highest levels of sensitivity to avoid unnecessary distress. It was stipulated before conducting the research that any issues that were raised during the interview may be addressed at the time if appropriate by the researcher, who is an experienced Oncology Nurse. This did happen on three occasions during data collection. As the participants knew that the researcher was a nurse, they seemed to feel comfortable raising issues and asking for help. Issues that were raised during the interviews included where to get financial advice, how to take tablets and how to manage a chronic drug-induced skin irritation. In all of these cases the researcher addressed the issue when it was within the scope of her field of expertise (i.e. who to arrange a benefits advice referral with), but was then also communicated to the patient's clinical team as appropriate to ensure that their concerns were addressed and that a high level of care was maintained. The involvement of the local cancer support and information service was also recommended where appropriate. Such encounters are common during qualitative interviews, particularly in the field of healthcare, and although the researcher should attempt to retain a neutral stance, it is difficult and potentially inappropriate to withhold advice or signposting that may be beneficial to the participant (Sivell et. al, 2019). Doing so may also undermine the rapport that has been established between the interviewer and interviewee. However, this responsibility must be carefully balanced with adhering to the ethical and professional boundaries of the role of the researcher.

Difficulty in such delineation of the 'nurse' from the 'researcher' role is a well-documented issue in nursing research (Dowling, 2006). Fortunately, in this study I was not involved in the care of any of the participants as their nurse. This helped to consolidate my identity as a researcher who worked separately from their clinical team. This degree of detachment from the clinical team was fundamental in ensuring that participants felt comfortable

discussing their experiences of care (Asselin, 2003), and reduced the risk of role 'blurring'.

Whilst attempting to distinguish myself as a researcher rather than a clinical nurse was intended to enhance the trustworthiness and credibility of my research, I also reflected on the methodological congruence of this with hermeneutic phenomenology. After all, hermeneutic phenomenologists value the interpretations of the individual, and encourage explicit discussion and awareness of prior knowledge and experiences as opposed to bracketing. In addition, reflexivity does not see the researcher as a neutral data-collecting machine. Rather it allows researchers to understand further their effects on their own research (Clancy, 2013). Therefore, it could be argued that researchers should embrace their nursing status and the benefits this may bring to the research process. Studies have shown that nurse researchers have been able to use their nursing identity positively. Nurses are seen to be trustworthy, caring, and accustomed to discussing issues that can be private and delicate (Leslie and McAllister, 2002). As it may be the nurse in the researcher who has motivated participants to become involved in a study in the first place, the question arises as to whether it is then acceptable to detach from this identity once the study begins.

Similarly to Leslie and McAllister (2002), I found myself experiencing both insider and outsider status as a nurse researcher. By being introduced to potential participants by the clinical team as a colleague who worked in the hospital, I was portrayed as a nurse with experience of the setting and empathy for their experiences, yet as a researcher I was also an outsider to their immediate clinical team. I felt that this position was beneficial to the recruitment process, particularly as the clinical team could introduce me as a trustworthy figure. However, it also demonstrated the weight of the moral responsibility on the nurse researcher, particularly when trusted with personal information. Ultimately, the balance between nurse and researcher roles must be managed carefully, but as suggested by Leslie and McAllister (2002), this juxtaposition requires acknowledgement and thoughtful consideration, rather than a choice between the two.



### **3.8.5.2 Professional responsibilities**

It was of paramount importance in this study to bear in mind that participants were undergoing treatment for an extremely serious and life-threatening illness. As a researcher and health professional, I had a responsibility to remain sensitive to the nature of their disease and co-morbidities at all times. Depending on the location and grade of their tumour, participants had issues with mobility, speech, memory and personality. They were also experiencing side effects from treatment such as nausea and fatigue. Being sensitive to psychological distress resulting from such a diagnosis was imperative, as was respecting the wishes and concerns of family members. It is possible that these highly sensitive and complicating factors have prevented extensive qualitative research with this patient group in the past. However, it could be argued that it is unethical to exclude people with acute illnesses from such research, which would otherwise be available for them to participate in. As long as ethical safeguards are put in place to protect the individuals involved, the views of such seldom-heard groups can offer a valuable insight into an under-researched area (Morrow et al, 2012). Prior to each interview, the suitability of the participants to continue in the study was re-evaluated, both with the participants and with the clinical team directly involved in their care. It was decided before the research began that if a participant lost capacity after an interview had been conducted the data would still be used, but would not include any identifiable patient details, and no further interviews would be conducted with this patient. This was specified on the patient information sheet and the consent form. The study was reviewed and given favourable opinion by the Brighton and Sussex NRES Committee (study code: 14/LO/1898, see appendix 1).

### **3.8.6 Confidentiality and anonymity**

Confidentiality of personal data was maintained at all times in accordance with the Data Protection Act (1998) and the HSCIC Guide to Confidentiality (2013), and participants were reassured as such. Audio recordings of interviews were sent securely to a specialist company for transcribing (via a

128-bit encrypted server), compliant with the Health Insurance Portability and Accountability Act (1996). The transcription company also signed a confidentiality agreement to ensure the anonymity of the participants and confidentiality of the data through the use of appropriate storage and file transfer. In order to preserve confidentiality, pseudonyms instead of names were allocated to all interview transcriptions, and any information that may have risked breaching anonymity was removed from the transcripts and results. Measures taken to protect anonymity and confidentiality were discussed with participants prior to their agreement to take part, and were referred to in both the participant information sheet and the consent form. The participant information sheet also stated that the researcher would only disclose confidential data if it was felt that withholding relevant information may risk the safety of participants or others (as per legal and professional obligations). Hard copies of signed consent forms were kept in a locked filing cabinet, which only the researcher had access to. Electronic data was held on a password-protected hard drive. The duration of data collection was a maximum of 24 months, therefore it was necessary to keep a record of personal data until the end of the data collection period. At the end of this period, personal data was destroyed as confidential NHS waste.

### **3.9 Conclusion**

This chapter has justified the use of a hermeneutic phenomenological approach to this study and has considered pertinent issues specific to phenomenology such as reflexivity, bracketing and ensuring quality. It has also explained the detailed design of the study, including the approach to data collection and the important consideration of ethical issues. The following chapter will discuss the ensuing data analysis process.

## **Chapter 4: Data Analysis**

## **4.1 Introduction**

This chapter will begin by exploring the background and issues associated with data analysis in a phenomenological study, before proceeding to discuss a selection of potential approaches to data analysis. It will then provide detail on the use of CAQDAS (computer-assisted qualitative data software) in this study, followed by a review of the issues relating to ensuring the trustworthiness of the data analysis process. The specific activities involved in data analysis will then be described and explained, including both adherence to the hermeneutic circle and the approach to longitudinal analysis.

## **4.2 Background**

Qualitative data analysis is a subject on which there is considerable controversy (Whitehead, 2004). The epistemological foundations of qualitative research, and in particular phenomenology, value the unique insights of research participants regarding their experience of phenomena, as well as the individual interpretation of the researcher. Green and Thorogood (2014: pg 206) suggest a comprehensive and encouraging definition of the aims of qualitative data analysis as being *“both to reflect the complexity of the phenomena studied, and present the underlying structures which ‘make sense’ of that complexity.”*

As discussed in the methodology chapter, Heideggerian phenomenology is the approach being used for this research project. Heidegger did not dictate a method of data analysis to be used in hermeneutical phenomenology. However, he did state that interpretation occurs through the hermeneutic process, whereby the researcher engages with and listens to the participant, repeatedly reads participants descriptions of their experiences of phenomena and immerses themselves in the data, before going on to develop thematic meaning (Mackey, 2004). Interpretation is based on what is already known about a phenomenon in terms of its background or context.

Whilst this form of analysis can result in highly insightful research findings, the subjectivity of the approach has resulted in the suggestion that it lacks scientific rigour, is open to bias and often does not inform readers of decision trails or details regarding the process of analysis (Whitehead, 2004). This assertion is supported by the suggestion that details of the analysis process in hermeneutic phenomenology are rarely found in the literature (Crist and Tanner, 2003). It is imperative therefore that the researcher using this method is aware of these conflicting opinions and ensures that these have been thoughtfully addressed in the design of any data analysis strategy. It is also important that the philosophical underpinnings of the research are acknowledged from the outset to allow the reader to judge whether or not the approach to data analysis was credible (Whitehead, 2004; Green and Thorogood, 2014).

Despite the subjective nature of this type of research, care must be taken to ensure that themes and meanings are identified during data analysis in a way that is consistent (Holloway and Wheeler, 2002), as consistent data analysis is a key process in any credible research project in order to ensure trustworthy results. Whitehead (2004) suggested that the dependability of a hermeneutical study is enhanced if the researcher stipulates a clear decision trail detailing how they arrived at their interpretations of the data, and also by stating how their personal experiences and prior knowledge may have affected any outcomes.

The issue of phenomenological data analysis offers many contradictions. In its purest form, the philosophical basis of hermeneutic phenomenology focuses on individual interpretations of phenomena, thus requiring the researcher to use their creativity to reach perceptive insights. As phenomenological research is an inimitable creative activity, it is difficult to prescribe the process in a series of steps (McWilliam, 2010). Despite this philosophical complexity, it is widely acknowledged that a structured approach to analysis will allow others to follow the process that has been undertaken and enhance the trustworthiness of any findings (Parahoo, 2006). Thus an important feature of credible qualitative data analysis is to

ensure that every decision taken by the researcher is transparent and justified (Whitehead, 2004). Green and Thorogood (2014) emphasise the importance of making explicit the practice of data analysis in terms of the procedures followed and the epistemological foundations of the approach. They also suggest that implementing a clear data analysis process not only assists novice researchers, who feel reassured by a well-defined set of steps, but also enables the reader to assess the research in terms of its trustworthiness and validity.

In reality, adopting an approach that balances the creative and inductive processes characteristic of hermeneutic phenomenology with a degree of structure will ensure trustworthiness and credibility, and is most likely to ensure findings that offer new perspectives supported by methodological accuracy. It is important to remember not to focus purely on a regimented process. Qualitative data analysis is often seen as an 'art', which requires the researcher to critically evaluate findings in a broader sociological context, and to make interpretations based on their knowledge and experience. However, any conclusions reached must be credible. Findings are fluid and open to more than one interpretation, as individuals may experience a phenomenon in different ways, but they must reflect the realities of the participants and be reached in a logical manner (Lopez and Willis, 2004). Green and Thorogood (2014: pg 204) summarise by stating that the key to successful qualitative data analysis is to ensure that it is both 'rigorous and imaginative'.

### **4.3 Approaches to analysis**

In qualitative research, data analysis may occur both during and after data collection. Some data analysis will occur at the time of collection as the researcher may need to recall and synthesise discussions from a previous interview when interacting with participants (Parahoo, 2006; Miles et al, 2014). It would be both unrealistic and detrimental to the researcher-participant relationship not to do this, as it is important for the participant to feel that their previous conversation has been remembered and valued. This reflective and interactive approach to data analysis fits well with the

principles of hermeneutic phenomenology, which acknowledge that the researcher will begin to process and reflect upon data collection as it proceeds. Once data collection is complete, a more systematic and thorough approach to analysis is also undertaken.

Two broad approaches to analysis can be classified as follows:

1. Deductive analysis - themes and explanations are derived from pre-existing concepts and theories.
2. Inductive analysis - themes and explanations are derived from the data and are not 'fitted in' to pre-existing concepts and theories.

(Green and Thorogood, 2014)

An inductive approach to analysis fits most comfortably with the epistemological foundations of hermeneutic phenomenology, which prioritises the generation of new insights based on an individual's experience of a phenomenon. However, hermeneutic phenomenologists acknowledge that the researcher will be influenced by their knowledge and experience, whilst also embracing the generation of new insights from the data (Green and Thorogood, 2014). Therefore elements of both deductive and inductive analysis were involved in this project.

#### **4.3.1 Thematic analysis:**

Thematic analysis is the most common approach to data analysis used in qualitative research (Green and Thorogood, 2014). The aim of thematic analysis is to identify key themes across the data, and to examine any variations and regularities. It is a way of reducing the complexity of numerous personal accounts into a summary of patterns or 'themes'. A number of researchers have come up with specific approaches, but they commonly include the following steps:

1. Familiarisation with the data
2. Identifying similar phrases, themes, sequences and patterns
3. Isolating patterns, commonalities and differences

4. Looking for any generalisations and/or relationships between themes
5. Comparing any generalisations or themes with available literature and research

(Miles et. al, 2014; Green and Thorogood, 2014)

There are considerable benefits to thematic analysis for the hermeneutic phenomenological researcher. The degree of structure is sufficient enough to support a rigorous approach, whilst at the same time offering flexibility for the researcher to follow a creative and relatively unrestricted process. When underpinned by a sound theoretical approach, thematic analysis can produce a rich description and detailed understanding of phenomena (Green and Thorogood, 2014).

As was previously mentioned, evidence in the literature of following a specific data analysis process in hermeneutic phenomenological studies is extremely limited (Crist and Tanner, 2003; Green and Thorogood, 2014). The following examples of specific approaches to thematic analysis were reviewed for their potential suitability for this research project. However, whilst these examples demonstrate the diversity of potential options, it is by no means an exhaustive list.

#### **4.3.2 Framework analysis**

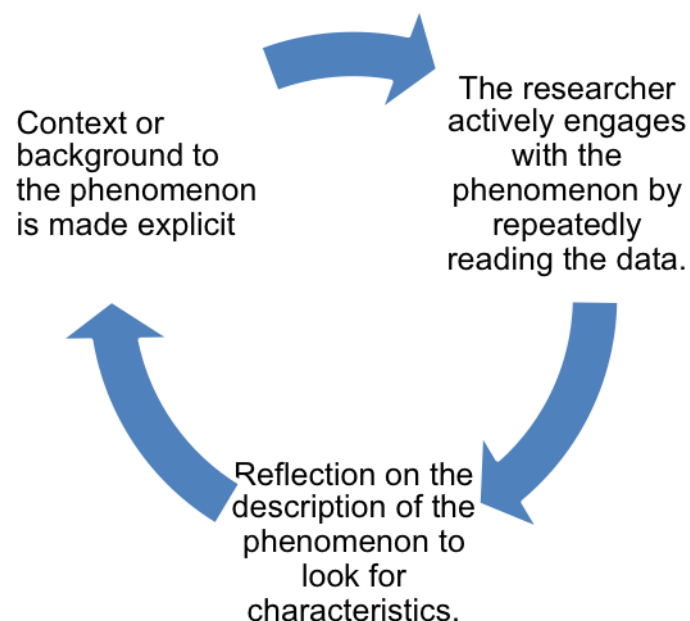
Framework analysis was developed in the late 1980s by the National Centre for Social Research ([www.natcen.ac.uk](http://www.natcen.ac.uk)). The main aim of Framework analysis is to assist in the identification of findings which may be used as a basis for organisational change, thus making it a popular approach with health and social care researchers (Ritchie and Spencer, 1994; Gale et. al, 2013). As with other thematic analysis approaches, the focus is on familiarising oneself with the data and developing themes (known as 'codes' in framework analysis) followed by comparison both within and amongst cases (Green and Thorogood, 2014). Framework analysis focuses on using summaries and spreadsheets to enable review of the contents of the data. Whilst this is useful for research projects involving a team of multiple researchers, as it enables them to collaborate and share data (Gale et. al,



2013), this approach does not easily facilitate hermeneutic interpretation and is also extremely time-consuming for a sole researcher, and is therefore not suitable for this project.

### **4.3.3 The Hermeneutic circle**

Koch (1995) suggests that Hermeneutics does not prescribe a set methodology, but instead focuses on the development of new understanding through the synthesis of context, data and interpretation. As such, attempting to implement a rigid process to phenomenological data analysis is methodologically inappropriate, which is perhaps why it is difficult to identify successful use of specific data analysis strategies in the phenomenological literature. One approach accepted as a means of interpreting data in Heideggerian phenomenology is the hermeneutic circle (Whitehead, 2004), which can be seen in figure 4.1. Rather than a linear procedure, this circular process of understanding involves the background of a phenomenon being made explicit before the researcher begins to engage with the data produced by the description of the participant. Next they must reflect on this to look for characteristics. The phenomenon is then interpreted in terms of context before the whole picture is revisited (Mackey, 2004).



**Figure 4.1: The hermeneutic circle (Whitehead, 2004)**

The hermeneutic circle is a reflexive and ongoing activity, the principle being that findings continue to evolve over time, both in terms of changing social and personal contexts, and by conducting further interviews with participants (Whitehead, 2004). To ensure that findings remain true to the methodology of hermeneutical phenomenology, researchers must be vigilant about remaining in the hermeneutic circle in order to ensure that interpretation of the data is not taken out of context (Whitehead, 2004).

One particular benefit of adopting the hermeneutic circle in Heideggerian phenomenology is the ability to make explicit and incorporate the prior knowledge and assumptions of the researcher as an integral and ongoing component of the interpretive process (Crist and Tanner, 2003). The fact that it is a non-linear process (and thus stages of data collection and analysis may overlap) also fits well with the aims and methodology of this project. The hermeneutic circle produces meaning through a cycle of reading, reflection and interpretation. This process continues until meaning is produced that is free from inner contradictions. However it is important to note that meaning is always tentative in hermeneutic phenomenology, as context changes continuously and experiences will always be unique (Lavery, 2003).

Following a thorough evaluation of the various approaches to phenomenological data analysis, it was decided that the hermeneutic circle was the most appropriate. The aim of this study was to generate a rich description of the perceptions and experiences of the SWB of people with HGG, and their impressions of how this was evaluated by healthcare professionals, but also to conduct a detailed longitudinal analysis and interpretation of any prevalent concepts, relationships, behaviours and experiences. The hermeneutic circle appears to be methodologically congruent with these aims, and also offers the opportunity for the researcher to balance a structured, analytical approach to analysis with a degree of creativity and interpretation (Green and Thorogood, 2014).

#### **4.3.4 CAQDAS (computer-assisted qualitative data software)**

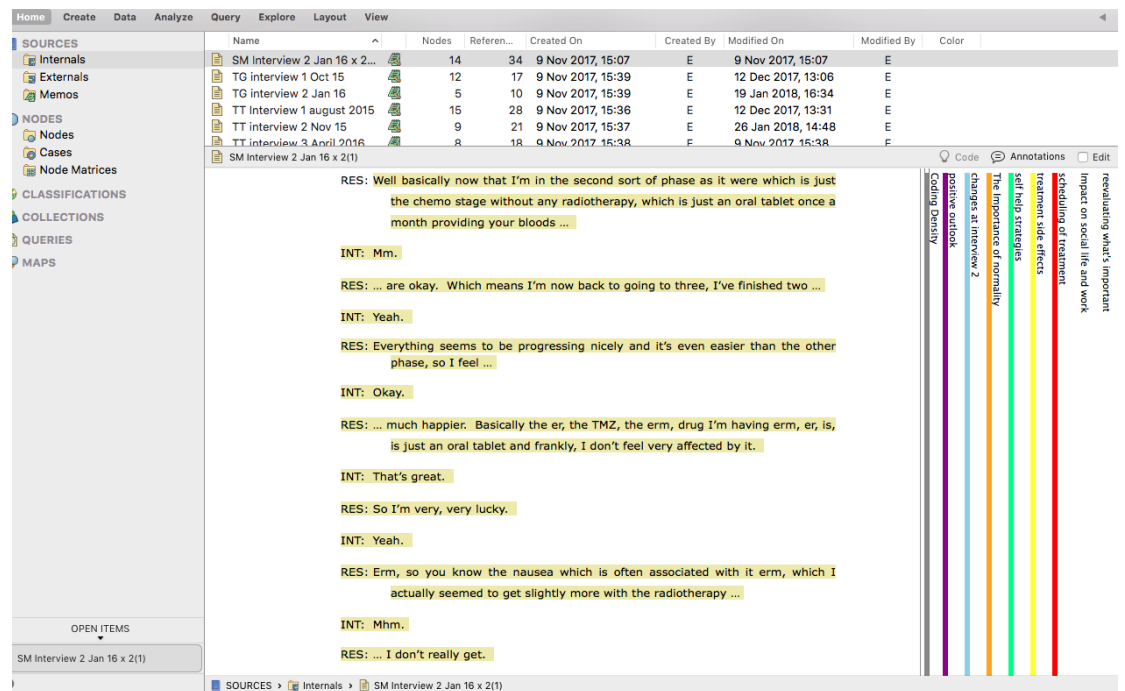
The analysis of high volumes of qualitative data is a labour intensive and time-consuming process. In recent years, several software packages, known as CAQDAS, have been designed to assist researchers with this task. Their specific capabilities are rapidly evolving, but one of the fundamental aims of using such a package is to store, manage and code data in one place (Miles et al, 2014).

NVivo (version 10) software was used in this project as a means of assisting data analysis. NVivo is one of the most commonly used CAQDAS packages used in published qualitative health research (Green and Thorogood, 2014).

All interview transcriptions were uploaded on to NVivo and read repeatedly. Themes (or 'nodes' as they are referred to in NVivo) were created and reviewed within the software. It was felt that there were limitations to the use of NVivo at the stage of reviewing the overall list of themes in terms of their potential to be assigned to groups. It was not possible to look at all of the themes at the same time, therefore at this point themes were printed off to allow a 'bigger picture' overview. Once the groups had been determined, these were allocated into 'node sets' in NVivo to allow data analysis to continue on the software.

On reflection, it was felt that using a CAQDAS package such as NVivo offered considerable benefits over the more traditional 'cutting and pasting' approach to data analysis. Formal training on the use of the software facilitated navigation of the system and management of the data. The ability to hold all data and undertake analysis in one place was also found to be highly advantageous and time efficient. This is a benefit that has been cited regularly by researchers who have similarly collected a large volume of qualitative data (Parahoo, 2006). Moreover using NVivo improved adherence to the cycle of reading, reflection and interpretation (central to the hermeneutic circle) as themes were easily reviewed and cross-checked, thus ensuring a thorough and systematic approach to analysis. It was also useful

to be able to see when significant codes had been referred to in multiple themes at a glance (see figure 4.2).



**Figure 4.2: Screenshot of NVivo**

Despite the many advantages offered by CAQDAS packages, it must be emphasised that their use is not a substitute for thorough and rigorous analysis. The researcher must continue to control the creative and cognitive process involved (Parahoo, 2006). CAQDAS is an assistive tool and does not replace the skills and abilities of a researcher to analyse data in a meaningful way (Green and Thorogood, 2014; Allen, 2010). Whilst offering an excellent means of storing and managing a large volume of qualitative data, thorough reading and immersion in the data was still necessary to identify significant statements and themes.

#### **4.3.5 Ensuring trustworthy data analysis**

Whilst qualitative data analysis involves a greater degree of subjectivity and personal interpretation than its quantitative counterpart, it is nonetheless imperative that qualitative researchers are committed to undertaking thorough and systematic analytic processes if findings are to be considered

trustworthy (Melia, 2010). Green and Thorogood (2014) offer useful ‘good practice’ guidelines, which were adhered to wherever possible in this study as a means of ensuring the credibility of the outcomes. These are summarised in figure 4.3 below:

Criteria	Possible methods
Transparent	Provide a clear account of procedures used. Keep an ‘audit trail’ that others can follow
Maximises validity	Provide evidence from the data for each interpretation made. Analysis of deviant cases and disconfirming data. Including enough context for the reader to judge interpretation.
Maximises reliability	Comprehensive analysis of the whole data set. Using more than one analyst. Simple frequency counts of key themes.
Comparative	Compare data between and within cases in the data set. Compare findings to other studies.
Reflexive	Account for the role of the researcher in the research.

**Figure 4.3: Features of rigorous qualitative analysis (Green and Thorogood, 2014: pg 226)**

#### 4.3.5.1 Transparency

Transparency is a particularly important element for ensuring rigour in qualitative analysis. It refers to the extent to which the methods used are made visible. The researcher should provide explicit detail of any procedures undertaken and conclusions drawn to enable readers to feel confident that they have been provided with a ‘complete picture’. (Miles et. al, 2014). Whilst this sounds like a straightforward exercise, the reality of articulating decisions made by the researcher is not always easy as they are often made at a subconscious level (Parahoo, 2006). Despite these challenges, it is crucial that steps are taken to make explicit the sequence of data collection and analysis so that an audit of the process could be undertaken. In order to achieve transparency in this study, notes were kept both as memos on NVivo and in a paper diary as analytical decisions were made. The allocation of data

to nodes in NVivo also displays the process of development of themes (see figure 4.4 below):

Name	Sources	Referen...	Created On	Created...	Modified On	Modified By	Color
financial issues	7	8	26 Jan 2018, 13:00	E	25 May 2018, 13:41	E	
impact on family	17	37	14 Nov 2017, 11:53	E	25 May 2018, 13:44	E	
Impact on social life and...	21	53	14 Nov 2017, 14:15	E	25 May 2018, 13:41	E	
living with uncertainty	14	19	21 Nov 2017, 12:55	E	25 May 2018, 14:26	E	
Meaning of wellbeing	15	32	14 Nov 2017, 14:20	E	22 May 2018, 13:54	E	

Source Name	In Folder	References	Coverage
AG Interview 2 Feb 16	Internals	8	15.47%
BD interview 2 Jan 16 x 2	Internals	2	13.37%
BD interview 2 July 2016	Internals	6	13.25%
BS interview 1 26.11.15	Internals	6	13.86%
BS interview 2 April 16	Internals	1	5.72%
IF interview 1 Oct 15 x 3	Internals	1	5.66%
KH Interview 1 Dec 15	Internals	2	8.43%
KH Interview 2 Feb 16	Internals	2	27.30%
LK interview 1 July 2016	Internals	2	8.24%
PE interview 2 April 16	Internals	1	6.70%
RGB - interview 1 Aug 1...	Internals	1	0.96%
RP interview 1 August 2...	Internals	2	5.73%
RP Interview 2 19 11 15 x2	Internals	1	3.87%
RS Interview 1 March 20...	Internals	1	5.04%
SM interview 1 Oct 2015	Internals	1	5.19%
SM Interview 2 Jan 16 x...	Internals	4	17.62%
TG interview 1 Oct 15	Internals	1	0.22%
TG interview 2 Jan 16	Internals	3	5.89%
TT Interview 1 august 2...	Internals	4	22.25%
TT interview 2 Nov 15	Internals	3	6.92%
TT interview 3 April 201...	Internals	1	1.67%

**Figure 4.4 Screenshot showing allocation of data to nodes in NVivo**

### 4.3.5.2 Validity

Validity is a contentious term in qualitative research. At face value, validity refers to the ‘truth’ of the interpretation. However, hermeneutic phenomenologists reject the positivist assertion of one single truth, as findings will always be subject to change depending on context (Green and Thorogood, 2014). This does not mean phenomenological researchers can disregard issues of validity, but instead must take a more pragmatic approach. The findings of the study must be an authentic representation of the data, and any anomalous cases or disconfirming data are presented and discussed rather than being omitted (Miles et. al, 2014). An example of this can be found in the ‘side effects’ theme of the findings. Perhaps surprisingly, six participants reported that they had experienced very few side effects from their disease and treatment, and did not feel that side effects were a significant issue for their wellbeing. This was an unexpected outcome, but

discussion of its presence in the data was crucial in terms of ensuring the validity of the findings.

#### **4.3.5.3 Reflexivity**

Reflexivity is a fundamental issue in qualitative data analysis. As was previously discussed in the methodology chapter, reflexivity is actively encouraged in interpretive phenomenology. As opposed to quantitative research, where the effect of the researcher is minimised as much as possible, phenomenology embraces the researcher's presence and the impact they may have on any findings (Green and Thorogood, 2014). However, the key to high calibre qualitative research is to make the effect of the researcher's knowledge and beliefs on any interpretations as transparent as possible. Reflexivity is the process for achieving this (Parahoo, 2004). Researchers are encouraged to keep reflexive notes throughout data collection and analysis, and to proactively consider how their values and experiences might impact on the research. Again, it may be easier to dictate the practice of reflexivity than it is to achieve it in practice. Cutcliffe (2003) suggests that the ability of researchers to reflect on their influence is limited by the fact that they will not always be aware of their own biases and cognitive processes, and many of their interpretations will be made intuitively.

Fortunately, as this research was undertaken as part of a University Doctoral Programme, the researcher had the facility to undertake critical and reflexive discussions with experienced PhD supervisors on a regular basis. One particular example of the importance of reflexivity during data analysis occurred as I noted a trend in my interviewing behaviour during repeated readings of transcripts. When conversations became focused on feelings around death and dying, I generally utilised my advanced communication training and experience to allow people to continue talking, even if it became upsetting, if it seemed that this was the direction that they wished the conversation to continue in. However, it appeared I had a tendency to try and steer the discussion towards more positive thoughts or practical issues if participants showed any signs of distress. Reflecting on this potential impact of my interviewing behaviour on data collection during a supervision session, I realised that having an awareness of this behaviour and making it explicit in

my writing would help to ensure the trustworthiness and integrity of my research. I was also reassured that my behaviour stemmed from a genuine desire to protect participants from harm in the form of psychological distress.

Another example of the importance of reflexivity to the integrity of my study related to the collection of data and analysis relating to the maternal role. I had a strong personal interest in the way in which the participants who were mothers related their experiences of the impact of their HGG diagnosis on their maternal identity. I felt both sympathy and admiration for the women who continued to prioritise the needs of their children despite their illness, and found the analysis of this data particularly challenging and emotive. On reflection, this was not surprising given the fact that I had two young children of my own. Discussing this experience with my supervisors helped to ensure that this was a transparent component of the research process, and was an important factor in my interpretation of the findings. It also heightened my awareness of the need to ensure that I included a balanced selection of the data, and avoided excessive reference to the participants I had an affiliation with.

#### **4.3.5.4 Reliability**

Reliability refers to the integrity and dependability of the research (Miles et al, 2014). Ultimately, attention to reliability ensures that any findings are credible, and that the way in which conclusions have been reached is specified. Examples of ways of ensuring reliability include open discussion of coding with colleagues, peer review, audit trails and the inclusion of raw data in the presentation of the research (Miles et. al, 2014; Green and Thorogood, 2014). Although only one researcher was involved in the data analysis process for this study (an acceptable approach for phenomenologists), the development of themes was discussed with experienced PhD supervisors on a regular basis. The findings chapter of this thesis also offers excerpts of raw data as evidence for the development of each theme.



#### **4.3.6 The data analysis process**

In total, 27 interviews were conducted with 15 participants. Each interview transcription was uploaded on to NVivo as a single piece of data, stored by participant identifier and as either interview 1, 2 or 3, depending on the time point at which data were collected. In order to adhere to the hermeneutic circle approach to data analysis, each interview transcription was read repeatedly, with any significant statements in each interview being highlighted and allocated to an NVivo node (Mackey, 2004). Once an initial review of all transcriptions was completed, the nodes were scrutinised to confirm that all statements reflected the identified theme. As themes were revisited through the re-reading and reflective stages of the hermeneutic circle process, any overlap between themes were merged, where possible, and those that no longer seemed to be justified by the data were reviewed and removed. Once satisfied that the identified nodes/themes were a true reflection of the data set, and that all significant statements had been clustered together and presented accurately, themes were again evaluated through the hermeneutic circle for their context, and compared for any similarities or relationships (Parahoo, 2006). At this point, groups of themes emerged which appeared to portray the findings in a concise manner. All groups of themes were read again and analysed through the hermeneutic circle to ensure that the statements included were relevant and justifiable. These were then also appraised in terms of their relevance to the aims and objectives of the project and mapped into diagrammatical format (see figure 4.5) as a means of maintaining order over the initial findings and presenting them in a more manageable style. From this point onwards, individual themes were defined as 'sub-themes', and theme groups were identified as 'themes'. A worked example of the hermeneutic circle process to develop themes can be found in appendix 12.

EXPERIENCES OF CARE	HEALTH
<ul style="list-style-type: none"> <li>• Surgery</li> <li>• Diagnosis</li> <li>• Monitoring QoL</li> <li>• Scheduling of treatment</li> <li>• Positive experiences of care</li> <li>• Negative experiences of care</li> <li>• Suggestions for improvement</li> </ul>	<ul style="list-style-type: none"> <li>• Surgery</li> <li>• Diagnosis</li> <li>• Symptoms of brain tumour</li> <li>• Side effects of treatment</li> </ul>
PSYCHOLOGICAL WELLBEING	DAILY LIFE
<ul style="list-style-type: none"> <li>• Impact on family</li> <li>• Impact on social life and work</li> <li>• Importance of normality</li> <li>• Facing mortality</li> <li>• Meaning of wellbeing</li> <li>• The importance of goal-setting</li> <li>• Negative psychological impact of diagnosis</li> <li>• Re-evaluating what's important</li> </ul>	<ul style="list-style-type: none"> <li>• Impact on family</li> <li>• Impact on social life and work</li> <li>• Importance of normality</li> <li>• Self help strategies</li> <li>• Daily activities</li> <li>• Financial impact</li> </ul>

**Figure 4.5: Initial theme and sub-theme groupings**

A key feature of the hermeneutic circle is the emphasis that is placed on making the context of the phenomenon explicit during data analysis (Whitehead, 2004). In addition to analysing each theme and sub-theme using the hermeneutic circle, it was felt that creating a synopsis of each participant in terms of their family, work and social life as well as their disease and treatment would both enhance interpretation of the interview and allow the reader to scrutinise findings in terms of their appropriateness and relevance. To achieve this, data were collected as per the demographic and clinical information forms (see appendices 7 and 8) from which the synopses could be written.

#### **4.3.7 Longitudinal data analysis**

Once initial coding of each interview had been conducted, longitudinal analysis could begin. Longitudinal data analysis (LDA) was an important part of this project as a means of exploring variations or consistencies in the

experiences of participants at different time points in their disease and treatment (Grossoehme and Lipstein, 2016). LDA allows the generation of rich data but is a complex and multidimensional task not widely discussed in the published literature, particularly in the field of health research (Calman et. al, 2013). Analysis occurs within each case as well as comparing across cases, and is focused on the impact of time and change on the data (Calman et. al, 2013).

In an attempt to provide guidance and structure to researchers navigating LDA, Holland (2007) suggested using both framing (e.g. what contextual conditions appear to influence and affect participant changes over time?) and descriptive questions (e.g. what increases or emerges through time?) to ensure a deeper level of analysis and interpretation. These suggestions are methodologically aligned to Saldaña's (2003) frequently cited guidance on analysing longitudinal qualitative data, which was adhered to in this project as a means of ensuring a thorough and reliable analytical process.

Saldaña (2003) offers valuable guidance on how to manage a large volume of longitudinal qualitative data through the visual imagery of 'pools' and 'ponds'. He recommends that the vast 'ocean' of data be firstly divided into smaller time pools. In this research these pools were classified as interview 1, 2 or 3. This allowed for the easier identification of any changes that occurred through time. Secondly, the pools of interviews 1, 2 and 3 were split into even smaller units of data (ponds) by participant (e.g. participant 8, interview 2). Once the data had been broken down in this systematic way, comparison from pond to pond, pond to pool and pool-to-pool ensured that a reliable and thorough approach to LDA had been taken (Saldaña, 2003).

Saldaña (2003) proposes a framework of sixteen questions (see figure 4.6) to guide the researcher through a process of description, analysis and interpretation. Whilst these are presented in 3 distinct subsets, Saldaña (2003) emphasizes that this is a fluid and iterative process.

### **Framing Questions**

1. What is different from one pond or pool of data through to the next?
2. When do changes occur through time?
3. What contextual and intervening conditions appear to influence and affect participant changes through time?
4. What are the dynamics of participant change through time?
5. What preliminary assertions (propositions, findings, results, conclusions, interpretations and theories) about participant changes can be made as data analysis progresses?

### **Descriptive Questions**

1. What increases or emerges through time?
2. What is cumulative through time?
3. What kinds of surges or epiphanies occur through time?
4. What decreases or ceases through time?
5. What remains constant or consistent through time?
6. What is idiosyncratic through time?
7. What is missing through time?

### **Analytic and Interpretive Questions**

1. Which changes interrelate through time?
2. Which changes through time oppose or harmonise with natural human development or constructed social processes?
3. What are participant or conceptual rhythms (phases, stages, cycles and so on) through time?
4. What is the through-line of the study?

**Figure 4.6: Questions to Guide the Analysis of Longitudinal Qualitative Data (Saldaña, 2003)**

Saldaña (2003) explains that framing questions allow for the systematic comparison of ponds and pools of data as a means of identifying contrasts and variability. He cautions against looking exclusively for what is missing between data sets, and instead advises focusing on what is different to ensure that observations are not limited to what is absent rather than what is present. He also emphasises that finding no difference between time points is still a noteworthy and valuable insight, which should be made explicit to the reader (Saldaña, 2003). For example, some of the participants in this study felt tired throughout interview 1 and 2 despite the fact that they were no longer undergoing radiotherapy at interview 2, whilst others did not mention tiredness as an issue at either time point.

The descriptive questions suggested by Saldaña (2003) encourage the researcher to think about not only what increases and decreases through time, but also about what develops and changes. In particular, researchers are urged to consider if any moments of epiphany occurred. Saldaña (2003, page 108) describes an epiphany as 'a significant event that takes participant change to a different level, direction or quality.' In this study, the point of diagnosis of HGG is a dramatic moment of epiphany, when participants often referred to the shock and disbelief that they felt having been told their diagnosis, and the irreversible effect that this had on their SWB. Other descriptive questions proposed by Saldaña (2003) include identifying idiosyncrasy and anomaly data such as inconsistent patterns and random contradictions. An example of idiosyncrasy in this research came from those few participants who had not experienced any side effects during their treatment. Saldaña (2003) reassures researchers not to worry about such findings. Human nature is often erratic and unpredictable, and it is normal to find individual differences within a group of participants, although discussion of such anomaly cases and inconsistencies is essential to ensure the trustworthiness of a study.

The analytic and interpretive questions offered by Saldaña (2003) promote a more complex analysis of the data in the hope of producing more revelatory findings. For example, in this study many participants spent a lot of time

discussing physical side effects of their disease and treatment. During analysis it was important to consider whether this was because it was their main concern, or more a result of social behaviours which led to people feeling more comfortable talking about physical symptoms and treatment rather than their psychological and emotional wellbeing.

Considering Saldaña's questions in relation to each set of participant data allowed for the creation of a richer, single narrative that highlighted any longitudinal changes on an individual basis (Grossoehme and Lipstein, 2016). These descriptive narratives will be presented as individual longitudinal participant summaries, as it was felt that this was the most effective way of communicating findings within the context of each participant's overall story.

#### **4.4 Conclusion**

This chapter has offered an exploration of the background and issues associated with phenomenological data analysis, and has presented a selection of potential approaches, including the hermeneutic circle, which ultimately offered the most appropriate option. It has also provided a review of the issues relating to the trustworthiness of the data analysis process, and how these were addressed in this study. The specific activities involved in data analysis have been described and explained, including both adherence to the hermeneutic circle and the approach to longitudinal analysis. The following chapter will present key statistics for the group, including disease and treatment duration. It will then provide the descriptive longitudinal participant summaries that resulted from the initial phases of analysis.

## **Chapter 5: Longitudinal analysis of participant data**

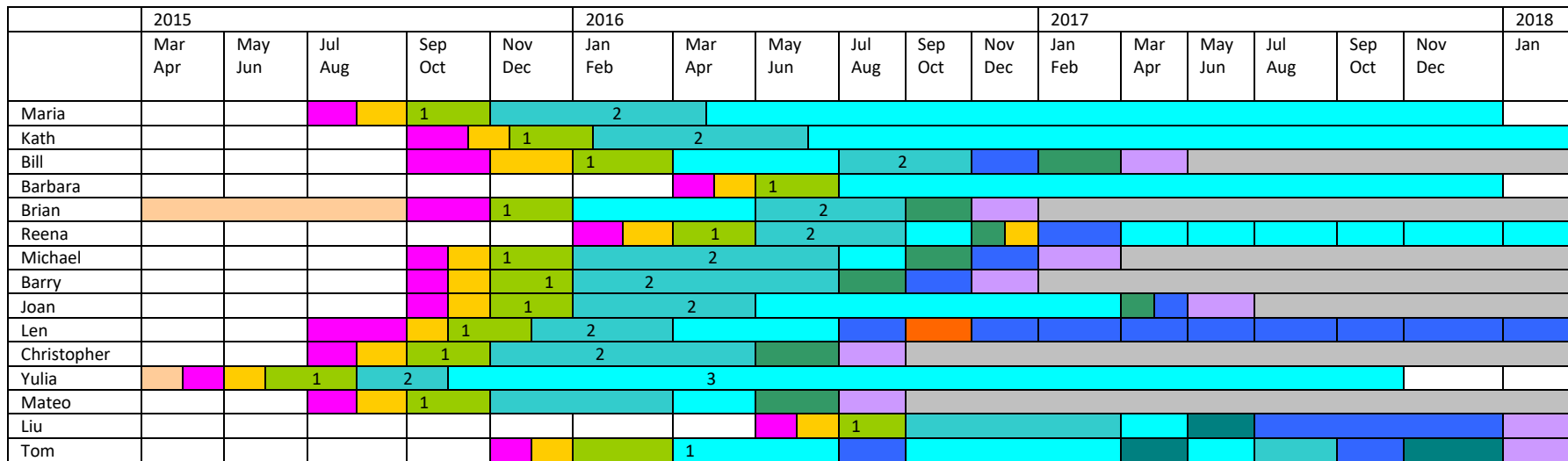
## 5.1 Introduction

In order to provide context for more detailed analysis of the findings, this first findings section begins by offering details on key characteristics for the group (table 5.1), as well as a chart (figure 5.1) representing disease and treatment duration for all participants. Descriptive, longitudinal summaries are then presented for all fifteen participants in alphabetical order. Each summary opens with a demographic information table, followed by a synopsis of each interview discussion. Finally, a discussion of the longitudinal findings for each participant is provided.

**Table 5.1: Key characteristics of participants**

Gender	Male	8
	Female	7
Age range	18-29	1
	30-39	1
	40-49	3
	50-59	5
	60-69	5
Marital status	Married	13
	Single	2
Nationality	Albanian	1
	Bengali	1
	Chinese	1
	German	1
	Russian	1
	Spanish	1
	British	9
Number of interviews	Interview 1	15
	Interview 2	11
	Interview 3	1
Health status in January 2018 (34 months after data collection commenced)	Alive	6
	Died	9





Data collection stopped in October 2016 due to commencement of my maternity leave. Participant histories could not be accessed after Jan 2018 as I was no longer an employee of the hospital and moved out of the area.

Low grade glioma	
Diagnosis of HGG	
Surgery	
Temozolomide with radiotherapy	
TMZ alone	
Other chemotherapy/radiotherapy	

Drug trial	
Progression/recurrence	
Stable disease	
Died	
No longer alive	
Data unavailable	

Interview 1	1
Interview 2	2
Interview 3	3

**Figure 5.1: Disease and treatment duration**

Figure 5.1 offers a visual summary of the disease and treatment duration of the participants. It can be seen from this figure that all participants were recruited between July 2015 and August 2016, and that all of the second interviews were conducted during the TMZ alone treatment phase. By the time data collection was completed in October 2016, seven of the participants had stable disease and were not on treatment, four were still receiving treatment, two had experienced disease progression, and two had died.

## 5.2 Participant summaries

### 5.2.1 Barbara

Age	45
Gender	Female
Ethnicity	White British
Social/family background	Married and lived with husband and three children. She was a stay-at-home mother and carer for her children. One of her sons was disabled and had high care needs.
Summary of cancer journey	<ul style="list-style-type: none"> <li>• April 2016: Diagnosed with HGG after having partial seizures.</li> <li>• April 2016: Tumour resection surgery.</li> <li>• June 2016: Commenced radiotherapy concurrent with TMZ chemotherapy, but missed the final week due to a low platelet count. This low platelet count also prevented her from receiving any further chemotherapy.</li> </ul>
Number of interviews attended	1 (May 2016) She attended the interview with her daughter, Kim.
Status at end of data collection	September 2018: alive with stable disease, experiencing neuropathic pain.

**Interview summary:**

Barbara had initially thought that she was fainting due to the pressure of looking after her disabled son. However, an MRI scan confirmed her HGG diagnosis. Despite feeling shocked, she was keen to get on with the surgery and move on with her life. She experienced some side effects following her surgery, the worst of which was constipation. She suffered with severe vomiting following the first chemotherapy, but this was now limited to nausea as a result of her anti-sickness medication.

She did feel tired with the treatment and found that she needed to lie down and rest sometimes. She thought it was important to stay positive but had had a 'little cry' over the past few days as her headaches had been so bad. She had organised carers to help with her disabled son over the next few months to help her manage. She had a diary, which she used to track her appointments and medications. This seemed to help her to feel more in control of her situation. She found it difficult to take time to do things for herself, such as having complimentary therapy, as she was so used to looking after other people. She had been very honest with her children, and she felt that they were coping well with her diagnosis. Her daughter said that her mum was 'the backbone to everything', and that her diagnosis felt 'a little scary'.

She did not feel that her husband was coping well with her diagnosis. She reported that her husband acted as if 'he was the one with the cancer', and she wished that he would support her more. She found it best to stay positive and just 'get on with things'. She felt that she had a lot to look forward to in terms of family life and focusing on these hopes for the future appeared to be important to her SWB. She continued to do all the housework, which she was pleased about as she felt that it was something that she could control and was important for her sense of identity. She felt that she had to stay strong to make it easier for her family to cope with her diagnosis.

### **5.2.2 Barry**

Age	47
Gender	Male
Ethnicity	White British
Social/family background	Unmarried and lived alone. Did not have children, but was very close to his mother and siblings. Worked in a leisure centre prior to diagnosis. Now worked as a volunteer in a charity shop for 8 hours per week.
Summary of cancer journey	<ul style="list-style-type: none"><li>• September 2015: Diagnosed with HGG.</li><li>• September 2015: Craniotomy and debulking surgery.</li><li>• October 2015: Commenced 6-week course of radiotherapy concurrent with TMZ chemotherapy.</li><li>• January 2016: Commenced 6 cycles of TMZ chemotherapy.</li><li>• July 2016: CT scan showed disease progression. Given 1 cycle of PCV chemotherapy.</li><li>• October 2016: Having difficulty walking, and vision had deteriorated.</li></ul>
Number of interviews attended	2 (October 2015 and April 2016) He attended the interviews alone.
Status at end of data collection	Died in November 2016

#### **Interview 1:**

Barry had felt apprehensive prior to starting his treatment and likened it to 'jumping on a rollercoaster'. However, he soon found the structure and routine of coming in for daily treatment reassuring, and it reminded him of his old work routine. He had found it difficult to adjust to taking tablets regularly, as he had never needed to before. He had not experienced any side effects but was mostly worried about the impact of his diagnosis on his mum. He had moved back in with his mum following his operation, and that

combined with the basic memory test he was asked to do in hospital had affected his sense of identity and made him feel like he had 'regressed 30 years'. He was determined to 'keep positive and be strong' following his diagnosis. He had been touched by the support of work colleagues and close friends, and it was clear that personal relationships were important to him. He enjoyed socialising and going for walks by the local river, which he felt significantly benefited his wellbeing.

### **Interview 2:**

Barry said that he was feeling mentally better than he did at the previous interview and had not been experiencing any side effects other than tiredness. He felt frustrated by the fatigue, as he wanted to be active but he didn't have the energy to do much. He spoke positively of factors that he felt had improved his wellbeing since the previous interview. For example, he had been on holiday to the Peak District and had done some 5-mile walks and socialising, which he had very much enjoyed. He had also recently painted his bedroom, which he had felt good about. He was pleased that he had managed to do it, and it was clear that this achievement had boosted his self-confidence and sense of identity. He enjoyed doing his voluntary work 3 days a week, as it provided him with a sense of purpose and an opportunity for social interaction.

### **Longitudinal analysis:**

Barry did not experience side effects other than fatigue throughout his treatment, and remained resolutely positive about his life and future. He felt consistently well supported by his family and medical team, and remained very active. He said that he felt 'mentally better' at the time of interview 2, and he spoke extensively of the things that he felt had improved his wellbeing, such as travelling, exercising and socialising.

### **5.2.3 Bill**

Age	60
Gender	Male
Ethnicity	White British
Social/family background	Married and lived with wife. Had an adult son and daughter. Worked as a consultant for an investment fund.
Summary of cancer journey	<ul style="list-style-type: none"><li>• October 2015: Diagnosed with HGG after attending his local Accident and Emergency department following a seizure.</li><li>• December 2015: craniotomy and debulking surgery to remove tumour.</li><li>• February 2016: Given radiotherapy concurrently with TMZ chemotherapy for 6 weeks.</li><li>• August 2016: Commenced 6 cycles of TMZ chemotherapy.</li><li>• November 2016: Commenced Lomustine chemotherapy, but only had 1 treatment (out of a proposed 4-6) before he became too unwell with confusion and left-sided weakness to be given any more.</li><li>• (He had been diagnosed as HIV+ a number of years prior to his HGG diagnosis.)</li></ul>
Number of interviews attended	2 -January 2016 and July 2016He attended the interviews alone.
Status at end of data collection	Died in March 2017

#### **Interview 1:**

Bill had been an active triathlete and had always exercised on a daily basis. He was finding he now spent a lot of time resting, but he tried to go for a walk as often as possible. He also found this beneficial as he felt that this was a way he could take some control over his life. He missed being able to drive and wished he could do more to help around the house. He also wished he

could still enjoy meals and wine with his family but could not eat and drink as much as he used to. Bill found that he was lacking in energy and felt quite 'lazy'. He had also experienced some nausea with the chemotherapy.

Bill had not had any experience of a QoL questionnaire, but felt that people were always asking him how he was, which he was pleased about. He wished someone could help him with some 'mind games', which he saw as a way of thinking about his mortality without feeling anxious. He had not had any counselling or psychotherapy.

He felt well supported by his employer and was still doing some work on an irregular basis. He had been surprised to find that he was happy to let his work 'drift', and he thought this was because he was more focused on himself and his treatment. He felt very lucky to have a wonderful wife and children, but also felt guilty about the pain that they were going through.

Bill was very impressed by the care that he received on the NHS. The only negative comment he made about his care was the amount of time he spent waiting around on his treatment days.

### **Interview 2:**

Since he finished radiotherapy, Bill had experienced difficulty with his hearing, which he found very frustrating. He had managed to do some low-intensity exercise, which he was very pleased about, and decided that he would like to do a triathlon to raise money for a brain tumour charity. He had found setting himself this objective very positive and wanted to do something for others as he felt that he had not done this much in his life. He recently managed to go for a swim and felt 'high as a kite' afterwards.

Bill had noticed that he had started to get a bit confused about dates and times, and had missed a couple of arrangements recently. He enjoyed reading Greek philosophy and found that this gave him a useful perspective on his situation. He enjoyed reading in general and felt that it offered him a form of escapism. Since he had finished the radiotherapy he felt more positive about

working and had decided he would like to work a bit more again. He felt that the financial issues associated with his disease and treatment were 'the biggest bugbear'.

He felt most comfortable only planning a month ahead, and was starting to think about his own mortality, particularly in terms of his children. He was considering writing them a letter.

Bill had felt a tremendous amount of guilt since contracting HIV and felt that he had let his family down. He had felt like 'taking matters into his own hands' before but had never taken it any further because of the psychological damage it would cause his family. He had discussed his feelings with a 'chap' (? Counsellor) at his local hospice but did not find it very useful. He felt that the care he had received was excellent, but that he felt a bit 'adrift' since he completed the radiotherapy and suggested that a phone call every now and then would be a comfort.

Bill said that this interview had been the first time that he had had a chance at the hospital to talk about his psychological wellbeing, and he appreciated the opportunity to talk more openly about topics that were difficult to discuss. He felt that a lot of his worries stemmed from his HIV diagnosis, and it was difficult to separate those issues from the feelings that had arisen due to his cancer. He had found the psychological impact of his diagnosis to be far more difficult to manage than the physical impact.

### **Longitudinal analysis:**

At the time of the first interview, Bill was spending a lot of time lying down, and was feeling that he lacked the energy to do much. This appeared to have a significant impact on his SWB, as he was used to a very active lifestyle. He was also not feeling motivated to engage in his work at this stage. By the second interview, Bill was managing to do some exercise, which he was very pleased about and which had enhanced his sense of identity and SWB. He was also starting to feel that he would like to get back into work and was craving the engagement and social side of his job.



At the second interview, Bill seemed to be experiencing worsening cognitive symptoms. He was struggling with loss of hearing and was starting to get confused about dates and times. He also made more reference to the impact of financial issues, which appeared to be an increasing psychological burden later in his treatment.

Throughout both interviews Bill referred to coming to terms with his own mortality, and found reading, in particular Greek philosophy, to be a useful activity.

#### **5.2.4 Brian**

Age	64
Gender	Male
Ethnicity	White British
Social/family background	Married and lived with his wife. Did not have children. Had retired from his office-based sales job nine years earlier and had been working as a gardener since then.
Summary of cancer journey	<ul style="list-style-type: none"> <li>• May 2014: Diagnosed with a low-grade glioma after experiencing seizures and episodes of loss of consciousness.</li> <li>• September 2015: Disease had developed into HGG.</li> <li>• December 2015: Commenced 6-week course of radiotherapy concurrent with TMZ chemotherapy.</li> <li>• May 2016: Commenced 6 cycles of TMZ chemotherapy.</li> <li>• September 2016: Disease progression, began to experience confusion and severe fatigue.</li> </ul>
Number of interviews attended	2 (November 2015 and April 2016) He attended both interviews with his wife, Ann.
Status at end of data collection	Died in December 2016.

**Interview 1:**

At the time of diagnosis, Brian and his wife felt disillusioned with their local hospital, as his condition seemed to be deteriorating rapidly and they did not feel that this had been taken seriously. Brian relied on his wife for a lot of the information on what happened during this time, as he could not recall the details. They spoke positively of the care Brian was receiving at the cancer centre. They felt that their Consultant was fantastic, and the Clinical Nurse Specialists were very supportive.

Brian used to cycle regularly and wanted to get back into it. He was managing to do quite a lot of walking but found that he got tired quite quickly. He spent his time reading and listening to music. He felt progressively tired throughout the week whilst having the radiotherapy.

Brian was still experiencing some seizures, which he likened to 'going into a black hole'. He was also feeling very tired. He was having difficulty finding the words to express himself, so felt that he often stayed quiet rather than starting a conversation that he might find difficult to finish. He felt that people did not understand how ill he was, as they often said that he looked well. His wife felt that they could not chat in the way they used to, which was understandably distressing for both of them, and had impacted on their relationship.

Brian felt that wellbeing was about the 'simple things' like being happy and going on nice holidays. Prior to his diagnosis, Brian had been enjoying his job as a gardener. He felt that it kept him active and he liked the social side of it. He had felt lonely since giving up work, and his wife felt that he had become more introverted. He was unsure about whether or not he would like to go back to work but felt he currently did not have the energy to do much. He had found the loss of independence very difficult and did not like having to rely on other people.

**Interview 2:**

Brian was feeling much better since finishing the radiotherapy and felt that he was almost back to normal. He had stopped having seizures, which he was very pleased about, and was not really experiencing any symptoms other than tiredness, which he managed by sleeping longer at night. He did feel that he needed less rest than when he was having the radiotherapy and was managing to do some gardening. He was also managing to do some useful things around the house like making cups of tea, cleaning the bathroom and vacuuming, which he felt were only small tasks, but had greatly improved his wellbeing.

Brian was not sure that he would ever go back to his gardening job, and he missed the contact that he had with people through his work. He was still struggling with his short-term memory, and found it difficult to express himself, which he found frustrating.

Brian wanted to reduce his drugs as much as possible, and that was one of his main goals for the future. He was also open to entering any new treatment trials. Brian and his wife did feel that the contact with the medical team had reduced significantly since they were no longer coming in for radiotherapy, and he did feel 'a bit forgotten about' and isolated, particularly as they lived quite far away. He knew that they could call, but they didn't want to bother people and it wasn't the same as seeing people on a daily basis.

**Longitudinal analysis:**

Brian was feeling very tired and needing to rest a lot at the time of interview 1. He was also experiencing some seizures. By interview 2 he was feeling much better and 'almost back to normal'. He had also stopped having seizures. At interview 1 Brian was not sure if he would go back to work, but by interview 2 he had reached the conclusion that he would probably never return to his job as a gardener, and he continued to miss the social contact that this provided.

By the time of interview 2, Brian was focusing on trying to regain a degree of normality. Reducing his drugs was an important goal for him, as was considering the potential to enter any new drugs trials. Whilst Brian and his wife felt well supported throughout his treatment, they had noticed the decrease in contact once the radiotherapy had finished and mentioned feeling ‘forgotten about’ and ‘isolated’ at this stage.

### **5.2.5 Christopher**

Age	60
Gender	Male
Ethnicity	White British
Social/family background	Married and lived with wife. Had two adult children. He worked as a self-employed fashion director and creative stylist.
Summary of cancer journey	<ul style="list-style-type: none"> <li>• March 2015: Attended his local A&amp;E after experiencing left-sided weakness, and was diagnosed with small cell cancer of the lung, which it was presumed had metastasised to the brain.</li> <li>• April 2015: Craniotomy and resection surgery, followed by cisplatin and etoposide chemotherapy for lung cancer.</li> <li>• July 2015: MRI showed that brain tumour grown.</li> <li>• August 2015: Diagnosis was reviewed and confirmed as HGG.</li> <li>• August 2015: Craniotomy and resection repeated.</li> <li>• August 2015: Commenced 6 weeks of TMZ chemotherapy with radiotherapy.</li> <li>• May 2016: CT scan confirmed disease progression. At this point his memory was worsening, he was leaning to one side and his vision was blurred.</li> </ul>

Number of interviews attended	2 (October 2015 and January 2016) He attended both interviews alone.
Status at end of data collection	Died in August 2016

### **Interview 1:**

Christopher described the relief he felt when he was informed of the brain tumour diagnosis, as he had been living with uncertainty around his lung cancer diagnosis, and it was a relief to know that he was getting the right treatment. However, he did say that he felt 'slightly peeved' that he had already gone through unnecessary treatment for the lung cancer.

Christopher said that his diagnosis was very scary and 'absolutely life-changing'. He felt that he had always been someone who was very much in control of his life. He had found it very difficult to get used to the fact that he did not have any control over the cancer, and this had detrimentally affected his SWB.

After the operation he had to learn how to do basic tasks like walk and get dressed again. He had found this loss of independence deeply concerning and detrimental to his SWB. He had experienced some nausea, but this was controlled with anti-sickness. He had also had diarrhoea and felt very tired. He was trying to go to exhibitions and see films so that he did not become too focused on the treatment, and he felt that this offered him a degree of normality.

Christopher and his wife had been planning to take more time for themselves now that their children had grown up and were less financially dependent. They wanted to travel and focus on doing the work that they enjoyed rather than what generated the most income. The diagnosis had made them realise that they wanted to get on with making these changes rather than putting them off any longer.

Christopher had been touched by seeing healthcare professionals looking after people, as he realised that they were motivated by factors other than money. He felt that this had positively changed his outlook as a person, and he was now much more likely to be sympathetic to others who were suffering, such as homeless people.

Christopher spoke highly of the care he received and felt well supported by the CNS whom he saw weekly and knew him very well. He said she felt like 'part of the family', and although the doctors were excellent the relationship always kept a bit more distance than it did with the CNS. The fact that he could call the CNS whenever he had a question and that she knew who he was had been invaluable to him and his wife.

He had told the consultant that he did not want to know too many facts and figures about his diagnosis, as he did not feel that this would help him, but he thought about his mortality a lot and was trying to enjoy his life as much as possible.

### **Interview 2:**

Christopher expressed his relief at no longer having to receive radiotherapy. He had some mild nausea and constipation which he was managing himself through his diet and exercise routine. He found his life was much more 'normal' now he wasn't having to come into hospital every day, and he felt that taking a tablet was much easier than going into a machine, which he had found quite scary and invasive. His co-ordination and walking had improved. He was starting to do some more work and had noticed that he wanted to socialise more than he had when he was having radiotherapy. He felt more confident communicating to people and was not as worried about having seizures.

Christopher felt that he trusted the team that were looking after him, and that he was pleased that his treatment felt much more under control than when he was misdiagnosed with lung cancer. This trust and confidence helped him to feel a degree of control over his life. He was planning to do

more work, and was hoping to do more running and cycling as he felt quite healthy. He was enjoying having some independence again and found it interesting that prior to his diagnosis he wanted to be extraordinary and now all he wanted was to be as normal as possible.

**Longitudinal analysis:**

Christopher felt much better on the single agent TMZ than he did when he was having radiotherapy, and he discussed many aspects of his SWB that he felt had improved. He found taking a tablet had very little effect on his wellbeing, and what side effects he did experience he was managing himself through his diet. He also felt that his independence had improved at the time of interview 2, and he was very pleased that he could do more for himself. He spoke hopefully of the future in terms of increasing his activity levels and making some changes to his working life. He felt more confident in social situations and was pleased that he had started wanting to interact with people again, which he had been avoiding during radiotherapy. He felt that his treatment was well-managed. This was a change from interview 1, when he talked more about his misdiagnosis and how this had led to him feeling out of control.

Work was very important to Christopher's sense of identity and SWB and was something that he had always enjoyed. At interview 1 he had put work on hold, but by interview 2 he was feeling positive about the changes that he was making to his studio and the fact that he was prioritising what he wanted to do work-wise.

Christopher mentioned his appreciation for the work of healthcare professionals and in particular his CNS in both interviews. He also spoke about feeling lucky in many regards throughout his treatment. For example, he did not feel that he had suffered with significant side effects, and was pleased that he didn't have to make a long journey to the hospital. On a more philosophical level he also felt grateful that he felt positive changes within his psychological wellbeing as a result of his diagnosis such as being more caring

to others and appreciating those who cared for people less fortunate than themselves.

### **5.2.6. Joan**

Age	54
Gender	Female
Ethnicity	White British
Social/family background	Married and lived with her husband and three children (aged 12, 16 and 19). Worked as a proofreader and editor of scholarly scientific articles.
Summary of cancer journey	<ul style="list-style-type: none"> <li>• October 2015: Diagnosed with HGG following a 4-month history of headaches and seizures.</li> <li>• October 2015: Craniotomy and resection surgery.</li> <li>• October 2015: Commenced 6-week course of radiotherapy concurrent with TMZ chemotherapy.</li> <li>• January 2016: Commenced 6 cycles of TMZ chemotherapy.</li> <li>• March 2017: CT scan showed disease progression. Started to experience left sided weakness and facial palsy. She also suffered with urinary incontinence and became wheelchair-bound.</li> <li>• April 2017: Commenced PCV chemotherapy, but this was discontinued after the first cycle due to a persistently low platelet count.</li> </ul>
Number of interviews attended	2 (November 2015 and February 2016) She attended the interviews alone.
Status at end of data collection	Died in June 2017



**Interview 1:**

Prior to her diagnosis, Joan had felt very happy in life, with all her children doing well at school. She was proofreading scientific papers for work, which she enjoyed. At the time of her diagnosis, she had initially been told that it was a low-grade glioma and 'nothing life threatening'. She was very disappointed with the process of receiving her diagnosis of HGG, as the news was given by a junior doctor whom she was not familiar with. She had been reading about brain tumours and knew that this was very bad news. She was angry that no one had warned her that it might have been a high-grade tumour. It was evident that this experience of receiving her diagnosis had traumatised Joan, and continued to have a negative impact on her SWB throughout her treatment.

Joan felt that she had recovered well from the surgery and was surprised by how 'normal' she felt afterwards. She had also not had any side effects from the treatment, although she had started to notice her fingers trembling. She had been given a Quality of Life questionnaire by the CNS, which she had filled in but didn't find particularly useful. She found the questions about anxiety and sexuality 'a bit strange'. She thought that the CNS was more likely than the doctors to ask her about her emotional wellbeing.

Joan said that her husband had been devastated by her diagnosis. They had told the children some of the facts around her treatment, but had not told them the reality of her prognosis. She had found protecting her children had been the hardest part, and she wanted them to carry on their lives as normally as possible. It was clear that safeguarding the welfare of her children was paramount to Joan's sense of identity and SWB, and was a subject that she revisited frequently throughout the interview.

**Interview 2:**

Joan had not experienced significant side effects with her treatment other than mild nausea, which had been managed with medication. She thought that not having to come in for daily radiotherapy was 'marvellous'. Some of her hair had fallen out and she had lost weight, which she thought made her

look like 'a sick person', although that wasn't how she felt. She wished that she could have normal conversations with people, rather than everyone asking her about the cancer all the time.

Joan again emphasised the fact that her priority was protecting her children, and keeping their lives as normal as possible. She had had to stop her work as she found that the light from the computer could trigger her seizures, and she couldn't be reliable enough whilst having treatment.

Joan felt that having a high-grade glioma took up most of her thoughts, but she kept herself together when her children were around. She felt that her diagnosis had changed how she was with her children, and helped her to focus on what was most important in life. For example, she watched a lot more television with her youngest son which she enjoyed doing, but wouldn't have let it happen in the past. She had realised that worrying about things like 'screen time' was trivial.

It was clear that the terminal nature of her prognosis had a devastating impact on Joan's SWB. She found the fact that the best she could hope for was 'stable disease' very difficult, as there wasn't a 'light at the end of the tunnel'. She felt very guilty about not telling her children the whole truth. She had started to think about doing memory boxes for them. She had also started to think about how her husband was going to manage with the children after she died. She talked about drawing up a 'death plan' as you would a birth plan. She said that she cried every day after her children had gone to school, and that it took up a lot of her energy to protect everyone from the truth of her diagnosis. She had spent a lot of time preparing her husband to be able to care for the children on his own, as she didn't want them to suffer. She had organised the house and arranged a gardener to help him. She felt like she had been given a 'death sentence' and found the idea of not seeing her children grow up unbearable. They had planned some holidays, and her husband had taken her to the opera, which had been 'amazing', and something that they would never had done if she hadn't been diagnosed. However, she was struggling to experience any joy in her life.

### **Longitudinal analysis:**

Joan had not experienced many side effects from her diagnosis or treatment at either interview, but was deeply affected by the psychological impact the HGG had on her and her role and identity as a mother. In interview 1 she talked about her shock and anger about how she was diagnosed. She was very much focused on her children and maintaining as normal a life as possible. Her determination to protect them was clearly fundamental to her sense of identity and SWB.

At the second interview, Joan talked at great length about planning for her family after her death. She had taken care of many of the practical elements of family life, but was distraught at the thought of not being around for her husband and children. At both interviews Joan focused on keeping her children's lives as normal as possible and protecting them from the reality of her diagnosis. At interview 2 she discussed planning family holidays and going to the opera but struggled to feel any joy in her life. At both interviews she expressed gratitude for the radiotherapy staff and CNS, but also disappointment at the communication between professionals and the way that the news of her diagnosis was given to her.

### **5.2.7 Kath**

Age	59
Gender	Female
Ethnicity	German
Social/family background	Not married and lived alone. Family lived in Germany. Worked as a Personal Assistant at a Consultancy firm.
Summary of cancer journey	<ul style="list-style-type: none"><li>• October 2015: Diagnosed with HGG after attending her local Accident and Emergency department. Had noticed reduced function in her fingers and had also collapsed.</li><li>• October 2015: craniotomy and debulking surgery to remove tumour.</li><li>• November 2015: Given radiotherapy concurrently with TMZ chemotherapy for 6 weeks, followed by TMZ alone for a further 5 months.</li></ul>

Number of interviews attended	2 (December 2015 and February 2016) She attended the interviews alone.
Status at end of data collection	September 2018: alive with stable disease, no significant symptoms or further treatment.

**Interview 1:**

Kath felt she responded well to the chemotherapy and radiotherapy treatment. Tiredness was her main symptom, but she said that this was to be expected and she did not find it too difficult. She managed by having a nap in the afternoon. She also experienced nausea and had very little appetite, but managed to eat enough by having six small meals a day. She didn't feel that she had many issues to raise when she was given the QoL questionnaire, but she felt that overall it was a good idea.

She enjoyed going to the gym and still tried to go regularly as it improved her SWB, but was finding it more difficult as she was feeling very tired. She likened attending for treatment to going to work, in the sense that she had to do a regular commute everyday, and it took up a lot of her time. She had been signed off sick from work since her diagnosis and felt her employer had been very supportive. She felt lucky that she was still getting paid and did not have to worry about finances.

Although she missed the social aspects of her job, she did not miss the stress of working. Her diagnosis had made her realise that if she could work again she would like to do something completely different, such as voluntary work, which she thought would be more rewarding and worthwhile. Recently she had been questioning why she used to spend so much time in a job that she did not enjoy. She felt that she had started to see each day differently and appreciated life more. She had been thinking of the hobbies that she had neglected such as photography, and wished she had taken more time to do them when she was well, as now she felt too tired with the treatment to do

them. She felt that in many ways her wellbeing had improved since her diagnosis. She reflected on whether this was because she no longer had to work, or because she had developed a different outlook and wanted to make the most of what limited time she had.

She had found that attending a day for people with HGG run by a brain tumour charity had been useful, and she appreciated hearing from other people with similar stories. She was planning to spend the break between treatments getting things such as her will and pension organised, as she thought that this would give her peace of mind and improve her wellbeing.

### **Interview 2:**

Kath felt that the TMZ chemotherapy alone had affected her more than the chemotherapy and radiotherapy combined. She had experienced more nausea and fatigue and had been feeling light-headed. Her appetite had worsened and she had lost weight, but she was still managing to eat small amounts frequently. She said that she was sleeping better, and she thought that this was because she was no longer taking steroids.

She had started yoga, which she enjoyed and found relaxing. She found that not coming in for radiotherapy daily had given her more time to do the things she enjoyed. She felt that when she was first diagnosed she was anxious about doing too much, but she had decided to enjoy life and planned a couple of weekends away. She had talked to the CNS about her issues with fatigue and loss of appetite, which she found helpful.

### **Longitudinal analysis:**

Kath's side effects appeared to have worsened between interviews 1 and 2. She had increasing problems with fatigue and loss of appetite, and had also started feeling light-headed. In the first interview, Kath reflected on how the diagnosis had impacted on her SWB in terms of realising that she had spent a lot of time doing work that she did not enjoy, and how her diagnosis had given her a positive opportunity to re-evaluate her life. At the time of the second interview, Kath had developed the confidence and positive attitude to

allow her to start spending time doing the things she enjoyed and looking after her wellbeing by spending time on her hobbies such as photography and yoga. This was also facilitated by the fact that no longer having radiotherapy had given her more time to do the things she enjoyed.

### **5.2.8 Len**

Age	53
Gender	Male
Ethnicity	White British
Social/family background	Married and lived with wife. Had two adult children. Ran his own greengrocery business.
Summary of cancer journey	<ul style="list-style-type: none"> <li>• August 2015: Diagnosed with HGG.</li> <li>• September 2015: Craniotomy and resection surgery.</li> <li>• September 2015: Commenced 6-week course of radiotherapy concurrent with TMZ chemotherapy.</li> <li>• October 2016: Commenced 6 cycles of TMZ chemotherapy.</li> <li>• July 2016: CT scan showed disease progression. Given 2 cycles of Lomustine chemotherapy.</li> <li>• September 2016: entered a drug trial, given a combination of bevacizumab, valganciclovir and ipilimumab.</li> </ul>
Number of interviews attended	2 (August 2015 and November 2015) He attended both interviews with his wife, Sam.
Status at end of data collection	January 2018: receiving 2 weekly bevacizumab treatments as a private patient and had stable disease.

### **Interview 1:**

Len felt that he had gone from being a businessman who looked after his family and was in control of his life to being a child who needed looking after. He had experienced seizures and memory loss, which meant that he needed

to be closely monitored by his wife. Len used to enjoy playing golf but hadn't played since he became unwell. His work had been very important to him, and not being able to run his business any more had been very distressing for him and had damaged his sense of identity and SWB. Despite this, Len said he felt that he was 'a lucky man' in terms of his wife and family, and all that mattered to him was surviving for as long as possible to be with them. SWB to Len meant living as normal a life as possible.

Len's wife thought that the questionnaires weren't particularly helpful, as they did not allow for the fact that he had good days and bad days, and his answers could change from day to day. Len and his wife felt that they would have benefitted from more support when he first became unwell, and that counselling should be offered to everyone, but that since they had been referred to the oncologist the care had been fantastic.

### **Interview 2:**

At the time of interview 2, Len felt that his wellbeing fluctuated between treatments. He was often tired and felt nauseous for a few days following the chemotherapy, before returning to 'normal' again. His speech also fluctuated depending on how tired he was. He got very frustrated by this and had tried speech therapy but hadn't seen much improvement. He also felt fed up with being at home all of the time but got tired very easily. Len found the unpredictability of his treatment (depending on his blood results) difficult to deal with, and this affected his ability to retain control over his daily life. He struggled with motivation and ended up watching lots of television. He got frustrated when he could not hold a conversation, and this upset him and resulted in him avoiding social situations. Len had not felt well supported by his GP, but often phoned the CNS for advice.

### **Longitudinal analysis:**

Len talked about how lucky he was at both interviews and focused on the importance of his wife and family to him. He talked more about adapting to not being able to work in interview 1, and also reflected on his recent surgery. At interview 2 his tiredness and speech impairment were more of an

issue, and he talked more about spending most of his time at home watching the television. Len and his wife spoke positively of the support they received from the CNS at both interviews. He did not discuss experiencing significant side effects such as nausea or loss of appetite at either interview, but tiredness and lack of motivation were factors that impacted on his SWB throughout.

### **5.2.9 Liu**

Age	68
Gender	Female
Ethnicity	Chinese
Social/family background	Married and lived with husband. Had two adult sons. Worked as a consultant for an investment fund.
Summary of cancer journey	<ul style="list-style-type: none"> <li>• June 2016: Diagnosed with HGG after noticing increasing problems with her speech.</li> <li>• June 2016: Craniotomy and debulking surgery to remove tumour.</li> <li>• July 2016: Given radiotherapy concurrently with TMZ chemotherapy for 6 weeks.</li> <li>• August 2016: Commenced 6 cycles of TMZ chemotherapy.</li> <li>• May 2017: Tumour progression, given 3 cycles of Lomustine chemotherapy</li> <li>• November 2017: Received 1 cycle of Carboplatin chemotherapy, but began to experience worsening memory loss and generalised weakness.</li> </ul>
Number of interviews attended	1 (July 2016) She attended the interview with her husband.
Status at end of data collection	Died in January 2018



**Interview summary:**

Liu went to see her GP when she noticed that she was struggling to find the words for what she wanted to say. She was sent for an MRI scan which identified the tumour. She found the operation and recovery unproblematic and was in hospital for six days without any pain. She had undergone a lobotomy two years beforehand, so felt that she knew what to expect. The diagnosis came as a shock, as she had been perfectly well only two months earlier.

Liu felt that she was coping well with the radiotherapy treatment but found the commuting and waiting around very tiring. Both Liu and her husband appreciated being told the facts of her diagnosis 'in black and white', so that they knew what they would be facing in the future. She had found the staff 'very good' and thought that having everything explained clearly to her had been helpful. Liu felt that she was managing because of the support of her family, which stopped her from feeling scared. She tried to stay positive but did have down days.

Liu was trying to keep life as normal as possible as a means of preserving her SWB. She found it helped if she had a rest for a couple of hours each day. She and her husband had been looking forward to doing more travelling once they had retired, but her diagnosis had led them to put their plans on hold. Liu appreciated the support of her friends and found talking to them about what she was going through helpful.

### **5.2.10 Maria**

Age	29
Gender	Female
Ethnicity	Romanian
Social/family background	Married with one infant son. Most of her family, including her baby son, lived in Romania. At the time of interview, she was living in a house share in London with her husband and working as a waitress before her diagnosis.
Summary of cancer journey	<ul style="list-style-type: none"><li>• August 2015: Diagnosis of HGG after attending her local Accident and Emergency department following a 30-minute episode of loss of consciousness. She underwent craniotomy and resection surgery shortly after diagnosis.</li><li>• September 2015: Received six weeks of radiotherapy concurrently with temozolomide (TMZ) chemotherapy, followed by a 5-month course of TMZ chemotherapy.</li><li>• Taking daily Levetiracetam (an anti-epileptic drug) to prevent further seizures or loss of consciousness.</li></ul>
Number of interviews attended	2 (October 2015 and February 2016) She attended the interviews alone.
Status at end of data collection	September 2018: alive with stable disease and reported her main symptom to be fatigue.

#### **Interview 1:**

Maria suffered severe vomiting for a few days after the TMZ chemotherapy. She then felt very tired for 1-2 weeks during the radiotherapy. She did not feel that she had any symptoms from the brain tumour, but she did relate her symptoms to the treatment. Maria spent a lot of time in bed during the first treatment period, but also liked getting some fresh air and relaxing in the garden. She found talking to people for a long time tiring. Maria felt that the quality of life questionnaire was helpful, as it helped to start a discussion

with the clinical nurse specialist (CNS). She talked to the CNS regularly about 'everything', including the treatment and how she was feeling emotionally.

She said that she was trying to be positive, as people kept telling her to be positive, but that she felt scared about the future. She said that she realised that life is short, and that the diagnosis had made her feel that she wanted to spend more time with her son, and less time working. Her aim following the first 6 weeks of treatment was to go to Romania to see her son, and she hoped to bring him over to the UK. She said her son was the most important thing in her life, and that all she wanted was to be with him. She managed to see him via the internet.

### **Interview 2:**

Maria said she had no appetite, felt very tired and was struggling to sleep. She had experienced constipation, which was very uncomfortable. She felt 'bad' the day after the chemotherapy finished, but after that she started to feel better. Towards the end of each chemotherapy cycle when she was starting to feel better she tried to eat healthily and found that this gave her more energy. She said this treatment was easier than radiotherapy as it was only for a few days at a time rather than every day. She did not feel she needed to contact the doctors and nurses between treatments, and only spoke to them when she was at the hospital.

Between treatments Maria flew to Romania to be with her son for 2 weeks at a time. She enjoyed being with him, and found the time went quickly when she was there as it helped her to forget about the treatment, and she did not have time to think about feeling tired. She found this was much better than staying in bed without much to do. Her husband stayed in London to work while she went to Romania, as they needed the money. She did not know what to expect after the treatment and was unsure about what to do regarding her child and work arrangements.

**Longitudinal analysis:**

At the time of interview 1, Maria experienced vomiting and was feeling very tired. She managed the tiredness by resting in bed regularly and taking walks in the garden. At interview 2 Maria no longer reported nausea or vomiting, but she continued to suffer with fatigue. She also reported a lack of appetite and had started feeling constipated, which was very uncomfortable. The side effects of treatment appeared to be Maria's main concern during both interviews. Whilst the nature of some side effects changed, with nausea and vomiting being more prevalent at the first interview, and loss of appetite and constipation taking precedence at the second), their impact on her SWB remained consistently high throughout the discussions. She continued to experience fatigue at each stage of her treatment. She found the second treatment easier than the first as it only took four days per month rather than being every day.

At interview 1, Maria talked about realising that spending time with her son was the most important thing to her, and by the time of interview 2 she was managing to see him more as the treatment was less time-consuming, which she felt improved her sense of wellbeing.

The nature of Maria's anxieties about the future appeared to evolve between interviews 1 and 2. As she processed the shock of her diagnosis in the earlier stages of her treatment, she talked about feeling scared about the future and the realisation that life is short. At the time of the second interview, when she had been living with her HGG for longer and had more time to consider the impact on her daily life, she talked about what would happen after treatment and expressed uncertainties about what to do in terms of her son and her work.

### **5.2.11 Mateo**

Age	57
Gender	Male
Ethnicity	Spanish
Social/family background	Married to a man and had one adult son. He was the head of the development programme for an international charity. He lived close to the majority of his family in Spain.
Summary of cancer journey	<ul style="list-style-type: none"><li>• July 2015: Diagnosed with HGG whilst in London on a business trip and decided to stay for treatment.</li><li>• July 2015: Craniotomy and debulking surgery.</li><li>• September 2015: Commenced 6-week course of radiotherapy concurrent with TMZ chemotherapy.</li><li>• December 2015: Commenced 6 cycles of TMZ chemotherapy.</li><li>• June 2016: Disease progression, began to experience confusion and anxiety.</li></ul>
Number of interviews attended	1 (August 2015) He attended the interview alone.
Status at end of data collection	Died in August 2016.

#### **Interview summary:**

On hearing his diagnosis, Mateo was unsure about whether to return to Spain, but decided to stay, as he felt safe in the hands of his medical team. He used to live in London and had many friends nearby and a nephew who he saw regularly. Mateo felt upset at the thought of the distress his diagnosis was causing his family. He said that he cried recently when he realised that he would never be a healthy person again. He had lost a lot of weight and was very sick after the chemotherapy. He felt like everything was going wrong for him ('So okay have a tumour, but did it have to be the worst tumour ever?'). He wanted to find somewhere that he could escape to 'for another life' where

he could forget about the cancer. He had felt very tired, but was trying to do some work, which he had found to be a very good distraction.

Mateo felt that prior to his diagnosis his life had ‘gone a bit crazy’. He was travelling all over the world for work, and he had finally had time to reflect and realise that he was not happy.

He was finding it hard to make any plans for the future, as he was not sure how his disease and treatment would progress. He found the uncertainty difficult to deal with, and he was not sure how best to cope with this. For example, he was facing renewing the contract on his flat, and he was not sure how long a contract to take out. He wanted to make a return visit to Uruguay; a country that he loved, but felt that this was impossible due to feeling it was a long way from a hospital.

### **5.2.12 Michael**

Age	68
Gender	Male
Ethnicity	White British
Social/family background	Married and lived with wife. Had an adult daughter. Worked as a self-employed builder.
Summary of cancer journey	<ul style="list-style-type: none"> <li>• September 2015: Diagnosed with HGG.</li> <li>• September 2015: Craniotomy and debulking surgery.</li> <li>• October 2015: Commenced 6-week course of radiotherapy concurrent with TMZ chemotherapy.</li> <li>• January 2016: Commenced 6 cycles of TMZ chemotherapy.</li> <li>• October 2016: mobility worsened, CT scan showed disease progression. Given 2 cycles of Lomustine chemotherapy.</li> </ul>

Number of interviews attended	2 (March 2016 and August 2016) He attended the interviews with his wife, Pat and his daughter.
Status at end of data collection	Died in February 2017

**Interview 1:**

It was clear that Michael had felt a significant impact on his SWB as a result of his HGG, despite the fact that he reported not experiencing any side effects from the treatment other than tiredness. Wellbeing to Michael meant ‘getting his health back’ so that he could work and go to the pub. He felt that his social life had been detrimentally affected, as he was too weak and tired to go out. He used to go to the pub regularly to socialise, which he was not doing as often. He also missed going to work, although he was managing to do some project management of building jobs.

He found taking things a day at a time was the best approach, and didn’t like being given too much information, as he found this made him more anxious. His diagnosis had made him reconsider what was important in life, and he had decided not to worry so much about work issues. He missed his independence and felt strange that he was suddenly the ‘centre of attention’ in his family. He had struggled to motivate himself to do daily tasks sometimes and found that he got frustrated with himself.

Michael hadn’t been given any quality of life questionnaires, but he felt well cared for by the CNS. The family were very pleased to have a named contact who knew them and whom they trusted.

**Interview 2:**

Michael had found the TMZ chemotherapy without the radiotherapy much harder than the combined treatment and appeared to be experiencing more side effects. He had been extremely tired, felt nauseous and had lost his

appetite. He had also had very itchy skin, which kept him awake at night. However, he was managing to get to the pub a couple of times a week, which he was pleased about and felt was a positive step towards returning to 'normal' life. He enjoyed going to meet friends and watch the football, but didn't drink much alcohol any more. He felt that getting out lifted his spirits. He still had not received any quality of life questionnaires, but his CNS regularly asked him how he was and he preferred it that way to 'keep things simple'.

**Longitudinal analysis:**

Many of Michael's concerns were consistent throughout both interviews. His tiredness, lack of independence and impact on his social life were significant factors for him. However, at the time of the second interview he was managing to get to the pub to see his friends a bit more, which he felt 'lifted him up'. He felt well supported by the CNS throughout his treatment. His side effects had worsened at the time of interview 2. His appetite had decreased and he was also suffering with itchy skin, which had a negative impact on his sleep. However, these appeared to be less important to his SWB than his ability to socialise.



### **5.2.13 Reena**

Age	37
Gender	Female
Ethnicity	Bengali
Social/family background	Married and lived with her husband and ten-year-old daughter. She worked as a housing benefits officer.
Summary of cancer journey	<ul style="list-style-type: none"><li>• February 2016: Diagnosed with HGG after suffering with headaches and loss of vision.</li><li>• February 2016: Craniotomy and resection surgery.</li><li>• April 2016: Commenced 6-week course of radiotherapy concurrent with TMZ chemotherapy.</li><li>• June 2016: Commenced 6 cycles of TMZ chemotherapy.</li><li>• November 2016: CT scan showed disease recurrence.</li><li>• December 2016: Re-excision of lesion.</li><li>• February 2017: Commenced PCV chemotherapy, but disease continued to progress, and she developed blurred vision.</li></ul>
Number of interviews attended	2 (March 2016 and August 2016) She attended the first interview alone, and the second with her mother.
Status at end of data collection	September 2018: Alive with stable disease.

#### **Interview 1:**

Reena began the interview by expressing her gratitude for her treatment, and the reassurance that she felt by being closely monitored. She had experienced some stomach-aches and nausea, and this had affected her appetite. She stated that she had found the nature of the treatment and medication overwhelming, and this had led to her feeling distressed.

Reena used to go running regularly, which she enjoyed, and missed doing. She was currently doing Islamic and Arabic studies, which she found to be a

good distraction from her treatment and helped her to feel positive and retain her sense of identity, but she had found that she got tired easily while she was doing it. Her diagnosis had led her to reflect on what she would like to do with her life, and she was hoping to undertake some further science studies.

It was clear that family was very important to Reena, and it was a fundamental part of her family role and identity to continue to protect those closest to her from harm or distress. She worried that her daughter had been badly affected by her diagnosis and was very concerned about her mum. She encouraged her daughter to pray and not to worry. She felt very lucky that she lived with her extended family, which meant that she felt well supported. She used to do the majority of the housework and felt sad that she could no longer perform this role due to tiredness. Her mother and aunty had taken this over. Her mum would not let her be in the kitchen on her own as she thought that she might forget that she had left the hob on. The fact that she could no longer undertake household tasks such as cooking and cleaning, and that these had now been taken on by others seemed to have damaged Reena's sense of purpose and self-worth.

### **Interview 2:**

Reena was feeling much better since finishing the radiotherapy, and her sense of SWB appeared to have improved. She felt physically stronger and was pleased not to be coming to the hospital every day. She was managing to do more of the cooking at home and was enjoying spending time with her daughter. She was also managing to get out to the park for a daily 30-minute walk and was enjoying the fresh air. She felt very well supported by the CNS, who she said was 'excellent'. She felt that she had been given plenty of information, and that the medical team were responsive to all her questions.

### **Longitudinal analysis:**

Reena was very positive about the treatment that she had received during both interviews. She also consistently highlighted the importance of her family and the support that she had from them. She was feeling very tired at

the time of interview 1, which meant that she couldn't get much exercise or help around the house. At interview 2 her SWB appeared to have improved significantly. She was pleased that she was able to contribute more to family life and was getting out for fresh air and exercise, all of which were fundamental to her sense of identity and control over her life.

### **5.2.14 Tom**

Age	50
Gender	Male
Ethnicity	White British
Social/family background	Married and lived with his wife and two teenage children. Worked as an Information Technology Director.
Summary of cancer journey	<ul style="list-style-type: none"> <li>• November 2015: Diagnosed with HGG after noticing weakness in his left hand.</li> <li>• November 2015: Craniotomy and resection surgery.</li> <li>• January 2016: Commenced 6-week course of radiotherapy concurrent with TMZ chemotherapy.</li> <li>• Unable to have further TMZ chemotherapy due to a prolonged period of thrombocytopenia (low platelet count).</li> <li>• July 2016: Had gamma knife radio-surgery.</li> <li>• April 2017: CT scan showed tumour progression.</li> <li>• August 2017: Commenced TMZ chemotherapy as platelet count recovered. However, his disease progressed again through this treatment and he commenced Lomustine chemotherapy instead.</li> </ul>
Number of interviews attended	1 (March 2016) He attended the interview alone.
Status at end of data collection	Died in January 2018.

**Interview summary:**

Tom felt that he had coped 'pretty well' with the surgery and radiotherapy and did not feel that his SWB had suffered significantly as a result of his disease and treatment. He had felt a bit tired, but was managing to cycle in for his treatment, which he enjoyed and felt was beneficial to his wellbeing. Once he had finished his radiotherapy he was managing to work 2 or 3 days a week again. He reflected on the fact that he had actually quite enjoyed not working and was surprised that he had found working part-time a difficult transition. He had valued spending more time with his family and being able to do 'stuff around the house'. He enjoyed watching films, going to galleries and doing nice things with his children.

In terms of monitoring his quality of life, Tom said that people often asked him how he was, but he didn't feel that there was much in the way of questioning that went deeper than that. He vaguely remembered being given a quality of life questionnaire early on in his treatment, but didn't fill it in.

Tom seemed particularly affected by his experience of trying to start a dialogue with his medical team about a treatment trial that he had heard about. This was clearly a distressing episode for him, as he felt that he was not being heard, or treated as an individual. He felt that the Doctor he was talking to was not interested and did not give him much of a response. This had made him feel very angry and frustrated, and jeopardised his sense of identity and self-confidence. He had wanted support to help him decide whether or not to participate, and he felt that he had been dismissed. He felt that when there was the option of treatment that was 'off the conveyer belt' that he would like to discuss he couldn't find anyone to help him, and that had made him feel like he was 'just a number'.

### **5.2.15 Yulia**

Age	41
Gender	Female
Ethnicity	Russian
Social/family background	Married, and lived with husband and children. She had a daughter at primary school and twin baby boys. She worked as a language teacher.
Summary of cancer journey	<ul style="list-style-type: none"><li>• 2006: Diagnosed with a low-grade glioma following seizures and an episode of loss of consciousness.</li><li>• April 2015: Tumour progressed to a HGG</li><li>• May 2015: Craniotomy and resection surgery.</li><li>• July 2016: 6 weeks of TMZ chemotherapy concurrently with radiotherapy</li><li>• September 2015: commenced TMZ chemotherapy on it's own, but discontinued after 2 cycles due to low platelet counts.</li></ul>
Number of interviews attended	3 (August 2015, November 2015 and April 2016) She attended the interviews alone.
Status at end of data collection	September 2018: Alive with stable disease

#### **Interview 1:**

Yulia had felt tired and nauseous during the chemotherapy and radiotherapy, and 'as if she had flu all the time'. She had used some savings to employ a nanny, as without this help she didn't think she would have coped. She had been very busy with the treatment and her work and family life, and she wanted to start taking more care of herself. Her diagnosis had made her reassess what was important to her. She had always been busy, and now she wanted to spend more time with her family and friends. She also wanted to go shopping and think about her clothes again.

Yulia was unhappy about the amount of weight that she had put on. It was making her feel clumsy and not very confident in her appearance. She had been referred to a dietician but felt that she needed some help with motivation to lose weight as she was so exhausted by the treatment, work and looking after her family that she was struggling to make any changes by herself.

Yulia had been given some QoL questionnaires but felt that it was more useful to talk to people. She had appreciated her regular appointments with the CNS, who had been very helpful.

Financial issues were having a major impact on Yulia. She was worried about how her and her husband were going to be able to pay the mortgage if she wasn't earning. She found living with the uncertainty of her diagnosis very worrying, and this was having an effect on her SWB. In some ways she wanted to be able to plan her future, but at the same time she was avoiding getting too much information about her diagnosis as she felt that it might be better not to know too much.

### **Interview 2:**

At the time of interview 2 Yulia still felt very tired, but she was not sure if this was a result of her treatment or because her babies had been waking up in the night. She was working at least 2 hours a day, as there were tasks that she had not been able to delegate and she felt that people were depending on her. She felt positive about working, as she knew that she was helping people and it meant that she was earning some money. This helped her to feel that she had retained some of her identity and sense of purpose, but she also wished that she had more time for relaxation. She wanted to be able to take her babies to the park, have fun with her daughter and go to the theatre more. She said that she really wanted to spend more time enjoying herself but couldn't seem to change her habits of working and doing chores instead.

Yulia said she wished that someone could coach her or give her tips on how to manage all the elements of her life and to help her focus on her SWB more.

Her diagnosis had made her think about how important her family and friends were to her, and she wanted to spend more time with them rather than being busy at work. She still had concerns about how she was going to manage financially. She had the necessary forms to claim benefits, but didn't know when she would have the time to fill them in.

### **Interview 3:**

At the time of interview 3 Yulia was returning for scans but was not having any treatment. She felt that life was very busy. She was still leading the language department at the school where she worked. She was trying to work more from home but had to go in for meetings. She felt that life was back to normal in many ways, but also that it had changed. She felt that she had learnt to say 'no' more at work, and to rest when she felt tired. She was managing to spend more time with her children, but still found it difficult to find the time to relax. She was finding living with the uncertainty of her diagnosis difficult and felt that this led to questions and doubts about how she should spend her time. For example, she had many clothes from when she used to attend glamorous parties and could not decide whether to keep them or not. She was not sure if she would ever attend such events again, or even if she wanted to, as they seemed superficial to her now.

She felt that she had stopped setting herself long-term goals, which was a bad thing as she was not pushing herself to achieve things in life, but at the same time she had stopped worrying about superficial factors such as wanting a bigger house and more money. She was hoping to travel more, but only to places where she felt medical help would be easily accessible.

### **Longitudinal analysis:**

Throughout the interviews, Yulia expressed her difficulty juggling her work, family life and treatment. At interviews 1 and 2 Yulia felt very busy with her work and family life and felt that she did not have enough time to look after herself. By interview 3 she had managed to start spending more time with her family but was still struggling to find time to relax. Yulia did not talk much about symptoms or side effects of her disease or treatment at any of

the interviews. Her pressures mainly came from other issues in her life such as financial and work concerns. Her anxieties around living with the uncertainty of her diagnosis appeared to increase through time. By the time of interview 3 she offered numerous examples of how uncertainty over her future was impacting on her day-to-day life.

### **5.3 Conclusion**

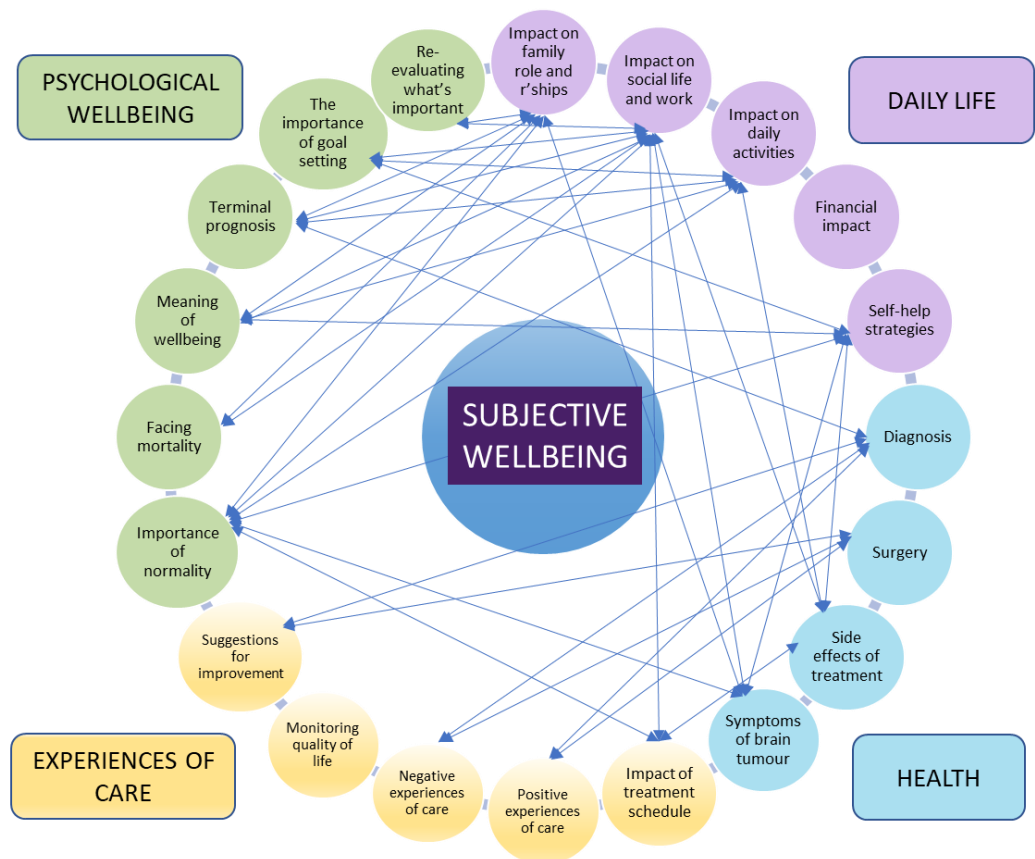
This chapter has provided context for the more detailed analysis of findings by offering key demographic statistics and information on disease and treatment duration for the participant group. It has also provided descriptive, longitudinal summaries of the situations, perceptions and experiences of each participant.



## **Chapter 6: Findings**

## 6.1 Findings introduction

The aim of this research was to explore the perceptions of people with HGG relating to the impact of their diagnosis on their SWB over time. Data analysis identified four key themes in relation to this question. These were 'health', 'daily life', 'psychological wellbeing' and 'experiences of care'. Figure 6.1 portrays the identified themes and sub-themes of this study. Although each sub-theme will be discussed individually, there were significant relationships and overlap between them. The arrows in the diagram represent these associations.



**Figure 6.1: Identified themes of subjective wellbeing**

## 6.2 The four themes of the findings

The four key themes identified in the initial stages of analysis were: 'health', 'daily life', 'psychological wellbeing' and 'experiences of care'. 'Health' focuses on perceptions of the impact of diagnosis, surgery, symptoms of disease and side effects of treatment on participants' SWB. 'Daily life' relates to the

impact of diagnosis on participants' daily activities, their relationships and roles with their families, their work, social lives and finances. It also includes evidence of self-help strategies which participants reported finding useful on a day-to-day basis. The 'psychological wellbeing' theme refers to a number of sub-themes that are relevant for people with a HGG, including the importance of normality, facing mortality, the negative psychological impact of their condition on SWB as well as the importance of goal-setting and re-evaluating what's important in life. It also includes evidence on the meaning of wellbeing for participants. Finally, 'Experiences of care' focuses on the impact of the treatment schedule on SWB, the effect of both positive and negative experiences of care, impressions of the monitoring of QoL and suggestions for improvement to care provision. Each of these sub-themes will now be discussed in more detail. Quotations will be identified by participant name (as well as their carer's name if relevant) and interview (I) number. For example, Maria's second interview is identified as Maria, I2)

### **6.2.1 Health sub-theme 1: Symptoms of brain tumour**

Perhaps unsurprisingly given the severity of the condition, the impact on SWB of symptoms resulting from the HGG was a highly prevalent theme in the data. For those who experienced them, seizures were a 'strange' and 'scary' event.

*I don't remember a thing about them, I just remember sliding into a deep hole, and that's it. It's a horrible feeling. (Brian, I1)*

*Seizures are like, scary for him because you don't know what is going on...very scary. (Len's wife Sam, I1)*

Barbara was so anxious about her seizures that she limited her daily activities to mitigate them:

*I was having the seizures. I knew when I was going to have them. When the seizures started I was having 10 a day, even with medication, I*

*stopped going up to the supermarket...I just wanted to stay at home and just wanted to be safe. (Barbara, I1)*

Joan revealed that her seizures had a significantly life-limiting effect on her, as even small everyday activities, such as looking at her phone or walking in the sunshine, could trigger their onset. She also felt forced to give up her work. This was distressing for her, as she had enjoyed her work. From an interpretative perspective, it is apparent that Joan's anxiety regarding her seizures and her subsequent need to give up work had a significant impact on her SWB, as her work gave her life a sense of purpose and was an important part of her identity:

*I had been offered a year's work where I'd be working every day managing a website. So I'd do the proof reading and the editing, commissioning articles, but I dropped that...if I was having seizures I'd have this horrible rising feeling. If I looked at a text, that could set me off as well. ...And so although it wasn't a big career it was still doing something, making a bit of money...(Joan, I1)*

Joan had also found that using a computer was more difficult since her diagnosis, an experience echoed by Christopher:

*If I went near a computer then I got this horrible feeling that I was about to have a seizure. (Joan, I1)*

*I do find it is more stressful on the computer in my condition and I can't quite concentrate quite so much when I am watching the screen so I have to be a bit careful. (Christopher, I1)*

As well as seizures, some of the participants experienced severe headaches:

*Sometimes waking up at like 2 or 3 in the morning with a headache (Bill, I1)*

*The headaches are from hell... Feels like my head is going to explode.  
(Barbara, I1)*

Other reported cognitive changes that were wide-ranging, thus emphasising the variability in symptoms of HGG depending on which part of the brain is affected. These included issues with hearing and balance, as well as other cognitive processes such as planning journeys, confusion over dates and times, and difficulty doing up buttons and shoelaces, all of which had the potential to detrimentally affect SWB as the sense of identity, self-confidence and independence of participants was threatened:

*The biggest bugbear... has been the being hard of hearing. So for example, it's amazing the noise of a cappuccino machine...and having to say pardon or what, you know it's just awful...and having to get the subtitles on the television. (Bill, I2)*

*His walking...he is very unstable on his legs. (Len's wife Sam, I2)*

*I seem to have problem in sorting dates and times. I've made a couple of foul ups, because I've got dates and times wrong. (Bill, I1)*

*I think there's part of the brain affected, which affects my sense of direction and space. I have a hopeless sense of direction at the moment. I used to have a motorbike but had to get rid of that. I came home a couple of times and I said to my wife "I've just taken a couple of wrong turns". And this is a route I really know. (Bill, I1)*

*I think things like planning things, planning journeys...he used to plan journeys, check the timetable, do all that, and he can't do that anymore.  
(Brian's wife Ann, I1)*

Many of these symptoms resulted in a loss of independence for participants, which severely impaired their sense of SWB and led to them feeling infantilised. They could no longer conduct their daily lives as they used to, as

they often required supervision or assistance from others. For example, Christopher discussed the fact that he had to re-learn how to dress himself:

*I know I am slower than I was. I came out of hospital and I couldn't do my buttons up, couldn't do my trousers up, I couldn't put my pants on the right way, really! I couldn't do my laces and my wife had to do them, my laces on my shoes! Imagine how bad I felt about that! Basically I am finding ways of putting things on that almost feel more natural for me.  
(Christopher, I1)*

Both Michael and Len's wife Sam discussed frustrations that resulted from this cognitive impairment. Michael felt that this was manifesting in an increased likelihood of losing his temper

*My nerves ... I snap quicker you know, temper you know ...it's frustration I suppose...(Michael, I1)*

*It fluctuates. He wants to be able to talk and be able to express himself more. And like he is getting frustrated you know with these pictures, you know if you had seen them you know he feels like a little boy already and then learning ... putting these things into categories and he just couldn't ... put things together and all that. You know and he feels deflated, because you know he can't do it.  
(Len's wife Sam, I2)*

Another example of the fact that people with HGG are cognitively affected in a variety of ways was offered by Brian, who had experienced an ongoing delusion of there being a third person in his marriage:

*Brian: There's strange little things that occur to you in the night or whatever when you ... you get an idea and it's hard to talk about it... remember I told you Ann?*

*Ann: You thought there was third person, didn't you?*

*Brian: I thought there was a third person. Part of our group if you like...Our marriage. And it wasn't anybody that was dangerous or anything, but it was just like a third party that was sort of beginning to help us sort things out.*

*Ann: You quickly say to me after "I'll go and tell xxx that."*

*Brian: Yeah. It's as if I was telling somebody else. It was reassuring in a way, having somebody like that...It felt absolutely real and normal...and not frightening or anything else. (Brian, I2)*

Brian had also been significantly affected by short-term memory loss. This was an issue that was raised at both of his interviews, and was clearly having an impact on his ability to interact socially, particularly with his wife, Ann. From an interpretative perspective, it was clear that this memory loss had a damaging impact on the SWB of both Brian and Ann, as it had significantly affected the relationship, which was fundamental to their happiness.

*Ann: I think it might be because of his short-term memory loss.*

*Brian: I don't know what to say do I?*

*Ann: No, because I think he feels, I think Brian's become a little bit more introverted than before, because he forgets what he's going to say.*

*Brian: Yeah, I can't think of the words to finish it off, so I tend not to say it.*

*Ann: Yeah you have become a lot, lot quieter, I've noticed that...*

*Brian: Yeah it's only short term, I can remember lots of things from way back (Brian and Ann, I1)*

Yulia felt that it was difficult to distinguish between symptoms caused by her brain tumour, side effects resulting from treatment, or simply indications of the stresses and strains of everyday life

*Sometimes I am slow...I cannot work out the logistics. But I don't know if I am slow because of my brain tumour or if it's just I have too much duties at the moment. (Yulia, I3)*

Such insights act as a useful reminder that support for people with a diagnosis of HGG must be tailored specifically to their holistic and individual needs. It may be difficult to decipher whether symptoms are a result of either the disease or the treatment. However, to the individual affected, this categorisation is less important than the effectiveness of the support given to help minimise the impact on their everyday lives.

Although there was no evidence of longitudinal changes in the reporting of most symptoms, the impact of seizures on SWB was highlighted most frequently in interview one. This may be a result of the fact that most participants were recalling their experiences around the time of diagnosis, when seizures were uncontrolled, and were also an unknown and daunting phenomenon. By the time of the second interview, the majority of participants were on medication to control their seizures.

### **6.2.2 Health sub-theme 2: Diagnosis**

Participants spoke extensively about the shocking and almost unreal experience of being diagnosed with a HGG. Unsurprisingly, this had a significant impact on SWB for many of them. Emotive language and metaphors were often used by participants to convey their experiences of being informed about their brain tumour, as per the quotations below:

*When I was first diagnosed, it was what we are calling Black Friday, it was extremely difficult when someone shows you a scan with a great big hole in your head that is showing you that there is a big tumour and you are going to have to have something done about it pretty soon. I'd say it is absolutely life changing. Just everything like flashes before you... you think about everything and you think about nothing at the same time. It sort of consumes you completely is what I found. (Christopher, I1)*

*It just – bang- you know? It was like a ton of bricks (Len's wife Sam, I1)*

*It's like jumping on a rollercoaster ...(Barry, I1)*



The use of terminology such as 'Black Friday', 'like a ton of bricks' and 'jumping on a rollercoaster' emphasises the devastating and life-changing experience of receiving a HGG diagnosis, its impact on SWB, and the desire of participants to express this in the strongest possible terms.

Two participants (Joan and Brian) spent a considerable amount of time discussing their experiences at the time of diagnosis, and how this had impacted on their SWB. Joan was clearly deeply affected by the process and felt 'really angry'. She had also lost trust in the medical team involved at the time of her diagnosis, as the following extract demonstrates:

*They sent me for an MRI scan on a Saturday and then when I came out there was a doctor waiting there. But in fact "it's nothing life-threatening" he said...so don't worry about it. He said it twice, nothing life-threatening, but that was all completely wrong because the MRI scan showed that it was my right temporal lobe. So he didn't realise that...and of course it ended up being a Stage 4 Glioblastoma. But he was hopeless...he was telling me things which basically, were untrue... So I assumed it was a low-grade glioma...No one ever said we have to warn you, these can be high-grade gliomas...so for that I am pretty angry because it was more advanced. Also I think it should be the person who you're dealing with beforehand is the person who delivers the news at the end. You should have a relationship with your doctor I think. I felt really angry because I trusted the consultant neurosurgeon, it's not a small decision so when they said low grade glioma I didn't consider it'd be anything other than a low grade glioma. I was really angry, they didn't warn me, say "well it could be a high grade one". (Joan, 11)*

Understandably, Joan felt extremely bitter about her experiences at diagnosis, particularly the handling of this by the health professionals involved. She was angered not only by the misdiagnosis, but also by the way this was communicated to her in a way that she felt led her to be misinformed. She felt let down by the medical team whom she believed had not been honest with her about the potential for her HGG to change from low

grade to high grade. This perception of professional uncertainty and deception had a significant impact on Joan's SWB throughout her treatment, as she clearly struggled to come to terms with her anger about this experience.

Brian and his wife Ann also discussed the traumatic experience that they had undergone when Brian became ill and was awaiting a diagnosis, and how this had affected the trust that they had in the medical team at their local hospital:

*When Brian was first diagnosed with his brain tumour, we were in hospital...there was no Neurologist there to come into the Ward to tell us... that Brian had got a brain tumour. He was stuck in a General Ward for a week and he wasn't, no nurses came to see him, I stopped over a lot, you know, most nights, because there was no care hardly, they didn't know anything you know...And there was a constant, they might put him on the wrong tablet, I don't know anyway.*

*I know it sounds awful. I didn't trust them. (Brian's wife Ann, I1)*

Longitudinal analysis of this sub-theme revealed that discussions around the impact of experiences at diagnosis on SWB almost exclusively occurred at interview one. This is most probably a result of the fact that it was more recent history at this stage. It was also found that asking participants to recount their experiences of diagnosis was an effective way of establishing a more free-flowing dialogue in the early stages of data collection.

Despite this concentration of discussions on the subject at interview one, it was clear that the impact of a traumatic experience at diagnosis on SWB continued to be felt throughout treatment for Joan, Brian and Ann, and that the loss of trust in some of the health professionals involved was long-lasting. Brian and Ann felt that his care at the time of diagnosis had been inadequate and were evidently traumatised by feeling he was not well cared for by either the doctors or nurses at what must have been an extremely frightening period. Fortunately they felt reassured by his treatment at the specialist cancer centre, but were so disillusioned by their local hospital that they

avoided Brian being admitted there again at all costs, even if this resulted in longer and more arduous journeys for them both.

### **6.2.3 Health sub-theme 3: Surgery**

Some participants were extremely positive about their experiences of surgery, and seemed genuinely surprised that the impact on their SWB had not been as bad as they expected:

*It was fine, I was amazed that you were so normal...every visitor that came to see me said they were astounded by how normal I was, because I could speak and walk and talk. (Joan, I1)*

*The operation was not too long and really quite, no pain or anything. (Liu, I1)*

Those participants who discussed their experiences of the surgery itself were also generally very impressed with the care that they had received at this point, particularly highlighting the skills of the surgeons. It appeared that such positive experiences had a constructive impact on SWB, as participants experienced a boost to their morale when they felt they had received excellent care, and had recovered more quickly than anticipated.

*Had the best surgeon, Mr xxx (Barbara, I1)*

*The technical skills obviously were... amazing. (Joan, I1)*

Barbara also discussed the gratitude she felt for one particular nurse on the surgical ward, and the benefit she felt of having a 'named nurse'.

*One nurse was lovely... She was so nice. So understanding. I think she got to know me and then she was allocated just to being my nurse. I think one day she wasn't there and I had someone else, and I was a little bit oh ... (Barbara, I1)*

Yulia was relieved that her CNS had helped her to swiftly resolve an issue with a wound infection.

*She has been quite helpful, yes and my wound it wasn't healing and it was my concern and I mentioned a couple of times and then promptly she kind of swiftly she recognised it and she just said go and see surgeon and then we started antibiotics (Yulia, I1)*

Despite these positive experiences, there were examples of participants feeling that the communication they had with various members of the healthcare team following their surgery was problematic, and detrimentally affected their SWB. Joan offered a particularly interesting insight into the potential for misinterpretation of comments made to her by the surgeon, and the devastating effect this had on her SWB when she realised the outcome was not as positive as she had been led to believe.

*Joan: when my husband arrived after surgery, he bumped into the neurosurgeon and she said it's gone really, really well. So he was delighted in that. But we didn't understand what really well meant. So I think she meant there was no damage. You know, or they didn't expect any damage...because that's what they do ... surgeons do isn't it? They cut and remove things and put things back together...and the technical skills obviously were ...amazing. But we didn't understand what extremely well meant. (Joan, I1)*

Christopher found the period immediately following his surgery very challenging to his SWB, particularly due to limitations on his independence and the threats to his sense of identity resulting from his incapacitation. However, he was extremely positive about the nursing care that he received post-operatively:

*Over the weekend when the catheter came out and I had a bowel movement, everything seemed to improve. Otherwise it is like you are bound to the bed and someone is changing things for you, ...they have*

*like peeing in the catheter and being constipated and not going to the toilet and those things kind of disable you in a way and you don't feel happy, and [the nurses] are wonderful, don't worry and they'll clean the bed if it happens or whatever but god you don't like it. Your dignity is completely, you just have to like...gone is your dignity. (Christopher, I1)*

Christopher mentioned the loss of dignity and feeling of disability post-operatively repeatedly during interview one. From an interpretative perspective, it became clear this unprecedented sense of dependence was highly detrimental to his SWB both physically and psychologically at this time, as he worried that he may not recover and was distressed at the thought of being disabled. Fortunately, his condition slowly improved and he gained some relief:

*After the operation I couldn't walk for four days, I had to have two physiotherapists to carry me. I really thought – This is it, I am wheelchair bound...I was so heavily affected you know when I couldn't do things for a few days after the operation but as they gradually came back I started to feel much better. (Christopher, I1)*

Barbara had a similar struggle to Christopher in the few days following her surgery, and also found this to have a significant impact on her SWB. She described being bed bound and struggling with pain and nausea. However, she was determined to regain her independence as quickly as possible, as this was fundamental to her sense of identity as a strong and determined person:

*A few days after surgery I wasn't too well, I had a lot of swelling, air in the brain and I had oxygen for about 3 days. And after surgery I was sick for about 2 days. You know, it was painful, but I got up day 2. The nurse went oh you got to ring the buzzer. I said what for? You know I can get up. I know how to go for a wee. Don't need any help. (Barbara, I1)*

Longitudinal analysis of themes revealed that experiences of surgery and its impact on SWB were more frequently discussed in interview one rather than in later interviews. This may be because first interviews were usually conducted only a few weeks after surgery, and therefore the experiences were still fresh in the memories of participants. It could also be a result of the fact that relationships between the researcher and participants were still new at the time of interview one. As the interviews progressed, and their format and direction was reflected upon, it became clear that asking questions around experiences of surgery proved to be an effective way of instigating and establishing a dialogue. Any assumptions that the impact of surgery on SWB was greater at an earlier stage in the treatment journey should therefore be made with caution, as interview technique may have been a contributing factor.

#### **6.2.4 Health sub-theme 4: Side effects of treatment**

The side effect mentioned most frequently by participants was fatigue. It was clear this impacted on SWB in a variety of ways throughout their treatment, particularly as it prevented them from participating in their usual daily activities, which jeopardised their sense of identity.

*A lot of the time I start with something and then because I'm so tired, you know, I have to sort of give up. (Reena, I1)*

*I am just exhausted ... I sometimes sleep in the afternoon. (Kath, I1)*

*A lot of tiredness ... because of the radiotherapy ... I'm tired nearly all the time (Maria, I2)*

Bill and Brian both mentioned that although they felt tired, they did not find their tiredness a difficult side effect to manage. This insight offers a useful reminder that rather than simply asking if a side effect exists or not, it is also important to consider whether or not this side effect is something that is having a detrimental effect on a person's life.

*The tiredness, it's not like extreme weariness... I thought, I've heard before from cancer patients that you know oh god you are exhausted all the time. You know it is really not like that. It's just feeling lazy. (Bill, I1)*

*Yeah I feel tiredness, but I'm probably getting used to it really. (Brian, I1)*

Many of the participants discussed their experiences of nausea and vomiting and the impact this had on their SWB. For some this prevented them from engaging in their usual daily activities, particularly for the first few days following chemotherapy. It also impacted on their ability to enjoy food, and subsequently threatened SWB as they could not engage in the social activity of sharing a meal with others. For some this nausea and vomiting seemed to be improved considerably by taking anti-sickness medication:

*It was a surprise, because you know, before I started the treatment, the Doctor was saying "Oh yeah some people feel nauseous but that's so rare, but we'll give you something for that". The first day I vomited four times. (Mateo, I1)*

*The first treatment I had, I threw up 2 hours nonstop. But now that I've got the right anti-sickness, it's helped but I've still got that constant nausea feeling and I forced myself to eat something yesterday but for 3 days I couldn't eat anything. (Barbara, I1)*

Longitudinal analysis suggests that nausea and vomiting were highlighted as an issue far more frequently in interview one (during radiotherapy and chemotherapy) than in interview two (chemotherapy alone). However, other significant symptoms such as fatigue were discussed equivalently throughout both interviews.

Joan and Barbara both discussed their experiences of hair loss, and the impact this had on their self-image. This seemed to be an extremely

important issue for them, with the idea that they might look 'sick' appearing to be incredibly detrimental to their self-perception and SWB:

*I mean the only thing was with the radiotherapy you get the patches at the side. But then because my hair was quite long, I combed it over all of them. It's not a big thing, but it made you look really like a ... a very sick person. And it's ... you don't want to think of yourself that way. (Joan, I2)*

*I had a little cry yesterday because my hair just came out in my hand...you know my hair is my hair, I will be really, really sad but I'll deal with it, somehow. (Barbara, I1)*

Both Kath and Michael had struggled with loss of appetite:

*I can't bring myself to eat large portions at all. I manage a little bit several times a day...I just think I didn't fancy anything at all. I'd gone off all kinds of foods. (Kath, I1)*

*I had no appetite ... (Michael, I1)*

Three of the participants mentioned side effects that none of the others did, but which nonetheless were significant to their individual SWB:

*My hands are trembling. (Joan, I1)*

*The one thing is the chemo brain. The longer I am away from the treatment the clearer I find I am thinking. (Bill, I2)*

*A lot of scratching. When I am in bed I start getting itchy. Then obviously I don't sleep through that. (Michael, I2)*

Whilst these side effects may appear to be minor when considered individually, from an interpretative perspective their potential impact on an individual's SWB should not be underestimated. For example, trembling



hands may interfere significantly with fine motor activities, and constipation may result in severe pain as well as detrimentally affecting the ability to enjoy eating.

Although it was clear that the SWB of many of the participants was detrimentally affected by treatment side effects, it cannot be ignored that six of the interviewees reported that they did not have any significant side effects, and were generally quite surprised by how well they were feeling:

*Touch wood I've had no side effects as yet. (Barry, I1)*

*I am surprised how great I feel and that I'm home (Yulia, I1)*

Having said this, a number of the participants who stated that they 'felt fine' at the start of an interview went on to reveal issues as the conversations developed. However, as was previously mentioned, it is often difficult to distinguish between side effects of treatment and symptoms of HGG. This complexity, particularly when combined with an awareness of the subjective interpretation of experiences, makes defining the impact of side effects on the SWB of participants particularly challenging.

### **6.2.5 Daily life sub-theme 1: Impact on family life**

A number of participants discussed how they considered support from their family to be fundamental to the preservation of their SWB since their diagnosis. Bill described his family as '*a great support*' (I1), and Liu stated that '*I don't think there's any time that I felt scared*' (I1), because my family is there.' It appeared that this support generally took the form of 'just being there' on a daily basis, so that participants did not have to face their treatment alone. Reena explained that she felt extremely lucky, despite her diagnosis, as a result of the close network of family that she had around her, and revealed how important she felt that this was to her SWB.

*I'm very fortunate I have to say to God I am very fortunate. I've got such a wonderful family...they're all there for me, all the time. We all have separate flats but still we all live... like a family. (Reena, I1)*

There was specific mention of the impact of having HGG on relationships with partners. Bill felt that going through the experience of diagnosis and treatment had brought him and his wife 'closer together' (I1) as it had triggered a focus on the most important aspects of his life. There was a sense for some of their diagnosis feeling like a shared experience with partners, and an acknowledgement that the impact on their SWB was also momentous. Christopher discussed the shock that both he and his wife had felt on hearing his diagnosis, and reflected on the devastating effect that it had on her:

*My wife and I just sat in a little green park and we just couldn't understand it, and also because my wife's father had died of a brain tumour about twenty years ago she just thought she had lost her husband too. (Christopher, I1)*

Brian's wife Ann revealed that the symptoms of Brian's diagnosis had detrimentally affected their relationship, as Brian's short-term memory loss had significantly impacted on his personality. Although still very close, Ann felt they had lost their ability to interact as easily, 'We used to have good conversations and that you know...' (I1). It was clear that Ann felt elements of their marriage she valued had been lost, and that this was extremely disheartening for them both.

Bill was determined to minimise the impact of his diagnosis on his wife's SWB. He was extremely grateful for her support, but hoped to limit the effect on her happiness by ensuring that it did not overtake her life too:

*She's been hauling me along for all these months, she's got to have her own life and I want her to have her own life, to do her own things. I don't want to limit that. She'll be happier if she's able to do stuff. (Bill, I2)*

Not all participants expressed a positive impression of their partner's support following their diagnosis. Barbara revealed that she felt her partner was 'wallowing' in her cancer, whereas she was determined to have a positive mental attitude as a means of preserving her SWB.

*I think it's affected my husband more. It's like he's the one that's got the cancer. He's feeling sorry for himself. When he's telling all his friends, oh my wife's got cancer, blah-blah-blah, it's like he's the one carrying the cancer, and he's not. He still gets his breakfast, still gets his dinner on the table... (Barbara, I1)*

This insight from Barbara serves as a valuable reminder that assumptions cannot be made about the impact of a cancer diagnosis on family relationships. Barbara suggested that there may have been tension in her marriage prior to her diagnosis '*...for the last 28 years I've been supporting you, and that's the truth. But that's another issue.*' (I1) It is important to remember that experiences since diagnosis are just one element in what may be an emotional and complicated family history.

Two of the participants (Reena and Michael) discussed their feelings around a change of role in their home lives.

*I don't do anything in the house. I used to do everything. Clean the house, do the washing, looking after the whole house was my business. I want to go back to actually, you know, working in the house and not everybody fussing over me. (Reena, I1)*

Both Reena and Michael felt dissatisfied by the way that their ability to offer a valuable contribution to family life had diminished. Thus highlighting the importance of having a sense of purpose and 'feeling useful' as a core component of SWB. Being 'fussed over' or given priority within the family group, whilst understandable, acted as a reminder of their illness and consolidated their feelings of futility.

Bill, Barry and Mateo all mentioned feeling guilty about the distress their diagnosis had led to for close members of their families. Whilst appreciating that this guilt was unjustified, it was clearly traumatic to see their loved ones suffering as a result of their HGG

*I am very lucky to have a fantastic wife and children. But the feeling of guilt, which I know it's irrational, and distress when I see the sort of pain that it causes them... (Bill, I1)*

*I'm worried obviously for my mum ... very, very traumatic to be seeing me like this...(Barry, I1)*

A number of the participants reflected on talking to their children about their diagnosis, and the importance they placed on doing this in a way that they felt was in their best interests. Discussions on this subject were numerous and in-depth, and revealed how passionately participants felt about protecting their children at such a difficult time. It was imperative to their sense of SWB to feel that they had done it in the best possible way, and was at least one element of the cancer journey that they could take some control over.

It was striking to see the variety of ways in which participants approached communicating with their children. Joan had told her teenage children that she had a brain tumour removed, and that *'they are going to use chemotherapy and radiotherapy to get rid of the bits that are left over'* (I1). She was conscious that she wasn't giving them the full picture of her prognosis and admitted that she felt *'pretty bad about it'* (I1). However, she was determined to protect her children from the unfortunate reality of her disease for as long as possible to minimise the psychological impact on them, as the following extract demonstrates:

*The main part is that they can live their lives just now, he can do his exams at Cambridge, xxx can do her GCSEs, the little guy can go to school with all his friends without crying. (Joan, I2)*

Reena had been relatively open with her young daughter about her diagnosis, but stated that:

*I don't want to let her in to too much. I'm just saying that I'm feeling fine and I'll do everything for you. You just, you know, keep yourself calm. Don't worry about me too much. You know she's the main thing because I don't want her to be affected. (Reena, I1)*

In contrast to Joan and Reena, Barbara had decided to be 'completely honest from day one'(I1) with her teenage children:

*You have to be honest with children. Sit them down, you know what I said to my little one, I said "mummy is going to have a tablet called chemotherapy, and then I am going to have something called radiotherapy and it's like a big x-ray machine which beams down and it's like a laser thing and it tries to kill the cells or put it to sleep. So hopefully it will do that but it could come back." (Barbara, I1)*

Despite her determination to be honest, Barbara understandably still felt the need to reassure her children:

*I said to him-"if we all stay positive and I have got faith as well, everything should be okay. And if it's not xxx, we'll just have to deal with it you know again. And the thing is mummy is strong and she will get through it." (Barbara, I1)*

There was a general sense amongst the participants who were mothers that they continued to put their children's wellbeing ahead of their own despite their diagnosis, and that their role as a parent remained their top priority regardless of their own health. For example, Maria travelled back to Romania between each chemotherapy treatment to see her infant son (who was staying with her parents) regardless of how well she felt. It was of vital importance to her SWB that she continued to perform her role as a mother to him, irrespective of the effort and inconvenience that this involved.

Barbara revealed that she was informed of her diagnosis just before Christmas, but kept it to herself for some time because she '*didn't want to ruin their Christmas (I1)*'. She felt that she had to be strong for her family, even though this felt exhausting at times, because '*if they see me being strong...it will be easier for them*' (I1).

Yulia had an extremely busy family life at the time of diagnosis, working full time as a teacher as well as looking after twin babies and an older daughter. She employed a nanny to ensure that she could continue to manage her daily life as well as coping with the additional burden of her disease and treatment. For Yulia, being able to pay for help had been an essential way of preserving her SWB.

*I have twins and a daughter, so no it wasn't easy but somehow I managed. I had to do homework with the older one in the evening and because I needed help with the little ones I had to employ a nanny ... without this I wouldn't be able to cope ... (Yulia, I1)*

Both Joan and Barbara talked quite specifically about the impact of HGG on their matriarchal role, and as Barbara described herself '*the captain of the ship*' (I1). Joan had focused on how to manage the practical elements of looking after the children and home after she died. She was considering encouraging her husband to employ a housekeeper, or asking one of the teaching assistants at school if they would contemplate looking after the children in the evenings. She had also ensured that a number of practical jobs around the house were done. Joan understandably became emotional when discussing her plans, but appeared determined to maintain a pragmatic approach:

*The other thing I did was, I gave him a tour of the house because obviously he never knew where the baby box was or ... our youngest, how he likes to be, you know, tucked in at night and all that stuff. (Joan, I2)*

It was extremely moving to hear how much emphasis Joan placed on her role as a mother and its paramount importance to her SWB. She was understandably devastated by the idea that she would not be there for them in the long-term. She referred to her children regularly throughout her interviews, and the threat to her maternal identity that resulted from the terminal nature of her HGG had shattered her SWB.

The fundamental importance of being a mother to her SWB was also strongly conveyed by Barbara. She talked about how much she had appreciated being able to go shopping for her youngest son, and the sense of satisfaction she got from being able to buy him things that only his mother would know he liked. Such events were extremely beneficial to her SWB, as they allowed her to continue in her maternal role:

*I did go to the supermarket and brought him things that I normally buy and he was like "oh mummy, oh this is so good that you've got me all these treats, like the old days." And it was so nice to see his little face. It was only like those little cans of drinks and... some sweets and other bits and pieces, the biscuits that he has. Only mummy would know that.*  
(Barbara, I1)

Joan felt that in some ways there had been a positive impact on her relationship with her son as a result of her diagnosis. She had realised the importance of spending as much time as possible together, and had come to appreciate that many of the parenting issues that used to concern her were not worth worrying about:

*With my youngest, you know, he certainly watches more television, which he thinks is marvellous ... and so I now sit and watch it with him. I enjoy being with him. ..and I massage his little feet. I mean he wouldn't have been allowed to watch so much television. But now I think "oh it's ridiculous, just watch it and enjoy it". So I'm a bit more relaxed about that sort of thing. At one point I wouldn't have liked this. But now I think*

*these things seem really trivial compared to worrying about a brain tumour. (Joan, I2)*

Although longitudinal analysis of this theme suggested the impact of diagnosis and treatment on family life was equally weighted throughout both interviews, there was a subtle change in the nature of participants' anxiety about their family over time. At interview one, there was considerable discussion around the shock of diagnosis and feelings of guilt concerning the impact of their HGG on others. By the time of interview two, when participants had been living with their cancer for a few months, the focus had shifted towards how the family dynamic had altered and planning ahead for how life would go on after they died as a means of retaining a degree of control over their situation (although evidence for this appeared to be limited to the mothers of the group). Conversations about the impact of their diagnosis on relationships with family were some of the most emotive interactions encountered during data collection. It was clear that this was an area of fundamental importance to the SWB of the majority of participants.

#### **6.2.6 Daily life sub-theme 2: Impact on social life and work**

It was mentioned by a number of participants that they did not feel that they wanted to return to work. This was particularly noticeable at interview one. There was a sense that participants identified other aspects of their lives that were more important to their SWB, such as spending time with family and pursuing hobbies. From an interpretative perspective, it also became clear that their HGG had led some participants to reflect on their lives and to re-evaluate what was important to their self-perception and SWB.

*Actually, I found not working quite okay. I can't say that I missed going in to work... (Tom, I1)*

For Bill and Joan, this appeared to be as a result of their perception that a considerable amount of their mental energy was consumed with thinking about their disease and treatment:



*Bill: I find this quite strange at the moment, this sort of mental sensation that I'd be happy to let [work] drift...I'm a little bit surprised at that sort of, rather passive role. I think it's probably because I'm thinking "Ok what is the next stage in my treatment?" (Bill, I1)*

*I probably could go back to proof reading and copy-editing and I might even be able to run the website. But the thing is you have to be reliable and you have to work hard sometimes... but I really don't feel like working really hard. Because the only thing I can think about is this brain tumour.(Joan, I2)*

For Brian, the physical nature of his job was the main obstacle:

*Now I'm not doing anything, I quite enjoy it. I'm not sure whether I've got the energy at the moment. (Brian, I1)*

Both Maria and Yulia said that their diagnosis had led them to reflect on their working lives, and felt that their SWB would be improved by working less and spending more time with their families, as they prioritised their roles as parents, wives and daughters.

*I'm thinking more to stay with my family and not work too much because before I used to work long hours. But now I just want to stay with my family and enjoy more of life. Because I realise it's very short. (Maria, I1)*

*I'd rather do something more relaxed and more enjoyable. More seeing friends, going to the cinema. Taking my babies to the park. Just more fun. (Yulia, I2)*

Kath spoke at length about her realisation that she was not happy in her work life. She felt that her SWB would be improved considerably by spending her time in a more altruistic role, which she felt would be more rewarding and give her a greater sense of purpose. Although she saw this as a positive

change in outlook, she did express frustration at the thought that she had realised this late in life, and in her opinion had wasted time in a job that she did not enjoy.

*The job itself I didn't really enjoy it. It was very demanding ... could be very stressful at times. It also made me think is this actually really what I want ... and now I don't have much time left, but if I am well enough to actually do some work I would like to do something different. I would like to do voluntary work. Something just more worthwhile and more rewarding. As well I am thinking now about the times when I was still at work and how much time I actually sometimes spent at work... why did I do that? (Kath, I1)*

Not all of the participants saw work as having a negative effect on their SWB. It was clear that for some work had offered a sense of purpose and satisfaction, and was therefore something that they looked forward to getting back to. Christopher had worked as a creative art director in the fashion industry, and evidently enjoyed his work, *'I like my work. So my work isn't a chore. It's not like I'm quietly pleased I'm not working' (I2)*. For him, being creative was a fundamental part of his identity, and was also intrinsic to his SWB. Indeed, he had decided to change the projects he worked on as a means of getting maximum enjoyment from his role and focusing on the aspects of his work life that offered the most fulfilment:

*I think I might going forward want to start to do some work again, but the kind of work I want to do and when I want to do it...(Christopher, I2)*

Bill had also realised that he had developed more interest in returning to work by the time of interview two. This appeared to be linked to his desire to increase his social interactions as a means of regaining his sense of identity and a degree of normality:

*I started to think well actually maybe I should go into the office for an hour or two and just start getting into it again, and I think I'd like that, like the conversations and engagement... (Bill, I2)*

On analysing the various attitudes towards returning to work expressed by participants, it is interesting to note that those who were more interested in working seemed to be in roles which offered a degree of flexibility in terms of level of commitment. Those who worked for themselves or had the option of doing reduced hours or working from home felt that this made returning to work more achievable and potentially beneficial to their SWB. On the contrary, those who had been committed to going into work for long, set hours were less likely to see any benefits in returning. Having said this, there was evidence of the additional stress that those who were self-employed faced in terms of maintaining their business:

*My wife and myself are partners in the business... we have had to sort of cut back with staff and things like that so you have to downsize a little bit. So you know that is a bit difficult to be honest. (Christopher, I1)*

*He was the superglue of the business basically and we have had to get rid of one of the staff now so that was a bit of a bummer. It is alright but no-one else can earn money unless you are there. (Len's wife Sam, I1)*

As well as conversations around the impact of changes in working life on the SWB of participants, there was also considerable discussion about how HGG had affected plans to travel. Indeed, it appeared that taking holidays and seeing the world was an important element of SWB for participants. It seemed that this was an aspect of their lives prior to diagnosis that represented a happy and fulfilled existence. Some reported significant distress at the thought of not being able to go on holidays that they had been looking forward to. Liu, Len and his wife Sam all felt that they had spent many years working hard, raising their children and were now at the stage when they had hoped to start enjoying holidays. Unfortunately his diagnosis had put this plan in jeopardy, and they had been forced to re-evaluate their

plans. From an interpretative perspective, the threat to these hopes for the future were extremely damaging to the SWB of both participants and their families:

*Our daughter had moved out and our son was going to uni and we were just getting our life sort of thing, and the business was starting to run itself and we were going to start taking holidays and things like that. (Len's wife Sam, I1)*

*We belong to the older generation, so our philosophy was that we study, we work, we bring up the children and then we retire to enjoy life. Now that we retire, obviously before this happened we sort of had a plan of travelling here and there, the world, and but now with this happened...(Liu, I1)*

Joan revealed that her family had been looking forward to 'the trip of a lifetime', and was extremely disappointed that she now felt this to be impossible to hope for:

*The worst thing was that we were all planning to go to Borneo or something like that. But that's not going to happen. I don't know if it would be okay to have a 10-hour flight. You can't get any travel insurance as well is another thing. (Joan, I1)*

Mateo also spoke of his regret that he would not be able to return to Uruguay as hoped, and the sadness he felt at the prospect of no longer having such plans to look forward to:

*Last year I went to this very restful place in Uruguay in December, and there's a fantastic beach. And I said to myself, you know, from now on, every December, I'm going to be here, for the whole of December...But of course, the thing is I can't go to Uruguay because it's a very remote place. So you know I need to be in a place near a hospital. (Mateo, I1)*

Practical concerns around needing to be close to medical facilities and the restraints this placed on travel plans were echoed by Yulia, who also felt that her diagnosis had restricted her ability to enjoy travelling:

*I wanted to travel, but I think with the tumour, I feel attached to the hospital. I'd rather not go to Africa, because I don't feel it is safe. If anything happened to me I would be scared. (Yulia, 13)*

Len, Sam, Joan and Mateo all sounded despondent during these discussions about limitations on their travel plans. Factors such as long flights, unpredictable healthcare facilities and difficulty getting travel insurance made such activities feel impossible. It appeared that to them having the freedom to be able to travel the world, and also to look forward to future travel plans was a key component of their SWB. Having this freedom taken from them by their HGG was a cause of great sadness and resentment, and was highly detrimental to their SWB.

Despite this evidence of a negative impact on SWB as a result of restrictions on travel, others suggested this was an area where they felt their SWB had improved. Barry had recently been on a walking holiday in the UK with his sister and found that he particularly enjoyed the opportunity it gave him to have a break from his treatment

*Just before Easter...my sister took me up to the Peak District. Loved every minute of it. (Barry, 11)*

Kath had also experienced a positive effect on her SWB from making travel plans that she felt she might not have done prior to her diagnosis.

*I'm going away for a long weekend at the beginning of April ...a weekend trip to the seaside. I'm planning to go away as well to Barcelona ...At first I found it a bit, it was like oh can I actually plan this? should I even be travelling? so yes, you know provided I'm well enough by then I can, but it's a difficult one to get my head around*

*because you know with this diagnosis I thought oh no my whole life's over. But then I thought no I don't have to sit at home. (Kath, I2)*

It was clear that Kath was delighted to have found the confidence to take these trips, and had experienced a significant psychological boost by realising that she could still enjoy traveling despite her diagnosis. From an interpretative perspective, making such plans offered something to look forward to, and helped to preserve her sense of identity and control over her life.

Some participants discussed how they had experienced a heightened sense of loneliness and isolation since their diagnosis, particularly as they were not working and spent a lot of time at home. It was clear that social interactions offered a sense of meaning for some participants, and the loss of this aspect of their identity had affected their SWB.

*I just enjoy meeting people. Having a drink, watching football. You get very bored. I get quite down. (Michael, I2)*

*I've been doing gardening for nine years. I miss meeting the people. The social side of it. I'm slightly lonely. I don't get to meet people like I used to. (Brian, I1)*

Brian and Ann had found that Brian's diagnosis had had a negative impact on their social life. Brian found having conversations more difficult due to his short-term memory loss. They both also felt that friends were less likely to approach them to make plans to socialise.

*I think because of Brian's illness, they tend to stay a bit clear.*

*(Brian's wife Ann, I1)*

It was interesting to see from the data that there was a change in desire to be sociable between interviews one and two. At the time of interview one, many participants discussed feeling isolated and 'stuck at home'. However, by the

time of interview two there was an increased suggestion that some people felt motivated to be more sociable.

*For the first time in the last few months I've rather got a lift from company. And I'm less happy in my own company for too long which is new for me. (Bill, I2)*

*Before I was like I didn't want to see anybody. I didn't want to be that sociable. You worry about seizures, you worry about how you are going to be etc. but now I feel that you know I don't mind making appointments to see people. I'm feeling more confident in myself in what I can do. (Christopher, I2)*

This desire to engage more with others could have been a result of a variety of factors. By the time of interview two, participants had completed their radiotherapy and were likely to have felt their energy levels recovering. They were also more likely to have their seizures under control. It is also worth remembering that at this stage participants had had longer to adjust to their diagnosis, and consequently may have felt more comfortable and confident in the company of others.

Whilst there were clearly a number of ways in which their diagnosis had detrimentally affected the social and work-focused domains of the SWB of participants, it is important to reiterate that some positive impacts were highlighted. Joan talked about how her HGG resulted in her and her husband having experiences that they were unlikely to have done otherwise:

*My husband got a box at the Opera House for the final production of our favourite opera. It was amazing. It was massively expensive, but I thought, he would never have done that. (Joan, I1)*

There were some interesting longitudinal changes noted within the theme of impact on social life and work. As was previously mentioned, participants

were more likely to want to socialise after radiotherapy had been completed. They were also more eager to travel and return to some level of working. This may have been related to a reduced burden of treatment, both physically and in terms of available time. It may also have been linked to a boost in confidence as the length of time that they had lived with their diagnosis increased.

### **6.2.7 Daily life theme 3: daily activities**

When asked about what was important to their SWB on a daily basis, it was striking to note the similarities in how people chose to spend their time. Daily activities largely revolved around spending time with family, resting, being outdoors, listening to music and reading. A number of participants felt exercising was an important part of their daily life:

*If I am going to do any exercise I normally try and do it first thing in the morning. (Bill, I2)*

*Try to fit in the gym ...(Kath, I2)*

For Tom, keeping fit had been important to his sense of identity prior to diagnosis, and maintaining his fitness during treatment had been extremely positive for him:

*I just cycle in and so that is great for me because, you know, it's kept me fit (Tom, I1)*

To some, exercise took the form of a gentle walk or being in the garden, which also offered the benefit of being outside which was cited as a positive contributing factor to SWB:

*I'm doing more gardening (Bill, I2)*

*I go to the garden ... (Maria, I1)*



Barry reflected on the importance he placed on keeping busy on a day-to-day basis as a means of preserving his SWB. He found his work in a charity shop highly beneficial, not only in terms of the opportunity it gave him to socialise, but also because he felt pleased to be doing something to help others, which gave him a sense of purpose and identity. *'I do some voluntary work. I do about six hours a week in a charity shop and I absolutely love it'* (I2).

Maria had found that spending time with her son was a positive distraction from her disease and treatment:

*I just feed the baby and play with him. It's ok because the time is going fast and I forgot a lot of things ... you know I don't have time to say I'm tired or to think too much. (Maria, I2)*

This idea of distraction and escapism was prevalent amongst discussions on daily activities and SWB. Many seemed to find this through cultural endeavours such as reading, listening to music and watching films:

*First thing in the morning I generally read the paper, I do a lot of reading... It's partly escapism but it's partly just engaging with something. (Bill, I2)*

*Going to art galleries, you know escaping, watching a film... (Tom, I2)*

The number of participants who highlighted the importance to their SWB of cultural distractions emphasises how beneficial such activities can be. Simple activities such as watching a film or reading or book may seem trivial, but their positive contribution to the daily lives of people with HGG should not be underestimated. Such activities offer an important source of distraction from their disease and treatment, and also allowed participants to feel that they had retained a degree of normality, which was important for their sense of identity and subsequent SWB.

Longitudinal analysis of this theme suggested that participants were more likely to spend time resting on a daily basis at interview one. This is most likely a result of the fact that they were undergoing both radiotherapy and chemotherapy at this point, which is both physically tiring and extremely time consuming. By the time of interview two, participants were more likely to have the time and energy for other activities such as exercising and going to art galleries and cinemas.

#### **6.2.8 Daily life theme 4: Financial impact**

Those participants who were on paid sick leave from work, clearly found it to be a great relief:

*Because I am still getting paid... that takes the additional pressure off ... not having to worry about finances, so that's a great help ... (Kath, I1)*

However, a number of the participants felt that financial issues incurred as a result of their diagnosis and treatment were having a significant impact on their SWB. There was noticeable concern that having cancer didn't stop bills needing to be paid, and that this was causing significant anxiety for patients and their families. Being able to provide financial stability was a key role for some participants, and was an essential aspect of their SWB. No longer being able to offer this threatened their sense of identity and jeopardised their feelings of control over their situation.

*The biggest bugbear is financial things. (Bill, I2)*

*INT: And your husband, does he go with you [to Romania] or he stays here?*

*Maria: No he stays here because he's working for us. We need the money'. (Maria, I2)*

Yulia appeared to be particularly concerned by financial issues. She had 3 small children and was working as a teacher at the time of diagnosis.

*I need to sort out my life because was taken mortgage with my husband with both of us on both salaries and then I have big change because twins were born so family suddenly expanded ... and then now I understand I won't be able to keep on working as I used to do...I would like to ... sort it out properly but nobody gives me clear answers at the moment, this is something that I really want to sort out...It is stressful, it is stressful for him and I feel our family is not protected, because I need to understand what benefits apply to me and which are not ... and we need to kind of sort it out because mortgage is every month...(Yulia, 11)*

Both Yulia and Brian's wife Ann mentioned that they were aware that they were entitled to some benefits, but seemed confused about what these were, and where they could get help to understand how the benefits system worked. Such confusion negatively impacted on their SWB, as it limited their ability to retain a degree of control over their lives:

*we don't get a lot at the minute. Oh, well you get your personal dependence payment, don't you? And I get a carer's allowance... (Ann, 12)*

*I wish I had more help ... someone on my behalf to sort it out.(Yulia, 11)*

Yulia also mentioned that she had the necessary forms to claim the benefits, but that she was finding it difficult to get these filled in:

*I have to do it but it's quite, as I said difficult for me to find time to concentrate. This kind of work ... it has to be done, I think, together and I think it has to be done online and, there won't ever been time. Usually our day off is Sunday... but we don't have nanny on Sunday. And so [chuckles]... It's looking after twins. (Yulia, 12)*

Longitudinal analysis of the data revealed that discussion of financial issues was more prevalent in interviews conducted at the later stages of treatment. This may well have been related to the fact that by this point some

participants had experienced a significant negative impact on their income for a number of months.

### **6.2.9 Daily life sub-theme 5: self-help strategies**

Many participants were happy to discuss approaches that they had adopted to manage symptoms and side effects and preserve their SWB. This was a topic where the conversation generally flowed freely, and about which it seemed that people felt happy to talk about positive steps that they had taken independently to improve their quality of life. This may be a reflection of the fact that being able to make beneficial changes to their lifestyle portrayed a degree of autonomy, which in itself enhanced their SWB. Examples of this included undertaking exercise, and making changes to diet to control symptoms such as nausea and constipation.

*I was on a real high, all I'd done was little 50m repetitions and stopped and you know for about 20 minutes or something and I was high as a kite afterwards (Bill, I2)*

*I've learnt how to deal with the constipation...I'm managing to work around it just with diet...(Christopher, I2)*

Fatigue was a side effect experienced by a number of people, particularly during radiotherapy, but one that most participants felt they could manage themselves simply by resting more often:

*I'm living with it really. I get up later [chuckling] and go to bed earlier. (Brian, I2)*

*So just go and lie down for a couple of hours and it helps. If I am tired I will just go upstairs to have a lie down. (Liu, I1)*

When asked how they felt they could help themselves to preserve their own wellbeing, some participants mentioned the importance of staying positive. Although interestingly, there was often a sense that they were trying to be

positive as this was what other people had told them to do, or that they were putting on a display of positivity to protect their family and friends from anxiety.

*Everyone is telling me that it's better to be positive than to get depressed and cry and things like that, so I'm trying to be positive.  
(Maria, I1)*

*My outlook on all of this is just to stay positive. (Barbara, I1)*

Barbara felt strongly that retaining a sense of control over her daily life was essential to the preservation of her wellbeing. The following extract summarises quite strikingly what appeared to be the most important self-help strategy to the majority of participants-to retain a sense of control in life wherever possible.

*I am just getting on. I am doing the ironing, hoovering, washing, everything. It's very important to me. Because it is only thing I can control. I am happy and I am in control of something. I am not in control of the cancer but I am in control of something else....(Barbara, I1)*

There were some longitudinal changes of note within this theme. At the time of interview one, there was more discussion of 'keeping positive' as a coping strategy, perhaps as participants were still adjusting to the shock and reality of their diagnosis. By the time of interview two, it became clear that some people had developed self-help strategies as they had grown more accustomed to the treatment and its side effects. For example, management of issues such as nausea and constipation were well-established as participants had had time to decipher which strategies worked best for them.

#### **6.2.10 Psychological wellbeing sub-theme 1: The importance of normality**

Craving a return to normality was expressed by the majority of participants as something that they felt significantly impacted upon their SWB. It was

interesting to see that what mattered most to people once they had experienced the shock of a terminal diagnosis was the simple, everyday aspects of life which may have previously been unappreciated, but which suddenly felt so important, as Christopher suggested:

*Most people say "I don't want to be normal, I want to be extraordinary" ...But now all I want is to do things in a normal way. (Christopher, I2)*

This desire to continue life as it was prior to diagnosis appeared to be essential to the sense of identity and SWB of many of the participants:

*I just want to carry on as before. There's no reason why I shouldn't apart from when everyone starts asking about it. You don't want to keep telling the same story again and again. (Joan, I2)*

*I'd just like to keep things simple, and just normal really. As normal as possible. (Brian, I2)*

*Ever since day one I've just carried on as normal as I can...we tend to sort of like to be as normal as we can. (Liu, I1)*

One of the most frequent ways in which people felt 'normal' was in doing household tasks:

*I just want to go and buy some food from the shops, cook a meal and all that, just do as normal. (Joan, I1)*

*At home, I try and do everything as normal... whether it's cleaning or cooking or whatever I do. (Kath, I1)*

From an interpretative perspective, this ability to perform relatively simple jobs around the house seemed to represent a preservation of independence and control, which was incredibly beneficial to their overall SWB.

For Joan, the sense that her family could continue to rely on her and live their lives 'as normal' was vital for her SWB, both at the time and in the future, as she demonstrated in the following example:

*I think them going on and doing their own thing is important. I think it's just because they see me as normal. So my son was moaning today that he needed his suit because he's making a presentation and his suit ... it's in our house and couldn't you bring it to me in Cambridge? (Laughter) Obviously if he thought I was ill he wouldn't ask me in the first place.  
(Joan, I2)*

Three of the participants felt that the ever-present need to think about taking pills had a detrimental impact on their ability to feel normal:

*It may be impossible to get back to where I was or normality, but looking towards doing more normal things without working around pills. (Bill, I1)*

*I don't want to be beholden to drugs. (Brian, I2)*

Having to think about taking tablets regularly was a new experience for many people, and seemed to cause resentment and a negative impact on SWB to those who had always felt that they had enjoyed good health.

Longitudinal analysis of this theme suggested that there was evidence of a return to what many felt was 'more normal' by the time of interview two. This appeared to result in a significant boost to SWB:

*I'm sort of getting back to normal now ... I'm almost back to doing normal things, that's what I think anyway. (Brian, I2)*

As with Joan and Kath, to Brian and his wife normality was represented by Brian's ability to do more around the house:

*I know this is stupid, but he went round and cleaned out all the plugholes... Because that's what he always used to do. He used to clean the plugholes out for me and he did it the other day... and it feels like normal... (Ann, I2)*

Christopher felt that the completion of the radiotherapy phase of his treatment had been a milestone in terms of his sense of normality and independence, and that he had felt an improvement in his SWB:

*Now that I'm in the second phase as it were which is just the chemo stage without any radiotherapy, I feel like ... a bit more normal. What's the word normal mean, but I feel I can try and do other things. I feel I can do more things myself more easily and well...I feel that I've got my independence back a bit now. And with my bags for example, I'm like no, please don't carry that, I want to carry it. (Christopher, I2)*

This is not surprising, as the burden of the intensive daily radiotherapy schedule did not allow time for participation in many other activities that may have been important to SWB. This improvement at interview two may also have been a result of the reduction in symptoms associated with radiotherapy treatment such as fatigue.

It is important to highlight some variation in how participants viewed their potential to return to normality. Kath felt that she had accepted the fact that her life was unlikely to ever return to normal:

*Sometimes I think I should get more rest, but then again I think I also want to have my life back to normal. Even though it will never be back to normal ... (Kath, I1)*

On the contrary, Yulia had found that once she was no longer attending hospital regularly she was '*leading a kind of normal life*' (I3). This comment was made by Yulia in her third interview, by which time she was no longer having any kind of treatment and was only attending hospital on a 3 monthly



basis for check ups. Unfortunately, Yulia was the only participant who managed a third interview. It would certainly be interesting to explore in more detail the experiences of those who enter a phase of stable disease without active treatment to see if this is a common theme.

### **6.2.11 Psychological wellbeing sub-theme 2: Facing mortality**

The severity of HGG led to many participants confronting their own mortality. Some expressed how this had made them fearful, but that they did not necessarily want to discuss their feelings on the matter in more detail. It became apparent that living with such uncertainty could be extremely damaging to SWB.

*I think there's just something there all the time, you know? Worries about the future. But not always discussing those worries. (Tom, I1)*

*With my son and my daughter, we've had little conversations where we'd just been creeping round the subject a little bit. I suppose the mention of mortality and, I think crikey... I suppose for a lot of people, I imagine that the impending mortality... I don't know, sometimes I think I've come to terms with that, I don't really know if I have or not. (Bill, I2)*

Some highly emotive language was used during discussions of mortality and facing an unpredictable future with the disease, which reflected the heavy burden that this placed on the SWB of participants:

*It's like a death sentence on you and you have to prepare for it. (Joan, I2)*

*He has to face the unknown. (Len's wife Sam, I2)*

It was clear that the realisation of the fragility of life placed a great emotional burden on a number of participants and their families, and that they faced a conflict between wanting to have more certainty about how their health might be in the future, and wishing to avoid too many unpleasant truths.

*There is something that nobody can tell me... you know how is it going to continue ... I think all of the information is there, it's just for me to actually go and get it. (Kath, I1)*

*How much time do I have left ... are things going to get worse, and how are they going to get worse. Usually if you want to find out something you do research ... online or whatever ... at the moment I'm extremely trying to avoid this kind of research because I don't want to even know what's going to ...But at the same time I'm thinking what do I need to do ... (Yulia, I1)*

Both Bill and Mateo mentioned that they had found the best way of maintaining their SWB and coping psychologically with this uncertainty was to limit plans to the short term.

*To be honest, for me it's very hard to make plans. I am debating between making plans and whatever happens will happen. I don't know if it's good for me to think, okay, you know, I'll go back, or if it's better for me to say okay, you'll never maybe go back to Uruguay. I really don't know what is the best way for me to cope. So, now I think I'm allowing myself to make plans until Christmas. (Mateo, I1)*

*I think we've always known you know what the possible consequences of this is. We've never asked anybody because no one can give us a probability, sort of time tables of this stuff, I know roughly what they are and that is probably all I need to know. And I will take each step as it comes. (Bill, I2)*

Joan mentioned a couple of incidents that had led her to confront her mortality in a raw and painful way. The first had been when she had been talking to her husband about whether or not to claim on her life insurance policy. As she stated 'you can only cash it if you've only got a year, so that's all pretty cold hearted.' She also revealed how activities that were meant to be

for relaxation such as watching the television and going to the opera could also lead to unexpected distress.

*All of a sudden there's things you're watching that you see in a different light. Anything with people dying in it. And even on television I hate it. People dying ... people are dying all the time. (Joan, I1)*

In interview two, Joan talked extensively about her mortality and the impact that this had on her and her family. It was clear that Joan's terminal diagnosis had unsurprisingly had an enormous effect on her SWB. The conversation was heavily focused on her husband and children, her despair at not seeing her children grow up, and her anxieties around how they would cope when she was no longer there. In an attempt to manage her grief, Joan had taken a highly practical approach to preparing her family for her death. The following extract is striking in the way that Joan talks about arranging routine matters at home:

*He took a day off work and I went round the house pointing at everything, where the baby box is, because he'll like to look and see these things. I wanted all the photographs put online. I wanted them all organised in a time frame and he did all that. And then I told him all the things that they liked and didn't like, you know, where I stored the Christmas decorations... I even cleaned out the basement, I cleared the whole house for him...I'd always meant to tile the bathroom and I've got that done. I had the decorator in and I even had a gardener in so that everything is nice and ready so that he won't have to do anything. And everything will be easy to find and he doesn't have to look for things and get frustrated and not know where anything is. And everything ... touch wood, everything is done. The bathroom's done, the hallway's done, so is the garden, so there will be nothing left for him to do. I've chosen 16 photographs and put them in a frame. Because I wanted them to remember all the happy times that we've had. And that's about it really. I don't see there's anything there he can't handle. Apart from being really sad, there's nothing I can do about him being sad...(Joan, I2)*

Joan had focused on the details of everyday life in an attempt to make life as easy as possible for her family once she was gone. It was clear that to Joan, her role as a wife and mother were of fundamental importance to her SWB even when faced with her own mortality. From an interpretative perspective, it was apparent that taking care of her family was one way in which she could retain both some control over her situation and her sense of identity as a mother, both of which were fundamental to her SWB. It was only at the very end of this quotation that Joan mentioned the sadness that her husband might feel when she died as the one thing that she could not control or plan for. As she wisely summarised *'It's like you know, you have a birth plan for your children? It's almost like you're drawing up a death plan, so you're trying to sort out everything for when you're not here'* (I2).

Joan discussed wondering about whether to write a letter for her children to read after she died, but didn't seem sure about this idea *'I mean what do you write?'* (I2) Bill had also considered this idea, but wasn't sure how helpful it would be:

*Sometimes I wonder, should I write them a letter...you know how good it's been. Don't know if it would help them or not. (Bill, I2)*

It was interesting to see that both Joan and Bill were interested in the idea of writing letters for their children to read after they had gone, but neither were certain how useful it would be and what the letter should include. This suggests that either they thought this was a customary action rather than something they genuinely thought would be beneficial, or that they would have appreciated some help with writing a letter, but were not sure who to ask for such advice.

The suggestion that health professionals avoided difficult conversations around mortality was implied by the experiences of most participants. Bill insinuated that he would have appreciated more honest discussions about his emotional response to his prognosis with his medical team:

*You are the first person that has asked about some of those things that I'd rather not talk about for obvious reasons. And yet I know how important it is. But I can't be taking up everybody's time with all this stuff. (Bill, I2)*

It was interesting to see that Bill did not feel that his SWB, and in particular his feelings about his prognosis, were important enough for health professionals to spend time discussing. It was almost as if he did not see this to be part of the care he could expect.

Yulia also felt that she was struggling to get answers to difficult questions:

*Sometimes I look at my babies and I really want to see them married ... Am I going to live so long? ...I wish I could talk to someone who is really experienced to explain to me this ... people are afraid of taking responsibility ... but I would like to get an understanding of what's ahead...(Yulia, I1)*

On a more optimistic note, some participants did suggest that facing their own mortality had had a positive impact on their SWB in the sense that it had led them to appreciate life more:

*I think I see each day differently now ... simply because I have got limited time. I am almost more interested in going out now. I appreciate things more and I see things in a different light almost. (Kath, I1)*

*You know this is really about appreciating every day, living in the moment and so that's a positive shift in some ways. (Tom, I1)*

Longitudinal analysis of this theme revealed that participants were more likely to discuss the impact of facing their mortality on their SWB in interview two. This is possibly a result of duration of time spent living with the disease at this stage, and consequently the amount of time spent reflecting on their prognosis. It may also have been a result of the fact that

the participant-researcher relationship was better established by this stage, thus making sensitive conversations more likely to occur.

### **6.2.12 Psychological wellbeing sub-theme 3: Meaning of wellbeing**

Some of the participants felt they had experienced a change in perception of what wellbeing meant to them since their diagnosis. As they had re-evaluated what was important to them in life, certain domains no longer seemed significant. Bill summarised the meaning of wellbeing to him and how this had altered in interview one:

*If you like the three pillars are the family, the exercise and the work. And they are all important parts and they are almost ever-present pillars. Except the work one has shifted a bit for now. And the exercise one too. (Bill, I1)*

Joan had also decided that 'being healthy' was no longer a priority for her:

*I'm not particularly bothered about being healthy at a time like this. That seems pretty trivial. (Joan, I2)*

It is interesting to consider what Joan meant by the term 'healthy'. It appeared that she considered it to be concerned with lifestyle aspects such as diet and exercise rather than the impact of her HGG. This was a sentiment echoed by other participants, who often related wellbeing to health in terms of pursuits such as exercise, rest and 'taking care of oneself'. For example, Kath stated that she had felt motivated to place a greater emphasis on her wellbeing since her diagnosis:

*For the first time I really feel I want to look after myself. But before I often did too much. Exhausted myself. And now is the time I have to look after myself ... (Kath, I1)*

She explained that she had experienced an 'increased awareness of the body', and had found participating in yoga 'quite beneficial' (I1).

Indeed, exercise was mentioned by a number of participants as a key component of their SWB:

*We have a river two minutes walk away, ... I just walk. I walk for a good four, five miles. I don't think about anything. I just like to be out in the fresh air. (Barry, I1)*

*I want to keep healthy. And be fairly fit, I don't mean going down the gym you know and get a six pack every week or anything like that ... I'm going to try to see if I can start to cycle ... and maybe just start to run a little bit now, rather than just walking. (Christopher, I2)*

Bill offered an insight into a perhaps more surprising benefit of doing exercise since he had been diagnosed with a HGG.

*I try to get out for a walk and things like that... And I think one of the benefits of it is feeling ones got a little bit of control over one's life. (Bill, I1)*

It was interesting to hear that not only did he feel a physical benefit from exercise, but also the fact that this was one domain of his life that he could still control gave him a psychological boost. This may perhaps explain why so many participants felt a benefit to their SWB when they incorporated exercise into their daily routine.

A number of participants discussed how important they felt 'the small things' were to their SWB, with repeated mention being made of the desire to keep things 'simple'.

*We live a simple life really...We're happy. (Brian, I1)*

*I want to simplify my life. (Yulia, I2)*

Conversely, when the ability to do things that they had previously found to be simple was taken from them, participants felt that this had a negative impact on their sense of independence and SWB. This led to feelings of redundancy and uselessness, as Tom explained:

*Not being able to drive means I can't do the small jobs to help, you know sometimes like just being able to do something like drive down and pick up something or whatever would just take the onus off my wife. (Tom, 11)*

Longitudinal analysis of this theme revealed that the meaning of wellbeing to participants was consistent regardless of what stage of their treatment participants were at. However, by the time of interview two there was a noticeable increase in the number of people reporting that they were able to partake in activities such as exercise and socialising, and that this had improved their sense of SWB. Terms such as 'happier', 'better' and 'more normal' were frequently used to describe how people felt at interview two as opposed to interview one. Again, this was most probably related to the fact that radiotherapy had been completed by this point, thus participants were likely to have experienced an increase in energy levels and more free time to pursue leisure activities.

#### **6.2.13 Psychological Wellbeing sub-theme 4: The importance of goal setting**

Many of the participants discussed the importance to their SWB of setting themselves goals for the future, and how their approach to this had altered since their diagnosis. For some, continuing to look to the future was integral to their ability to cope. Barbara revealed that focusing on her childrens' futures helped her to remain positive. She also felt that this determination not to 'give up' was fundamental to her survival:

*If you give up then you've already got one foot in the grave. There's so much I have got, my daughter is in university in September, you know*



*my son is going to be a teenager in July, my older son is going to be 26 at the end of this month. I've got so much to look forward to. (Barbara, I1)*

Bill was also looking forward to the future, and was considering setting himself the target of undertaking a charitable triathlon. This objective not only gave him a positive aim to focus on, but also offered him the opportunity to regain his fitness, which had been important to his sense of identity prior to his diagnosis. The idea of taking on a challenge for charity also appealed for its potential to do something altruistic, which he had not done before:

*I did have a thought that when all this finishes I might find a triathlon. I would do it for the brain tumour charity. I thought it would be an objective, it would be for things that I believed in and I've never done it. Sort of, it's about setting objectives, moving towards something instead of this trickling all the time. (Bill, I2)*

Despite these examples of the positive effect of looking to the future, it was clear that a number of the participants felt that limiting any aspirations to the short term was the best way to preserve their SWB. It seemed that for many looking too far ahead was a rather daunting and scary prospect:

*I've stopped daydreaming. You know when you kind of dream of something that will happen in 10 or 20 years, but sometimes you just stop yourself from doing this because of the tumour developing. (Yulia, I3)*

*As a coping strategy I have taken the view that we are not going to think too far ahead. (Bill, I2)*

Their HGG diagnosis had led to some participants re-evaluating their goals, and there was frequent mention of how people hoped to spend their time in the future. These generally revolved around working less and enjoying life more:

*My wife and I were thinking with our business that we would start to have a life that is a bit easier and I hope that can happen and I can have that. That is more important than work... I think to try and do things that you really enjoy doing like a holiday or going to see exhibitions that you like. (Christopher, I1)*

*I would like to do all these things that I have actually neglected, going to the Tate looking at art ... taking my camera, going out to take photos... all these things which I want to do, if I get the chance ...(Kath, I1)*

Longitudinal analysis of this theme did not suggest any patterns associated to specific time points. Instead, it appeared that the approach taken to setting goals and having hopes for the future varied amongst individuals. Some participants felt looking forward to future aims was crucial, not only to their SWB, but also to their survival, whereas others found thinking beyond the next week or two extremely daunting. It is therefore vital to remember that personal goal setting is both highly individual and fundamentally important to the SWB of people with HGG.

#### **6.2.14 Psychological wellbeing sub-theme 5: Terminal prognosis**

Unsurprisingly, many of the participants revealed that the terminal nature of their prognosis had a negative impact on their SWB. Joan was particularly honest about this and was clearly significantly affected by the shock of being diagnosed with HGG. She discussed how overwhelming it all felt and how she now struggled to enjoy life. This was an issue she discussed at both of her interviews:

*I mean the experience has been the absolute worst, it's the worst thing in the world. My focus is just on this all the time...the whole thing's just so sad. (Joan, I1)*

*It sucks the joy...Every day, you know, there's no joy in your life. But beforehand there was masses really. (Joan, I2)*

There was also discussion with some of the participants about the impact on their SWB of not only having cancer, but having a type of cancer which has such a poor prognosis. They found this particularly problematic to talk to people about, as the severity was so difficult to convey.

*I just think everyone is thinking oh you poor thing. It's a grade 4, oh my god, does that mean you are going to die? (Barbara, I1)*

*I have this feeling that anything to do with medical, it goes wrong for me. So okay have a tumour but didn't have to be the worse tumour ever? (Mateo, I1)*

Joan talked about the impact it had on her when people tried to encourage her to think positively, particularly when they conveyed positive stories from others, but which Joan knew were not relevant to her:

*My friend had an acoustic neuroma and it was curable because they removed it... so for him when he was speaking to me, it was clear the worse thing or what he thought that I was anxious about was the neurosurgery and he was saying how great it was and how well you were after three days...but mine was never curable by surgery. (Joan, I1)*

*There was a school teacher that I was talking to said you can grit your teeth ... get on with it and there's light at the end of the tunnel but for me I don't think there is going to be any light at the end of the tunnel. (Joan, I2)*

Both Bill and Joan said that they had found the psychological impact on their SWB of being diagnosed to be far greater than the physical aspect of their disease. They were both finding it extremely distressing to come to terms with the fact he had a terminal cancer, and the feelings of hopelessness that this had led to:

*Actually the psychological side is extremely difficult. I would say that's the bit I've found most, actually it is the mental side of the last couple of months, since about April I remember it really kicking in and really sort of struggling to get around this. (Bill, I2)*

Joan had also been affected by the realisation that the doctors could not continue to offer her new treatment options, which again had resulted in her experiencing loss of hope for the future and a subsequent damaging impact on her SWB:

*I think the thing that the doctors are hoping for is there's nothing that hasn't grown or hasn't changed. And that's a bit disappointing.... But what happens next? And I said to the doctor what happens and I remember him saying well nothing, we just do it all over again. (Joan, I2)*

Three participants talked about how they felt they must put on a brave face to 'deal with' their HGG. It was interesting to note that all three of these participants were mothers, who felt the need to protect their children by 'staying strong'.

*Yes I'm trying because everyone is telling me that it's better to be positive than to get depressed and cry and things like that so I'm trying to be positive. (Maria, I1)*

*I have had, in the last few days, a bit of a, not meltdown, that's not the right word, had a bit of a cry....but I just need to stay strong.....(Barbara, I1)*

*I just wish I could stop crying because I cry every day. I wait until I get them off to school and then xxx goes to work and it's the only time I have so I can go on the internet, and I can find questions, you know, I want answers to, you know, things with the stats and all the rest of it which*

*are awful. But that's the only time I could do it really, I can't do it in front of them...It's pretty exhausting...(Joan, I2)*

Both Christopher and Len felt that their SWB had been detrimentally affected by the feeling of loss of control and independence that resulted from their HGG. They both struggled with how they had gone from dictating their own lives, and in particular their businesses, and their futures were now controlled by their cancer and treatment, and this had severely affected their sense of identity:

*I am the sort of person with the sort of job I had before, I am very much in control of other people and very much in control of my life and my work and what I do, so suddenly all that control has gone. I am in the control of specialists...It is really hard to cope with that; I found it quite difficult to ... to accept that I have got to run with things and that actually you don't understand how these things are going to go... (Christopher, I1)*

*He is not happy with his life because he is not doing what he used to do; he can't drive, he can't run his business. He says that he has gone from a man to being a child now. Where he has always been in control of his life and now it has been taken away from him. He hasn't got no control. The tumour has got control of our life basically you know. (Len's wife Sam, I1)*

Longitudinal analysis of this theme suggested that there was a substantial negative impact on SWB resulting from their diagnosis throughout both interviews. There was more discussion of it at interview two, however this may have been a result of the researcher-participant relationship being better established by this point. It did appear that there was a tendency to refer more to the shock of the diagnosis at interview one, whereas in interview two conversations were more focused on the realisation that they were unlikely to return to normal health and an awareness of their mortality.

### **6.2.15 Psychological wellbeing sub-theme 6: Re-evaluating what's important**

It appeared that many of the participants had experienced a sense of realisation that there were elements of their life they wished to change having been faced with a terminal diagnosis. This often correlated to a reflection on how they had spent their lives previously, and an awareness that they had worried unnecessarily about things that no longer seemed important now that they knew their lives were finite.

*Before you'd be worried about work and ...but now I just take it day by day and that's it ... there are things in life that bother you ...they don't bother me now ... brings everything home to you ...(Michael, I1)*

Many participants commented that they had felt this to be a positive change. For example, Kath stated that she felt that her SWB had improved in some ways since her diagnosis:

*I appreciate things more, and I cannot understand why I couldn't see it before... I have neglected hobbies, I have neglected lots of things because there was never time ... in some ways I am actually in a better place than I was before, which sounds strange because I have this diagnosis. But at the same time it's waking up in the morning and actually looking forward to a day ... even though it involves coming here... (Kath, I1)*

It was surprising to hear Kath speak so positively about the impact her diagnosis had on her life. Not only in terms of her outlook, but also more generally in the sense that she felt her SWB had improved as a consequence of how she now spent her time. This positivity was consistently present at both interviews one and two.

Christopher also spoke optimistically of how he felt his HGG had improved him as a person, and how his more altruistic approach had contributed positively to his SWB. He reflected on the fact that his career had largely been driven not only by money, but also by his own creative outputs. He had been

struck by the realisation that people who worked in the caring professions were driven by different goals, and was determined to behave in a less self-centred way in the future, as the following extract demonstrates:

*I feel that I have probably been a bit mean, selfish...to the point that I would walk along the street and if somebody was begging I would never put money in their cap and I would almost scowl at them. I now put things in the cap. I feel that people are probably more important ... sorry, very important and I was the sort of person that never quite saw that. Now I have found that the nurses I have had in the hospital...I can't believe what these people are doing for probably not much money...they are doing a fantastic job!. It has made me feel that I need to be a better person. That is really a positive change. (Christopher, I2)*

In a similar way, there was mention by some of the participants that their diagnosis had led them to reflect on the superficiality of their prior concerns, and how insignificant these seemed to them now:

*I just think the things that people worry about are so trivial. I was probably like that beforehand as well. You know, it's North London, everyone's worried about house prices and schools... and that's fair enough. But some things I hear people concerned about and I just think 'that's nothing compared to having a brain tumour'. (Joan, I2)*

*I used to go to lots of balls and special occasions, but for me probably it is too superficial now. (Yulia, I3)*

One of the aspects of life which people repeatedly mentioned as being of upmost importance to their SWB was spending more time with family:

*I'm thinking more to stay with my family and not work too much because before I used to work long hours. But now I just want to stay with my family and enjoy more of life. Because I realise it's very short. (Maria, I1)*

*I want to do more things which I always put aside, like see my parents more often ... Spending more time with the children ... enjoying life...(Yulia, I1)*

Related to this realisation that the most important thing in their lives was family, was also an expression of regret about how much time they had devoted to working. Mateo seemed particularly bitter about this newly found awareness that he had not been happy at work, particularly as it had only resulted from his life-limiting diagnosis:

*I see it now and I want to go back to life and work, but not that life, not that work. Working like that for years and years and I think this is unfortunately the first time I've had time to just look and see the rubbish life I was having really. Well I have my son, he's not rubbish. But the poor quality of life...being on my own all the time...working, working, working...(Mateo, I1)*

Three of the participants discussed their hopes to take their careers in a new direction should they be well enough to do so. Having such hopes for the future appeared to have a positive impact on their SWB. Both Kath and Reena had decided that they would like to take on more charitable roles. Kath felt that she would like to do more voluntary work, and Reena had been inspired by the healthcare professionals who she had interacted with:

*It has made me think is this actually really what I want?... and now I don't have that much time left but if I am well enough to actually do some work I would like to do something different. (Kath, I1)*

*Being in the hospital, it's amazing to see the people and you think, wow. I wish I could be there. I want to study ... I want to do some science study. (Reena, I1)*

Christopher felt that his diagnosis and awareness of his own mortality had intensified his determination to change his work focus to more creative and



fulfilling pursuits. This was something that he had always hoped for, but had never quite managed to achieve. His HGG had led him to realise that life was too short for such complacency.

*Before I was work focused...making money...now I want to do something that is of interest to me and not to bring finance in. I feel like we want to have a new start. I hope I can be well enough to do those things. I now want to change things to be something that is now more about myself and my wife. So it has created a massive change in our lives. It has changed our focus quite completely. (Christopher, I1)*

Unfortunately, it was not always easy for participants to make the changes that they had realised they wished to instigate. Yulia mentioned that she wished there was someone who could help her to re-focus her energy, as she was struggling to implement change on her own:

*I do ask myself every day, "what's important?" Then I notice I still do the same things ... I truly want to change...to spend more time with my family... this is something that I was missing for many years because of work. (Yulia, I2)*

Longitudinal analysis revealed that this desire to change lifestyles as a result of re-evaluating what was important to the SWB of participants was a consistent issue throughout both interviews. But, as Yulia highlighted, realising the need for change and actually implementing such change were different concepts, and were not necessarily something that she managed to achieve.

#### **6.2.16 Experiences of care sub-theme 1: Impact of treatment schedule**

It became clear during the interviews that the intensity of the treatment schedule during the combined chemotherapy and radiotherapy treatment phase had a significant impact on the SWB and daily life of the participants. For six weeks they attended for daily radiotherapy on weekdays. They had

weekly clinic appointments with the medical team and the CNS, saw the pharmacist who dispensed oral TMZ chemotherapy and also required regular blood tests. Participants discussed the burden of this schedule and likened it to a 'workload' and a 'full time job'.

*It's every day you know, we set an entire day by the radiology appointment because they are held at different times during the day. So an hour before it you have to take your chemo, and then half an hour before chemo you have to take the anti-sickness. So we have to factor that in as well. And then I am on the anti-epilepsy medicine, I have to take them at nine o'clock in the morning and nine o'clock in the evening, and then I have to take antibiotics as well on a Monday, a Wednesday and a Friday...(Joan, I1)*

*I'm actually so busy with the treatment ... you can hardly do anything ... (Yulia, I1)*

*Your life is full of the medication and the treatment and I think that can be not so good because it is all a bit worrying. Did I take the tablets, did I get this?...you just fill your life with the treatment. (Christopher, I1)*

There was frequent mention of the amount of time spent waiting around in hospital on treatment days, which led to feelings of frustration and loss of control of their time:

*It took up a lot of the day, sitting in there waiting for the treatment (Bill, I1)*

*The treatment was really quick, it's just hanging round. (Liu, I1)*

*I don't like Thursdays. Thursdays is so long, you know? You're waiting forever to see the doctor. And then another wait when you get medication. (Reena, I1)*

Some of the participants, discussed the need to be well-organised, and managed their schedule by keeping a calendar. For example, Barbara kept a diary, and Joan had found it useful to manage her treatment schedule with a colour-coded chart. This strategy appeared to help establish a sense of control over their daily lives, which was beneficial to their SWB:

*We draw up a whole week of this schedule every weekend ... it's all colour coded so I know which drugs I am taking, and when. So I carry it around with me. And that's my whole life is fitted into that slot. (Joan, I1)*

However, she found it stressful when delays occurred at the hospital, which was also experienced by a number of others

*So if they're running late for that appointment, then I would be late for neurology. So at first that was stressful. (Joan, I1)*

Some likened the treatment schedule to a working day, including a commute:

*I find that it's almost like going to work ... it's having to travel in everyday and it has become my new routine...(Kath, I1)*

Interestingly, Barry felt that he experienced benefits from coming to hospital for treatment in a similar way to those he used to appreciate going to work, in the sense that he enjoyed having structure to his routine and valued the opportunity for social interaction, which appeared to be important to his sense of identity and SWB.

*I know this is going to sound quite strange, but I feel very, I've got a routine now where I've got my timetable of events on a daily basis. For example today I know I've got to get up at 8 o'clock, I'm on the 9:25 train... I had, Doctor xxx for 11:15 ...so I could, in my head I think 'right you need to catch that train at so and so time' ... so, but I think structure...that was missing before. (Barry, I1)*

*Do you know what? I really enjoy coming up here. And catching up... I mean I was upstairs, a lady comes up to me ... She said, "I saw you over at ... when we had a really good conversation over at the radiotherapy." And I don't ... I'll be honest with you... I can't remember her because I talk to so many people. But, it was nice... And, um... See people and...Thing is I'm a people's person and I do like that. (Barry, I2)*

Longitudinal analysis of comments regarding the scheduling of treatment implied a significant improvement in SWB at interview two (once radiotherapy was completed) as participants had more time to spend on activities which enhanced their SWB such as exercise and spending time with family.

Many commented on the relief of finishing radiotherapy, and the liberation that they felt only needing to come to hospital once per treatment cycle and taking chemotherapy tablets for only 5 days every 4 weeks.

*Another great thing about it is you only do 5 days and then the next 23 you don't do anything. That's marvellous... that's fantastic. I don't have to do anything but take my pill that's it. (Joan, I2)*

Kath and Christopher both reported positively on no longer needing to attend for daily radiotherapy. This had given them the time to spend doing things that benefitted their sense of identity and helped them to regain some control over how they spent their time.

*I seem to have a bit more time outside of these hospital appointments, which is nice, concentrate on other things. (Kath, I2)*

*It's even easier than the other phase, so I feel ...much happier...because it's really one week with the drugs and then three weeks off ... So I feel like ... a bit more normal. What's the word normal mean? But I feel I can try and do other things. (Christopher, I2)*

### **6.2.17 Experiences of care sub-theme 2: Positive experiences of care**

There was a considerable praise for the hospital where participants were receiving their treatment. This positive feedback encompassed a wide variety of staff and systems, as well as an overall 'feel' of the service, but appeared to be particularly noticeable when people felt they had been kept well-informed of their disease and treatment:

*The people are very good, they explain it to you at every stage. So it doesn't make it scary. And also the way that the treatment gets scheduled, it's all sort of quite smoothly done. (Liu, I1)*

*Support here has been really good. I feel it's good to come here, it doesn't feel like a hospital as such. (Kath, I1)*

Michael expressed his gratitude for being treated as an individual:

*The hospital I can't really fault them you know, I think they do everything they can and they do make you feel as if you're a person rather than a number...(Michael, I1)*

There was a general impression that participants trusted those caring for them at the cancer centre, and that they placed a great deal of value on this trust and its positive impact on their SWB since diagnosis.

*I feel it all feels in control, I feel I'm confident with those treating me. (Christopher, I2)*

*There was the decision whether I could follow treatment in Spain or not. I decided to stay because I felt I was in very good hands. I couldn't think of any other place. (Mateo, I1)*

A few of the participants specifically mentioned having their phone calls returned, suggesting how important this specific display of trustworthy

behaviour is to participants and their families, and helped them to feel a degree of control over what was happening to them.

*It sounds so ridiculous but such a relief to have it, is when I phoned the phone number the lady who takes the call she does what she says she's going to do, always without fail, so she says she's going to phone you back, she phones you back. (Bill, I1)*

*There's always someone you know if you call, if I call them out with a question, or something I need to clarify, you know I always get a call back and you know, its followed up. (Kath, I2)*

Many of the participants spoke positively of the staff in the radiotherapy department, and appreciated the warm reception that they received there, which helped to lift their spirits:

*The people in radiography are really nice, they are very cheerful in their job. The radiographers are always like "what are you doing at the weekend?" The receptionists there are really nice as well. (Joan, I1)*

*I see people every day and they are administering the treatment and they are really lovely and they smile all the time. I can't believe it, I am sitting in the radiotherapy waiting area where you have all sorts of people with all sorts of conditions not just brain conditions and they seem so positive the radiotherapists. (Christopher, I1)*

There was a significant amount of acknowledgement and gratitude for the CNS. With many participants and their families expressing how crucial they had found her support to be in terms of managing the impact of the cancer diagnosis and treatment on their SWB. Having access to a knowledgeable professional who also knew them personally not only helped them to feel as though they were being treated as an individual, but also promoted a sense of control over their disease and treatment.

*The specialist nurses on that unit, again I speak most highly of...they have done things which you know I would almost have thought do I have a right to ask for and they've done them. That has been great, it's been great also for the family to be able to talk to somebody in common language, and say what does this mean or something. (Bill, I1)*

*We've got the CNS xxx she's really good. Every week she likes to see him. And she always says you know, "Ring if you need, if you need anything ring me". (Barry's wife Ann, I2)*

Christopher spoke at length about the importance of the CNS to him and his wife; even likening her to a family member, and emphasised how valuable he had found it to have someone to bridge the communication gap that may sometimes be felt between patients and Consultants. He also appreciated the supportive information that he could access from his CNS.

*I feel the nurse almost becomes part of the family or someone you like whereas the consultant always remains slightly on that higher level. I am not saying that they are unapproachable because you can talk to them but they are just that bit, not hard to talk to but... But having a clinical nurse assigned to you, I find that very, very good...what I tend to find myself doing is calling my clinical nurse...a few things I haven't been sure about I have called the clinical nurse about four times already within two and a half weeks...So I have actually used that service quite a lot. Getting access to the right people is quite important. The fact that you are assigned a clinical nurse and they would talk about all the things, emotional and medication and how your body is, I actually find that... really good. (Christopher, I1)*

Bill had been so impressed with the NHS that he had felt compelled to share his experiences with other industries in the hope that they might learn something about the benefits of personalised care.

*All the way through I've been very impressed with the professionalism and conscience of the people I've dealt with. All the way through it's been a good experience for me. (Bill, I1)*

The majority of positive feedback was focused on the specialist centre where the participants were being treated. However, Barry was also appreciative of the care that he had received from his local GP and Accident and Emergency department when he had been admitted between chemotherapy treatments with an infection.

*So I had to call my local surgery and they sent out a locum doctor, very, very good. She took my temperature. And it was ridiculously high. She said, "Look, [name] what I'm going to do, I am going to call an ambulance and whisk you off." So they whisked me off to my local A&E in xxx. They were excellent. (Barry, I2)*

Longitudinal analysis of this theme revealed that reference was made to positive experiences of care in both interviews, suggesting that participants and their families remained generally satisfied with the quality of the care that they received throughout their treatment. However, there was discussion of the impact of a reduction in the frequency of contact between interviews one and two, which will be presented in more detail in the 'suggestions for improvement' theme.

### **6.2.18 Experiences of care sub-theme 3: Negative experiences of care**

One area where a number of participants reported how negative experiences of their care had impacted on their SWB was communication with and amongst health professionals. Joan had particularly felt this to be an issue at the time of her diagnosis. She felt confused by how the multi-disciplinary team worked, and was disappointed by the way her case seemed to 'jump from one [doctor] to the other.'



*I didn't understand the multi-disciplinary team... I didn't know anyone on it, they didn't give me a list of people that was on it ...I wasn't referred to the neuro-oncologist who was on the multi-disciplinary team, and I felt that he or she would know my case best of all. (Joan, I1)*

Joan was initially told that her tumour was a less severe low-grade glioma. However this diagnosis was later changed to high grade. Joan was angry about the way that this was communicated to her. She felt that she was not warned of the potential for this significant change in her prognosis

*There's never any explanations about you know why they thought it was a low grade...or that there was a possibility it might be a high grade. So you know I think that was wrong. And you know they give you possible bad news for surgery but they didn't give me a possible bad outcome for diagnosis. (Joan, I1)*

Joan also expressed her frustration at the tendency for some staff to trust their computer systems over the patients themselves. This felt impersonal, and sometimes resulted in her feeling undervalued as an individual. As a result of this, her sense of identity and SWB were threatened:

*the communication between the xxx and xxx is just appalling. I mean they're slaves to the computer, 'oh you're not on the system'... It's always the computer. (Joan, I2)*

Tom offered an insight into a specific experience he had relating to exploring the option of clinical trials. He was clearly dissatisfied with the way in which he felt that this suggestion was dismissed by the medical staff. In the first incident he described, he had conducted research into internationally available trials for HGG. He had spoken to a doctor running a trial at a treatment centre in the USA, and was interested in participating. However, when he tried to talk to his medical team about his potential suitability he felt that he was 'brushed off'. This had led him to feel disrespected as an

individual and not in control of his own future, which was unsurprisingly damaging to his SWB.

*I tried to introduce it to the team here in terms of, you know, is this a possibility for me... and it was incredibly frustrating to even get a dialogue going. Ultimately, it turned into something I couldn't do because my tumour sample wasn't frozen. I was told you know, I was emailing Dr xxx, and Dr xxx wasn't replying. And I got the response back from his secretary that, oh, he's already talked to xxx about it, and I'd had no feedback on that so I was pretty angry at that. (Tom, I1)*

In Tom's second example he described his experience of a consultation in which he was hoping to have a discussion about clinical trials that might be available to him. He felt that once the doctor realised that his blood results would make him ineligible for a particular study, the dialogue came to a close. Unfortunately this again led him to feel that he was 'just a number' rather than a person, and it was clear that this interaction had been harmful to his sense of identity and SWB.

*I had a consultation with him then and I found that really, really frustrating. It was almost like he didn't want ... as soon as he realised the platelets were low... it was like he ... didn't even want to discuss it or explain it. It was like every question we were asking him was a real intrusion. It was a horrible, horrible consultation. And then followed on with this very blunt response around, the other trial...and then when you ask about these things... It's almost like, well, hang on...We can't be doing that. And what I wanted was a dialogue to say, "What do you think about this? You know is it something you recommend?" I felt that to be a failure in the system in some respect you know? (Tom, I1)*

A number of participants referred to the frequency and duration of waiting which had occurred on their appointment days, and the negative impact that this had on the experience of their care and their SWB in general.

*It's the sheer amount of time spent hanging round. You know this appointment was one of the first ones today, it was still getting on for an hour late. (Bill, I1)*

Tom had extensive experience of enduring long waits, as he had needed to come in on non-treatment days for blood tests to check his low platelet count. It seemed that, for Tom and others, waiting due to unforeseeable patient factors was tolerable, but delays caused by inefficient processes resulted in considerable frustration and a sense that they did not have control over how their time was spent.

*What I'd find was I'd come in and then a lot of the time I'd be asked to wait around, so that if the platelets dropped to a level where I'd need a transfusion. So I was advised to wait around but then getting the message back to me as to what the platelet level was and if I needed to come in or not...the system didn't seem to work. Because I would call the number, and they would be able to see on the computer that, yeah, the results are in...But they'd need a doctor to be able to look at it.. and tell me what the result was. That was really frustrating. The quality of my life actually was... affected because all I was doing was coming in for a blood test. The blood test would take two minutes. But there's five hours of my day gone. (Tom, I1)*

Some of the participants discussed negative experiences of their local hospitals, particularly at diagnosis

*I think probably the only thing I would say was actually getting them to listen in the first place at A&E ... I think they tried to send us away, it felt like they weren't listening. (Michael's wife Pat, I1)*

*Brian became really poorly, he had fluid on the brain...I went in to see him and I couldn't wake him up. One afternoon in bed, and he'd gone into a coma. And that's really what made us think, they're quite slow you know. (Brian's wife Ann, I1)*

Two of the participants also mentioned that they had not felt particularly well-supported by their GP

*You phone up and just leave details and then you know you just wait for somebody to get back to you, well we are still waiting...He was getting a cough, and I phoned up my doctor and said like, I need an appointment, oh it will be next Friday I said no, I said my husband is going through chemo, she said okay well I am going to have to try and fit him in then and you just think, yeah great..sort of thing. (Len's wife Sam, I2)*

Comments on this theme generally appeared to link to specific incidents which occurred at any time during treatment. These incidents varied considerably, although waiting times was most consistently mentioned when participants were attending the hospital on a daily basis. A reliable longitudinal pattern to negative experiences of care could not be identified.

#### **6.2.19 Experiences of care sub -theme 4: Monitoring Wellbeing**

A number of participants had been given questionnaires (either a Quality of Life survey or a Holistic Needs Assessment) as a means of monitoring their wellbeing. Maria said that she found this questionnaire useful, as they acted as a prompt for a later conversation with the CNS:

*I think there are things I want to know ... and later I speak with the nurse about it...and she let me know about everything. (Maria, I1)*

Yulia had found the experience of completing the questionnaire beneficial, as it had led her to reflect on how well she was managing, and realise that she did have issues to discuss which she otherwise might not have considered:

*It's interesting because I felt absolutely okay, I thought I am coping really well but when I was filling these questionnaires I understood I was somewhere in the middle, quite medium ... (Yulia, I1)*

A few of the participants had been given a questionnaire, but had not filled it in

*I think we are going to do that aren't we, we are going to do that. I haven't filled it out yet. xxx did give it to me. (Barbara, I1)*

*Um, I, xxx gave me one very early on actually, and to be honest I never filled it in so...(Tom, I1)*

Joan had completed the questionnaires, but suggested that she only did it because she liked the nurse rather than because she found it useful, and felt that it added to the burden of paperwork already given to her:

*I mean it's, you do so many of these things now so I just, if she wanted me to do it and she's so nice I would have done it. So normally it comes through the door and goes straight into the recycling. But you know, that's part of her job, I'll fill it in.*

Two of the participants offered interesting insights into how they felt when presented with the questions on the Holistic Needs Assessment:

*It had things like do you have anxiety? You know I don't know who has a brain tumour and isn't anxious. Some of them are a bit obvious. It's like, some are like, you know is it affecting your sex life or something? (Joan, I1)*

*There were certain factors within that questionnaire I thought why are you asking me this? It goes into like faith..religion...there was one question about, I seem to think are you currently sexually active or something and I'm thinking ... well why are you asking me that in a questionnaire? (Barry, I1)*

Len's wife Sam felt that the forms were useful, but that it was important for the carer to be involved in giving the answers to ensure that the responses were accurate

*I don't think [the patients] are truthful with the forms but the carer is, if that makes sense. A lot of the time he would tick no to everything; I am fine, I am fine. But the carer I think is the person that picks things up. I am with him 24/7 so I know. (Len's wife Sam, I1)*

She suggested that the forms were limited in their relevance in the sense that they only offered an insight into the SWB of the patient at the time they were filling in the form. Thus not allowing for variations on a day-to-day basis.

*If you gave him one of them forms today for him to fill in today, it would be okay but tomorrow could be another day do you know what I mean? (Len's wife Sam, I1)*

Sam also proposed that it would be more useful to do them at a number of intervals to show how things change over a period of time.

*When it comes to questionnaires answering one day I think it should be like across a period sort of thing...like if you had spoken to us at the beginning of the treatment when we first started in July his speech was much better, he was a bit more bouncing around if that makes sense? But now he has started to get to that peak of the tiredness and his speech gets a bit tied up you know? It varies you know? (Sam, I2)*

Tom supported the suggestion that monitoring needs to take into account how a person is feeling throughout their treatment, rather than just on how they are feeling the day they are in clinic, and proposed that encouraging people to make notes or write down questions between appointments would be more useful

*You know the trouble with face-to-face discussions is that you don't remember everything that you would've wanted to bring up so maybe if there was some sort of ... a sheet that you might want to make notes on as ... if you're coming to a clinic with some little headings. Kind of how is your... You know quality of life..just so you think about it beforehand so you just kind of make a note and then ... so it's not a questionnaire but it's a "oh yeah, I wouldn't mind speaking to them about that or as you go through the week you might want to write the odd thing down because I think the little things you probably just forget. (Tom, I1)*

Two of the participants mentioned that they felt that they were only really asked medical questions, and that discussions around their SWB sometimes felt brief and superficial. Such insights appeared to reinforce their perceptions that they were not being treated as individuals, and could therefore be potentially damaging to their sense of identity.

*The first thing Dr xxx always says is bloods okay, you know...Every so often with that, they say, you know, how are you doing, I say I'm fine. (Joan, I1)*

*I mean, everyone says, "How are you feeling?" [Chuckle] and, you know, and that's fine and I guess that's the opportunity if I'm, if I'm not feeling well to... But yeah, there's not a lot of... I don't think there's a lot of anything deeper than that... (Tom, I2)*

Some of the participants said that they preferred a conversation rather than a questionnaire, and felt that this was how their SWB was generally monitored.

*I have a clinical nurse on a Monday and she goes through things with me and it is the same person all the time and I am very happy with that. ...I tend to talk a lot anyway so I say things first. She has certain questions about what the drugs are doing, to see how I am feeling, but definitely about the wellbeing and how I am feeling emotionally and*

*how I am with life generally is sort of part of it. I feel pretty good with that. (Christopher, I1)*

*Much more useful to talk to someone than to fill the questionnaires. (Yulia, I1)*

*Questionnaires? I don't know. I mean... I would've thought that by the time I've sat and gone through 10, 15 questions on a questionnaire then the same questions could've just been asked face-to-face, I suppose. (Tom, I1)*

Longitudinal analysis suggested that discussions on the monitoring of SWB were more prevalent in interview one as opposed to later interviews. As with the surgery theme, this again could have been a result of the fact that asking questions around experiences of quality of life monitoring felt like a relatively 'safe' direction to take the interview at the point when the researcher-participant rapport was still being established. It may also be a reflection of the fact that Holistic Needs Assessments were most frequently conducted around the time of diagnosis, but were not necessarily repeated at later intervals.

#### **6.2.20 Experiences of care sub-theme 5: Suggestions for improvement**

A number of the participants proposed that increased availability of psychological support in the form of a counsellor or psychotherapist would help them to deal with the mental and emotional burden of their diagnosis, and consequently enhance their SWB:

*I did wonder if I had a psychotherapist at one point because the impact is, for me it was absolutely massive. (Joan, I1)*

*I think once someone is diagnosed with any form of cancer or a low-grade tumour, they should be saying "would you like counselling?"; it should be given to you straight off. Because it is a life changing thing,*



*even if it was a low grade tumour that we had starting off with, that was still a life changing experience for us. (Len's wife Sam, I1)*

Bill felt that he would appreciate the opportunity to find out more about psychological coping strategies that he could implement as a means of taking control of his psychological wellbeing:

*I would be kind of interested to talk to somebody who had some advice on some of those kind of mental games I can play to deal with this. Because obviously in the back of all of this is issues of mortality and all the rest of it. And so on, and I've kind of put those aside as far as I can. But maybe thinking about that at some point might be useful...I suppose in a way I was looking for coping strategies, you know just little tips to help straighten me out or whatever. (Bill, I1)*

Despite this suggestion that increased access to psychological support would be beneficial, it is important to note that, as with all elements of care, psychological care needs should be discussed on an individual basis. Not all participants felt that they would benefit from this. In fact, Christopher felt the offer of seeing a psychiatrist had a detrimental impact on his SWB, in the sense that it had led him to question his own psychological state.

*But seeing a Psychiatrist makes you feel like ... how bad am I? How stressed? (Christopher, I2)*

A particularly interesting insight to emerge at interview two was the common feeling that support from the hospital reduced once radiotherapy had finished and participants were no longer attending on a daily basis. This led to feelings of isolation, and the loss of reassurance, which had been so beneficial to their sense of control earlier on in the treatment pathway:

*I tell you what would, would be nice is like a personalised phone call every week or once a week. How's things xxx? You've not been in clinic, you're not due in clinic till next week, but how are things? (Barry, I2)*

*I guess if there was a suggestion at this stage, and I am conscious of resources, is why not a phone call to say how are you doing, or you know is anything going on...(Bill, I2)*

At two of the interviews, the advantages of connecting with others to share similar experiences were highlighted as a means of improving care for both participants and their families. Kath had attended an event for people with HGG provided by a brain tumour charity and had found it 'very useful, just hearing other people that had the same diagnosis... and also get ideas about alternative treatments' (I2). As an extension of this proposal, Barbara's daughter Kim emphasised that she had noticed a lack of support for the children of people with cancer, and felt that having the opportunity to communicate with others in the same position would be beneficial.

*I don't think like there's enough support for kids when their parent becomes ill. My mum is going through this, there's nothing wrong with me but, maybe it would be nice to talk, perhaps someone my age has parents in the same position. I tried to speak to xxx and she was like "oh we have talks" but that's for teenagers with cancer, not actually teenagers whose parents have cancer. (Barbara's daughter Kim, I1)*


Longitudinal analysis of comments relating to suggestions for improvement revealed that a comparable number of references were made to this theme throughout both interviews. However, at interview one these were mostly related to support at the time of diagnosis and reducing anxiety about starting treatment. At interview two, a number of participants suggested increased contact and support once radiotherapy had been completed. The potential benefit of professional psychological support was highlighted at both interviews, thus implying that participants felt that this would be a

positive addition to their care , and a means of preserving their SWB throughout their disease and treatment journey.

### **6.3 Prevalence of themes at each stage**

As can be seen in figure 6.2 below, the themes of diagnosis and surgery were more frequently discussed at interview one, and could be seen as 'epiphanies'. These were significant events, which were at the forefront of the minds of participants at this point, when the impact of diagnosis and surgery on their SWB was at it's most intense. The relevance of these then decreased as time passed and other issues became more pressing. By the time of interview two, participants were more likely to talk about the impact of financial issues on their SWB. This may well be linked to the fact that they had experienced financial pressures for some months' by this time. It must also be remembered that the increased prevalence of the diagnosis and surgery sub-themes may have been related to the fact that posing questions focused on these specific experiences had proven to be an effective way of encouraging dialogue in the early stages of the interviewer-participant relationship.

Indeed by the time of interview two it was noticeable that participants felt an increase in their confidence and ability to improve their SWB. As well as setting themselves aims to travel and exercise more, they experienced a boost to important aspects of their SWB such as their social lives, energy levels and self-image. They were also more likely to undertake activities such as gardening and household tasks, which they had felt were unachievable at the time of interview one. These were extremely positive changes for many of the participants, which heightened their sense of identity, hope and control over their lives, and were generally linked to the fact that they no longer needed to attend for daily radiotherapy.

	Interview one	Interview two/three
		
HEALTH	Diagnosis	
	Surgery	
		Symptoms of brain tumour
		Side effects of treatment
DAILY LIFE	Daily activities	
	Impact on family	
	Impact on social life and work	
		Financial impact
		Self-help strategies
PSYCHOLOGICAL WELLBEING		Importance of normality
		Facing mortality
	Meaning of wellbeing	
		Importance of goal setting
	Negative psychological impact of diagnosis	
EXPERIENCES OF CARE		Re-evaluating what's important
		Treatment schedule
	Positive experiences of care	
		Negative experiences of care
	Monitoring QoL	
	Suggestions for improvement	

**Figure 6.2: Longitudinal prevalence of theme**

## **6.4 Anomaly case**

It is important to highlight that not all participants experienced this improvement in SWB by the time of interview two. Joan reported that she felt worse at this stage, and was experiencing an increase in levels of nausea, fatigue and loss of appetite. It would be difficult and potentially unreliable to attempt to explain this anomaly. Possible associations may have included disease progression or changes in the dosage of chemotherapy, but these cannot be assumed with any degree of confidence.

As per Saldaña (2003), it was also important to consider which themes remained constant over time, as well as those that were more temporal in nature. In the case of this study, there were a number of issues that appeared to threaten SWB along the disease trajectory. These included symptoms of their brain tumour, the importance of normality and facing mortality.

## **6.5 Limitations of this longitudinal analysis**

At this point, it is important to highlight some specific limitations of the approach taken to longitudinal analysis of the data. Firstly, as data from interview three was limited to one participant, it was decided that this would be combined with data from interview two as a means of showing changes in the later stages of their treatment. It was felt that the limited nature of interview three data was insufficient on which to propose thematic changes. Although the individual experiences of this participant were of course still valuable in their own right, and therefore could not be entirely excluded.

A further limitation of this analysis arose from the approach of basing analysis on the number of interviews during which sub-themes were mentioned. This method was adopted as it was felt that it was the most reliable way of assessing which issues were most prevalent at different time points in such a large volume of data. However, it is important to remember that just because an issue was mentioned, it did not mean that this was when the impact was at its worst. For example, the sub-theme of 'impact of treatment schedule' was discussed consistently during both interviews, but it

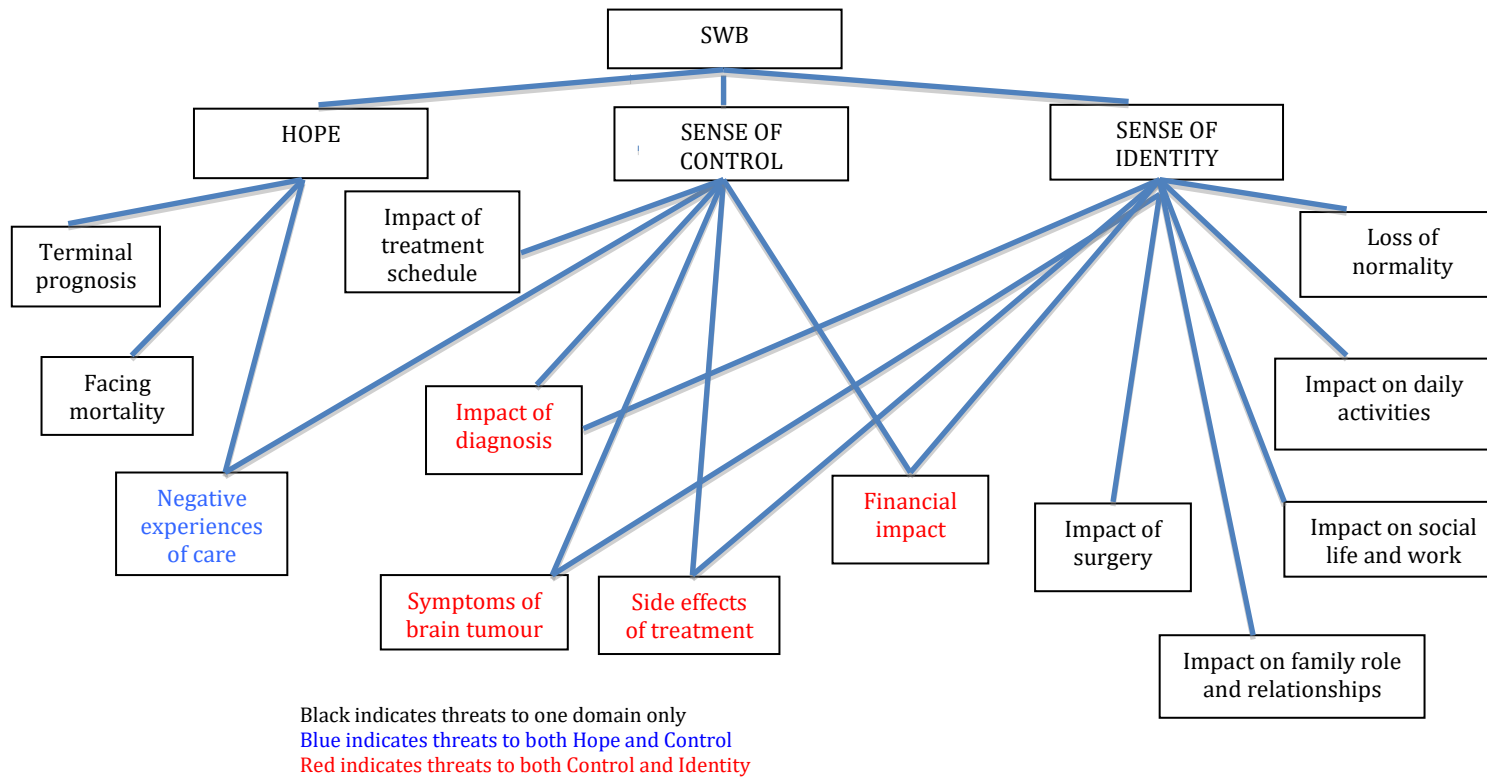
was often mentioned in a more positive way at interview two, as participants were referring to the fact that the impact of the treatment schedule on their SWB had lessened by this point. Fortunately, the analysis undertaken of data saved regarding changes at interview two on NVivo, as well as the detailed longitudinal analysis conducted within each sub-theme, allowed for detailed examination of the prevalence of sub-themes as a means of ensuring that findings were not misrepresented.

## **6.6 Significant relationships between sub-themes**

As could be seen from the mind map of themes earlier in this chapter, sub-themes did not occur in isolation from one another. There were numerous interrelationships in terms of the relevance of data to multiple themes, which could be seen in the coded data in NVivo as analysis progressed. Of particular note was the concentration of overlap between the 'psychological wellbeing' and 'health' themes. Both the 'family roles and relationships' and the 'impact on social life and work' sub-themes were linked to all of the sub-themes in the 'psychological wellbeing' domain, thus emphasising the fundamental importance of family, work and social life to SWB, and their close relationship to concepts such as the importance of normality, facing mortality and re-evaluating what's important.

## **6.7 The identification of three fundamental domains of SWB**

As the interpretive analysis of the findings progressed and immersion in the hermeneutic circle continued, it appeared that the identified themes generally and repeatedly took the form of 'threats' to three fundamental domains of SWB. These domains were 'Hope', 'Sense of Control' and 'Sense of Identity'. The nature of the threats posed to these domains of SWB fluctuated over time, but they were consistently relevant. The formation of this interpretive construction of the phenomenon of SWB from the perspective of the participants was a fundamental moment in the analysis and interpretation of the data, and is represented in Figure 6.3 below.



**Figure 6.3: Threats to proposed domains of SWB following diagnosis of HGG**

As can be seen in Figure 6.3, some sub-themes threatened more than one domain. For example, symptoms of their brain tumour had an impact on both Sense of Control and Sense of Identity. It is also important to highlight that there were a number of sub-themes associated with managing these threats to SWB. These included 'self-help strategies', 'positive experiences of care', 're-evaluating what's important' and 'the importance of goal-setting'.

## **6.8 Conclusion**

Interpretive analysis of the findings led to the identification of 20 sub-themes relating to the four main themes of health, psychological wellbeing, daily life and experiences of care. There were considerable interrelationships between many of the sub-themes. Continued immersion in the hermeneutic circle process of interpretative analysis identified that these sub-themes generally and repeatedly took the form of 'threats' to three fundamental domains of the SWB of people with HGG. These domains were 'Hope', 'Sense of Control' and 'Sense of Identity'. The nature of the threats posed to these domains of SWB fluctuated throughout the disease and treatment trajectory. In addition to the identified threats to the three domains of SWB, sub-themes were also identified which represented strategies for preserving SWB.

The following chapter will provide details on a literature review which was undertaken to explore the research question 'What is the impact on wellbeing/quality of life of a diagnosis of high grade glioma?' and the relationship of its outcomes to the findings of this study. The discussion chapter will follow the literature review.



## **Chapter 7: Literature Review**

## **7.1 Introduction**

A literature review was undertaken to explore the research question ‘What is the impact on wellbeing/quality of life of a diagnosis of high grade glioma?’ in order to provide up to date context for the study, and to allow exploration of how this research related to the evidence already available. The literature search was undertaken in January 2019, and it was interesting to note the increase in literature available on the subject compared to when a similar search of the literature was conducted for the concept analysis in May 2015. Conducting the literature search both at the time of the concept analysis and following the review of the findings promoted a thorough and up to date appraisal of available evidence in the field, and also allowed for a more focused analysis of how this study could address any knowledge gaps.

This chapter will begin by explaining in detail the approach taken to searching for literature, before proceeding to offer a scoping review of the quantitative data available concerning the impact of a HGG diagnosis on wellbeing/QoL. It will then discuss a review of the relevant qualitative literature and implications for this study.

## **7.2. Literature search process**

In the first instance, the databases CINAHL, MEDLINE, Embase, Web of Science and PsycINFO were chosen for offering a comprehensive selection of nursing and general health literature, as well as including the discipline of psychology as it was thought that this may offer further insight into research relating to wellbeing (see Table 7.1 for summary of database subject areas).

The Open Grey system ([www.opengrey.eu](http://www.opengrey.eu)) was searched for any relevant ‘grey literature’. Examples of grey literature include unpublished research reports, doctoral theses and official publications such as government reports. A search conducted on the Cochrane Library to identify any systematic reviews undertaken in the subject area produced 372 results. However, these were predominantly clinical drug trials, or were articles that had already been identified in the database search, and were therefore not included.

**Table 7.1: Summary of databases searched in the literature review**

<b>Database</b>	<b>Discipline/subject area</b>
CINAHL	American-based resource for nursing and allied health literature
Medline	All areas of medicine and professions allied to medicine
Embase	International collection of peer-reviewed journals covering all aspects of biomedicine
Web of Science	International literature in the sciences, social sciences, arts, and humanities.
PsycINFO	Psychological literature from 49 countries

(Aveyard, 2010; Jesson et. al, 2011)

The PROSPERO register of prospective systematic reviews was searched. This revealed one systematic review currently underway reporting on the impact of a brain tumour on self-reported quality of life. However, the population for this study was children rather than adults and it was therefore excluded on the grounds of limited relevance to the review question (Bell et. al, 2018). Next, prominent brain tumour charity websites were searched for any pertinent research projects. Finally, an academic library search was undertaken for any significant books.

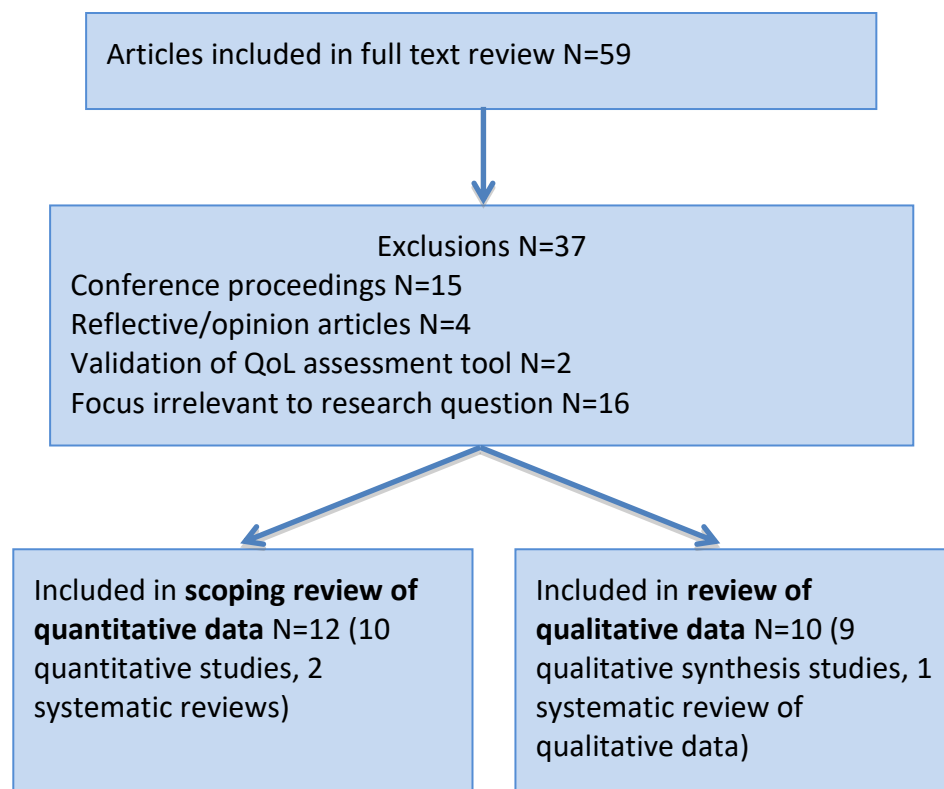
Keywords were used consistently across the databases as a means of conducting as thorough and reliable a search as possible (Jesson et. al, 2011). The Boolean operators AND/OR were implemented wherever databases allowed, as were wild card and truncation techniques. The wild card technique involves using a '?' to identify all potential spellings of a word. The truncation technique of affixing '\*' to the end of a term enables identification of all possible endings of a word (Aveyard, 2010). Limitations on date of publication were not applied as it was felt that this might exclude seminal works on the topic (Aveyard, 2010). Inclusion criteria were 'adults aged 18 and over' as this was the relevant population for the study.

Initial keyword search terms used were: (wellbeing OR “quality of life”) AND (brain tumour OR Glioma OR Glioblastoma). MeSH terms were used in MEDLINE, Web of Science and the Cochrane Library searches (although these were not available for wellbeing). Quality of Life was added as a search term in addition to wellbeing as only one article could be found to contain the terms wellbeing and glioma, and as was previously acknowledged in the concept analysis chapter, there is considerable overlap in the use of the terms ‘wellbeing’ and ‘quality of life’ in the field of healthcare. Once duplications had been removed, the total count of relevant articles retrieved by the database searches for journal articles was 629. At this stage, titles were reviewed for their relevance to the subject matter and any irrelevant articles were removed. Exclusion criteria included a sole focus on carers rather than patients, survivors of childhood cancers, emphasis on the end-of-life stage and brain tumour types other than high-grade gliomas (HGG). Reference and citation lists were also reviewed for any potentially relevant material. Following this review step, 153 articles remained. These were stored on RefWorks Version 2.0 online reference management software. This allowed for easier access and organised storage of the collected literature. A summary of the literature search process can be seen in Table 7.2 below:

**Table 7.2: Summary of literature search process**

Source	Initial yield	Included after title review	Included after abstract review
Bibliographic databases (inc. reference and citation searching)	629	153	59
Open Grey	9	0	0
Cochrane Library	372	1	0
PROSPERO register	17	1	0
Library search for books	5	3	0
Brain tumour research/charity websites	2	2	0

Following a review of journal article abstracts, a further 94 were removed for either being irrelevant to the study or previously unidentified duplicates. Articles focused on the development and validation of quality of life questionnaires and clinical trials documenting QoL outcomes following specific medical interventions were excluded as they did not explore the patient perception and experience of factors influencing their wellbeing and/or QoL. This resulted in a total of 59 journal articles being identified for full text review. The outcome of this review is shown in Figure 7.1. At this stage, articles such as conference proceedings and opinion articles were excluded on the basis that they did not provide enough detail to assess their methodological integrity. Hard copy books and grey literature evidence (which included publications from the National Institute for Health and Care Excellence and a brain tumour charity) were reviewed and subsequently excluded for having too broad a scope.



**Figure 7.1: Outcome of full text review**

Twelve papers were identified that used quantitative research methods, which offered a useful insight into the focus of past research in this field. However, as this study is concerned with exploring experiences of the impact of a high-grade glioma on SWB from the individual's perspective using a phenomenological approach, it was felt that qualitative data would offer the most methodologically appropriate and relevant insights. It was therefore decided that a scoping review of quantitative data would result in a useful background summary, prior to undertaking a more detailed review of qualitative studies.

### **7.3 The scoping review**

A scoping review is considered by Jesson et al. (2011) to be a useful way of setting the scene for a future research agenda, and is a valuable process of identifying what is already known and which gaps in the knowledge exist before conducting a more thorough systematic search. It is important to emphasise at this point that even when a review is considered to be 'less-detailed' or 'scoping' in nature, it is imperative that a systematic approach to identifying, analysing and synthesising literature is maintained as a means of assuring quality (Aveyard, 2010).

This literature review followed the guidelines offered by Jesson et. al (2011) as a means of appraising the quantitative studies included in the scoping review (see Figure 7.2). Once the methodological quality of the papers had been evaluated, the key components of each were tabulated to allow for easier comparison (Table 7.3). At this point, any apparent similarities and differences were identified and papers re-read to confirm the accuracy of emerging findings (Aveyard, 2010).

<p><b>Introduction</b></p> <p>Are the aim and objectives of the study clear?  Why was the study undertaken?  Why now, in this context?  Is there a link to theory?</p>
<p><b>Method</b></p> <p>What is the research design?  Is there detail about the sampling frame, how and why the sample was selected?</p>
<p><b>Data</b></p> <p>What types of data are there?  How and where, and by whom was the data produced?  How trustworthy, reliable and valid is the data?</p>
<p><b>Analysis</b></p> <p>How was the data analysed?  How rigorous and trustworthy is the analysis?</p>
<p><b>Results</b></p> <p>Are the results a true representation of the data?  Do the results relate back to the research question?  Do the authors discuss the methodological limitations of their study?</p>

(Jesson et. al, 2011:pg 121)

**Figure 7.2: Quality appraisal of quantitative studies checklist**

**Table 7.3: Papers included in scoping review**

<b>Author /date</b>	<b>Aim</b>	<b>Setting</b>	<b>Sample details</b>	<b>Eligibility criteria</b>	<b>Method</b>	<b>Findings</b>	<b>Strengths and Limitations</b>
<b>Klein, et. al, (2001)</b>	Evaluate HRQOL and cognitive functioning of HGG patients in the post-neurosurgical period. To compare the HRQOL of HGG pts with NSCLC pts as well as healthy controls.	6 hospitals in the Netherlands	68 HGG pts and 40 NSCLC pts Control data taken from a larger cross-sectional study and age/gender-matched to the NSCLC and HGG groups.	Exclusion criteria: (1) had a life expectancy of less than 3 months; (2) were not eligible for radiotherapy; and (3) were unable to communicate in Dutch.	HRQOL was assessed using SF-36 and BCM 20 post-operatively and prior to commencing radiotherapy.	HRQOL of glioma patients comparable with patients with NSCLC. Comparison of glioma and NSCLC patients with healthy controls revealed significantly lower scores in all HRQOL domains. Similarity in self-reported HRQOL of glioma and NSCLC patients is not unexpected as both patient groups have a poor prognosis, which is reflected in their similar perceived uncertainty concerning the future.	Focus on same population as my study.
<b>Bosma et. al, (2009)</b>	Compare HRQOL of long-term to short-term HGG survivors, and determine the prognostic value of HRQOL for overall survival.	6 centres across the Netherlands	Convenience sample of 68 pts	Newly diagnosed HGG able to communicate in Dutch.	Pts asked to complete SF-36 and BCM-20 questionnaires every 4 months following diagnosis.	Long-term survivors show improvement in HRQOL during course of their disease and attain levels comparable to healthy controls, whereas short-term survivors start at a lower level and hardly show improvement	Small sample size for quant study.



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<b>Yavas et. al (2012)</b>	To assess quality of life and cognitive and emotional distress in patients treated for HGG	A single centre in Turkey	118 newly diagnosed adult HGG pts	Patients who were unable to read or write and patients with KPS <70 and/or an expected survival time <3 months were excluded	HRQoL measured using EORTC QLQ C30 and QLQ BN20 MMSE was used to measure cognitive function, HADS was used to measure anxiety and depression Questionnaires completed just before radiotherapy (baseline), at end of radiotherapy and then 3, 6, 12, 18, 24 and 30 months after radiotherapy. Baseline scores, scores at end of radiotherapy and at 18 months were included in statistical analysis.	Patients at 18 months did not report any significant difference in symptoms of depression or anxiety when compared to baseline values Global score, physical, role and emotional function, insomnia, appetite loss, seizure, leg weakness, drowsiness, bladder control, motor dysfunction, future uncertainty, visual disorder and communication deficit significantly related to disease progression.	Attrition rate- Only 19% of pts completed the 18 month assessment.  Authors did not identify any limitations of their study or propose any areas for future research.

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<b>Peters, et al (2014)</b>	To understand how QoL and fatigue impacts survival in recurrent HGG.	University hospital in North Carolina, USA	374 identified as meeting eligibility criteria over a 2 year period. 237 consented to participate.	WHO grades III to IV malignant glioma with recurrent disease on MRI, At least 6 months from original diagnosis age $\geq 18$ years, and ability to read and understand English.	Questionnaires administered at any time after diagnosis of recurrent disease. Tools used to measure QoL and fatigue were: FACT-Br, FACT-G, FACIT-F and Br-CS	Subjective measures of fatigue, using the FACIT-F, are an independent predictor of survival in this population. Other measures of QoL do not add prognostic value.	Only assessed at 1 time point. Pts were at various stages of treatment/disease. Large sample size. Caution required when making any causal links. There are multiple causes of fatigue. Would alleviating fatigue therefore improve survival?

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<b>Russell et. al (2014) (systematic review)</b>	Examine current literature regarding QoL and experience of patients living longer with adult HGG and their caregivers, with a view to understanding the burden of treatment on patient abilities and deficits over time		Focused on those who had lived longer than 18 months from diagnosis.	Search limited to adult humans, published in English between January 2000 and September 2013. Key terms relating to low-grade disease, paediatric populations and biological aspects were also applied	The electronic databases of Medline, PsychINFO and CINAHL were searched using a systematic approach for empirical studies which included a term relating to glioma in combination with an aspect of the quality of survival.  Quantitative, qualitative and mixed methodology empirical studies were included. 12 studies identified. Nine quantitative, one qualitative, and two using mixed methods.	Conflicting accounts of how longer-living HGG patients view their QoL. Significant burdens particularly in psychosocial domains. Other studies found that self-reported QoL was largely unaffected despite significant impairments in neuro-cognitive and functional domains. Findings may testify to the subjective, contextualised nature of QoL.	Focus on long-term survivors and carers means limited relevance to this study. Findings now >5 years old.

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<b>Halkett, et. al, (2015)</b>	Determine HGG patients' levels of distress and QOL during chemoradiotherapy, explore predictors of distress and QOL	Four neuro-oncology units in Australia	116 pts diagnosed with grade 3-4 HGG commencing chemoradiotherapy.	Unable to complete questionnaires for language, literacy or physical reasons Aged 18yrs or older.	Participants completed questionnaires at 3 time points: during chemoradiotherapy and 3 and 6 months later. Questionnaires comprised: demographics, the Distress Thermometer, FACT-G, FACT-Br; SCNS-34, BrTSCNS and information needs.	Poor physical function, lower education levels, loss of employment and a financial impact of the diagnosis were consistently linked with multiple domains of distress, poor quality of life and high unmet needs.	Large sample size compared to other studies. Rigorous statistical analysis undertaken.  Subjective causality inferences proposed.
<b>Baumstarc et. al (2016)</b>	Examine if QoL of patients and caregivers is influenced by coping processes.	Neuro-Oncology dept of a public hospital in France	Convenience sample of 42 pts and their carers.	Newly diagnosed HGG without cognitive issues	Cross-sectional study using tools inc. EORTC QLQ C30, French version of Patient-Generated Index (PGI) for both pt and caregiver, and the CareGiver Oncology Quality of Life (CarGOQoL) for caregivers  Coping strategies assessed using Brief Coping Orientation to Problems Experienced Scale (BriefCope)	QoL for patients and their caregivers is directly related to the coping strategies that they use. Those who used problem-solving or positive-thinking strategies reported higher QoL scores	Causality inferences could not be made.  Exclusion of most seriously ill pts may have led to overestimation of QoL of the population

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<b>Sagberg et. al (2016)</b>	to assess the quality of survival for patients in the 1st year after diagnosis of GBM	A university hospital in Norway	53 identified as eligible. 30 participated. Remaining 23 either declined, were too unwell or did not speak Norwegian.	Adults who had undergone surgical treatment for GBM	Postoperative follow-up with longitudinal assessment of HRQoL were performed after 1, 2, 4, 6, 8, 10, and 12 months using EQ-5D-3L	HRQoL most often seemed to stabilize after surgery, until an abrupt decline occurs with tumour progression.	<p>Longitudinal study design, which did not exclude those with poor performance status. However, proxy reporting was necessary in 13% of data collection episodes which may not accurately represent the perspectives of the pt.</p> <p>Small sample size for quant study. Did not use brain tumour-specific tool.</p>

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<b>Culos-Reed et. al/ (2017)</b>	Examined feasibility of recruiting HGG patients to an exercise-based study and performing fitness assessments; exercise counselling and programming preferences; and associations between fitness, physical activity (PA), and QOL during treatment.	Neuro-Oncology group, Alberta, Canada	91 pts identified as eligible. 35 approached (the rest lived outside of area or declined to speak to study staff). 16 recruited in total	18 years or older, able to speak and write English, diagnosis of HGG, be postsurgical, not received previous treatment for brain tumour	Assessments of fitness, physical activity and QoL were conducted prior to starting chemotherapy with radiation, and again at 2 months and 8 months. FACT-Br measured QOL.	Positive associations were found between PA and QOL and fitness and QOL. QoL declined across treatment trajectory. Most participants preferred to exercise at home, unsupervised, with walking as their choice of exercise modality. The researchers hypothesised that individualized exercise therapy for HGG patients may decrease chemotherapy-induced toxicity, improve chemotherapy completion rate, and improve survival.	Low numbers and significant attrition mainly due to disease progression/death. Baseline assmt N=16 2 mth assmt N=10 8 mth assmt N=3.  Causal inferences cannot be made due to cross-sectional nature of study.

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<b>Flechl, et al (2017)</b>	Evaluate development of patients' neurocognitive function and QoL every 3 months from diagnosis.	Medical University of Vienna	All eligible pts referred between March 2010 and Jan 2013 were informed of study and asked for consent. 42 participated.	Newly diagnosed GBM 18 yrs or older, WHO performance score 2 or less, communicate in German language	Prospective longitudinal study. Pts assessed every 3 months from diagnosis using EORTC QLQ C30 and BN20 to assess QoL, and NeuroCog FX for neurocognition	Most patients maintained their global QoL and cognitive functions until progression of disease. Fatigue was mentioned exclusively during the first months after diagnosis. Particularly younger patients complained about financial difficulties due to their disease	Recruitment included those with adverse prognostic features. However, 84% of pts dropped out before 6 <sup>th</sup> evaluation, mainly because of disease progression. Results may be biased towards a more favourable outcome.

<b>Author /date</b>	<b>Aim</b>	<b>Setting</b>	<b>Sample details</b>	<b>Eligibility criteria</b>	<b>Method</b>	<b>Findings</b>	<b>Strengths and Limitations</b>
<b>Gately et. al (2017) (systematic review)</b>	to examine the current literature regarding the survivorship issues encountered by long term survivors of glioblastoma	Searches were conducted in three databases (Medline, PsychInfo, EMBASE)		Adults with HGG alive > 2 years since diagnosis Excluded review papers, case studies, and studies with a biological focus	Synthesis was performed by tabulating the specific details of the included studies. Data extraction and synthesis were thematic.	3 relevant studies identified. Significant neurologic deficits were reported in up to 85% of patients Less than 30% of patients returned to work following diagnosis Psychological symptoms consistent with anxiety, depression, or distress were reported in 30–35% of patients Overall QoL appeared to be unaffected despite the frequency of deficits. Fatigue and drowsiness were the most frequently reported symptoms. Future uncertainty was frequently reported as a concern.	Small sample size Focus on those alive > 2years  In all 3 studies, patients were identified in outpatient clinics. Patients must therefore have been able to attend an appointment, leading to a potential bias of only including patients of a good performance status (PS).



<b>Author /date</b>	<b>Aim</b>	<b>Setting</b>	<b>Sample details</b>	<b>Eligibility criteria</b>	<b>Method</b>	<b>Findings</b>	<b>Strengths and Limitations</b>
<b>Sacher et. al (2018)</b>	To determine the socio-demographic, clinical and personality factors influencing the QoL of patients and their caregivers	Neurosurgery dept in university hospital Leipzig, Germany	45 pts who had surgery for HGG and their carers. 48 initially met criteria, 3 opted out.	3 months min since diagnosis. Excluded if had a severe cognitive/functional deficit. 18 years or older and conversant in German.	Prospective, mixed-methods design. Pts and carers were examined once with 3 self-report questionnaires (MDMQ, SF-12, CES-D) and a semi-structured interview.	Higher QoL scores significantly associated with those who had better physical and cognitive function and those who had a partner. Caregiver well-being and caregiver depression predicted patient well-being and depression  75% of couples required psychological support.	Those with low KPS (functional impairment score) were excluded, estimates of distress may be underestimated. Very little info on qual data analysis process. Only assessed once therefore no longitudinal data

(see appendix 10 for full terms relating to tool abbreviations)

## 7.4. Findings of scoping review

This review identified that relevant studies had been conducted internationally, including research from Europe, Turkey, North America and Australia. Dates of publication ranged from 2001 to 2018 (when the review was conducted). All of the empirical studies identified in the scoping review involved measuring the Quality of Life (QoL) of people with high-grade glioma (HGG) using validated assessment tools such as the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C30 and FACT-G questionnaires (see appendix 10 for list of tool abbreviations). Most (n = 11) studies found that QoL was significantly impacted by a diagnosis of HGG (Baumstarck et. al, 2015; Halkett et. al, 2015; Klein et. al, 2001), and some longitudinal studies highlighted that this worsened along the disease trajectory (Bosma et. al, 2009; Culos-Reed et. al, 2017). These findings are not unexpected. However, perhaps more surprisingly, three studies also found that QoL was preserved by many individuals following diagnosis until the point of significant disease progression (Flechl et. al, 2017; Sagberg et. al, 2016; Yavas et. al, 2012). Indeed, in those who went on to survive for longer than 18 months, QoL appeared to 'recover' to a level comparable with healthy controls as long as their disease burden remained stable (Bosma et. al, 2007). Such fluctuation and diversity in the preservation of SWB was also identified in my study. These conflicting accounts of the impact of a diagnosis of HGG on QoL are also consistent with the findings of a systematic review conducted by Russell et. al (2014) exploring the literature regarding the QoL and experience of patients living longer with HGG and their caregivers. This review (which was largely focused on quantitative findings, but did include some mixed method studies) also identified contrasting findings relating to the impact of HGG on QoL, with some experiencing a far greater effect than others. The reasoning behind such differences in perception and experience is not widely discussed in the literature, although Russell et. al (2014) suggest it may be testament to the highly subjective nature of QoL, which was indeed the case in my study.

#### **7.4.1 The relationship between QoL and disease progression**

Three studies identified in this scoping review explored the links between QoL and disease progression/survival (Bosma et. al, 2009; Yavas et. al, 2012; Peters et. al, 2014). For example, Yavas et. al (2012) determined that QoL domains such as physical, role and emotional function, insomnia, motor dysfunction, future uncertainty and communication deficit were significantly related to disease progression. However, these findings must be considered with caution, as the attrition rate in this study was particularly high, with only 19% of participants completing an 18-month assessment. Another study undertaken by Peters et. al (2014) to examine how QoL, and in particular fatigue, impacts survival in recurrent HGG determined that fatigue was an independent predictor of survival in this group. However, it would be ill-advised to assume a causal link between fatigue and overall survival on the basis of these findings, as it is impossible to understand with any certainty the complexities of the connection. Suggesting that alleviating fatigue would improve survival does not take into consideration what the underlying causes of fatigue might be (for example, if the fatigue was caused by a high disease burden).

#### **7.4.2 Identification of factors which impact on QoL**

The remaining studies in this review can be organised into two distinct categories. Firstly, there are those which focus on factors associated with a reduction in QoL such as lower education levels, loss of employment, significant financial impact and short-term survival (Bosma et. al, 2009; Halkett et. al, 2015; Flechl et. al, 2017). Secondly are those which identify elements related to maintaining a good QoL. These include sustaining physical activity levels, maintaining physical and cognitive function, having a partner, and the use of problem-solving and positive-thinking coping strategies (Baumstarck et. al, 2016; Culos-Reed et. al, 2017; Sacher et. al, 2018).

A recurring issue in this scoping review was the fact that despite several correlations being identified between factors occurring as a result of HGG and QoL, very few studies were able to identify a causal relationship. For

example, it has been suggested that there is an association between adopting positive-thinking coping strategies and preserving QoL. However, it is not possible to establish whether positive-thinking directly impacts on QoL, or if the personality type of people who would adopt such an approach predisposes them to evaluate their QoL more optimistically. This issue will be discussed in more detail later in the chapter.

## **7.5. Limitations of findings of scoping review**

There are a number of recurring limitations identified in the quantitative studies analysed in this scoping review. These result from the specific challenges presented by conducting research with people who have been diagnosed with a cancer which has such a poor prognosis and debilitating symptom profile.

### **7.5.1 The issue of attrition**

High levels of attrition are an issue regularly cited by authors of the included studies as restricting the reliability of any findings, particularly in relation to longitudinal studies (Yavas et. al, 2012; Sagberg et. al, 2016; Culos-Reed et. al, 2017; Flechl et. al, 2017). For example, in the study conducted by Flechl et. al (2017) which aimed to continuously evaluate the QoL and cognitive functioning of people diagnosed with Glioblastoma Multiforme every 3 months following diagnosis, 84% of participants dropped out before the sixth assessment, largely due to disease progression. Yavas et. al (2012) also evaluated the ongoing QoL, cognitive functioning and psychological distress of 118 Turkish HGG patients in their prospective, single-centre study. Patients were given questionnaires just before radiotherapy, at the end of radiotherapy and every three months thereafter. However, the number of patients who completed follow-up assessments was 34% at 12 months, and just 19% at 18 months, as a result of the majority of participants experiencing significant disease progression or death by this point. High attrition rates such as those demonstrated in these studies are of critical importance to the validity and objectivity of the results. Those who had become too unwell to complete the questionnaires would probably have reported a significant decline in their QoL, however this data could not be

collected. Therefore the findings are highly likely to display biases towards more favourable results. This is a particularly important issue to bear in mind when considering the hypothesis that patients with HGG may maintain a good QoL after diagnosis. It is also a relevant factor for my study, where 11 of the 15 participants attended a second interview, but a third interview was only achieved with one participant.

### **7.5.2 The exclusion of those with poor prognosis and/or performance status**

Closely linked to the issue of high attrition was the exclusion of those with a poor prognosis and/or performance status from a considerable number of studies (N=5) at the time of recruitment. This is a complex issue familiar to those conducting research with people who have life-limiting illnesses. It is particularly pertinent in the field of brain tumour research, where a degree of cognitive impairment is likely (Sterckx et. al, 2015). Gaining an insight into the experiences of those diagnosed with advanced disease is an extremely valuable yet challenging endeavour. However, the ability and desire of such patients to participate in research when their health is poor and time is limited may result in considerable ethical barriers for the researcher. Two studies conducted an assessment of functional impairment using the Karnofsky Performance Status (KPS) to determine eligibility for their study (Yavas et. al, 2012; Sacher et. al, 2018). Those who were deemed to have significant functional impairment (represented as a low KPS score) were automatically excluded. This was an understandable attempt not only to ensure that participants were functionally able to participate, but also not to overburden those who may have found completion of assessment tools difficult. However, as many of the researchers identified, the resulting bias of any findings cannot be ignored (Baumstarck et.al, 2016; Gately et. al, 2017; Sacher et. al, 2018). Excluding those who are likely to report the most detrimental impact on their health may have led to a more positive impression of QoL than is justified.

Some attempts to overcome the issue of excluding those with poor performance status were made by researchers. For example, in the study

conducted by Sagberg et. al in 2016, which aimed to assess the quality of survival for patients in the first year after diagnosis, those with low KPS scores were included. This was a specific attempt by the researchers to acknowledge the importance of attempting to collect data which reflected the true profile of those with HGG. When patients in their study had considerable cognitive impairments, or were otherwise too ill to answer, carers and relatives were asked to assess the patient as they thought the patient would respond (i.e. from a proxy-patient perspective). In total, 13% of their data was proxy reported. Whilst this approach had the benefit of including data from those with poor performance status, it is well known that proxy collected data cannot guarantee a true interpretation of the patient's personal experience, and that outcomes including data from a proxy-patient perspective may well generate different results to those which only include patients (Pickard and Knight, 2005).

### **7.5.3 What is the knowledge gap resulting from the findings of the scoping review?**

The papers identified in the scoping review have provided some interesting insights into the impact of a diagnosis of HGG on QoL. However, it is striking to note that all of these studies relied on validated questionnaires as a means of measuring QoL. Not only that, but there was a strong inclination towards a handful of the most popular tools such as the EORTC QLQ C30 and BN20, the FACT-G and the FACT-Br (Yavas et. al, 2012; Peters et. al, 2014; Halkett et. al, 2015). There are obvious benefits to using these tools. They are well-validated and widely-used, which helps to assure reliability and generalizability, and allows for easier comparison of data. On the other hand, such a dependence on a limited number of approaches may considerably restrict findings. For example, this scoping review has identified studies that have proposed a relationship between reduced QoL and factors such as lower education levels, loss of employment and significant financial impact (Bosma et. al, 2009; Halkett et. al, 2015; Flechl et. al, 2017). However, it could be hypothesised that people who report such factors as having an impact on their QoL would see them as issues regardless of their HGG diagnosis.

The limitations of using such tools are also demonstrated by the evidence that fatigue has been identified as one of the most prevalent symptoms reported by people with HGG (Gately et. al, 2017). This may well be the case, but it is not possible to ascertain whether this is something that all participants feel is of importance to their SWB. In other words, it might exist as an issue, but it cannot be assumed that this means it matters to all who report it. Using quantitative tools such as questionnaires does not allow for such individualised and subjective reporting. There is an apparent gap in the available literature between which factors of QoL healthcare professionals measure, and which are actually most relevant from the patient's perspective. An important question has therefore arisen from this scoping review; *'Which particular domains of QoL and/or wellbeing matter most to people with HGG?'*

## **7.6 Conclusion of scoping review**

In conclusion, this scoping review has provided useful background information on quantitative research that has investigated the impact of a diagnosis of HGG on QoL. Ten studies were identified which had used validated tools to identify the positive impact of factors such as physical activity levels, maintaining physical and cognitive function, having a partner and the use of coping strategies on perceived QoL of people with HGG. Elements which appear to have a negative association with QoL such as short-term survival and diminished employment and income have also been proposed. Historically, there has been a significant focus on identifying a link between QoL and overall survival, possibly as a result of the majority of research traditionally being conducted from a more positivist/medical approach, however this is of limited relevance to this more interpretivist study.

Perhaps the most interesting finding of this scoping review is the level of conflict between accounts of the impact of a diagnosis of HGG on QoL, which was also apparent in my study. For many, such a diagnosis has an understandably detrimental impact on their QoL. But for others, QoL appears to be maintained until the point of significant disease progression,

and also appears to recover to a level comparable with healthy control groups in those who live longer than 18 months with stable disease. However, these findings may be influenced by the high levels of attrition experienced during studies conducted with people diagnosed with HGG. It is also important to remember that the exclusion of those with the poorest prognosis in five of the studies may have resulted in a deceptively positive result.

All of the studies included in the scoping review used validated questionnaires to collect data on the impact of a HGG diagnosis on QoL. Whilst this is recommended has resulted in a useful overview of prevalent issues, the identification of which factors are most important from the patient's perspective is absent. It is hoped that undertaking a critical review of the qualitative studies available on the subject will address this knowledge gap. The discovery of further studies which include longitudinal data as well as data collected from those with poor prognosis and performance status would also be beneficial in terms of addressing the paucity of studies which include these elements thus far.

## **7.7 Review of qualitative studies**

It can be argued that qualitative research is interpretivist in nature; specific to the context in which it was conducted, and is therefore not generalisable. However, in the case of healthcare, the ability to combine and compare the findings of qualitative studies as a means of informing policy and practice is fundamental to its value, particularly as the body of qualitative evidence has grown exponentially in recent years (Thomas and Harden, 2008). It is therefore fundamental to the success of a qualitative systematic review to maintain an awareness and respect for the subjective nature of qualitative research whilst at the same time presenting findings in a meaningful and manageable account. With this challenge in mind, approaches to both synthesis of the findings and critical appraisal of the literature were carefully considered prior to commencing the review of qualitative studies.



## **7.8 Approach to synthesising findings**

A number of approaches to the synthesis of qualitative research findings have emerged in recent years as the volume of this form of evidence has increased. Some of the most commonly used methods include meta-ethnography, meta-study and meta-narrative (Aveyard, 2010). Whilst the mutual aim of these approaches is to synthesise multiple findings into a meaningful account, their epistemological foundations and approaches to interpretation vary considerably (Barnett-Page and Thomas, 2009). For the purposes of this review, Thomas and Harden's 'Thematic Synthesis' approach was utilised (Thomas and Harden, 2008) because of its commitment to maintaining a trustworthy approach whilst at the same time preserving the context of the original research findings. Thematic synthesis encourages constant checking that transfer of concepts from one study to another is appropriate, and highlights the importance of explicit recording of development of themes and displaying structured study summaries to ensure dependability (Thomas and Harden, 2008). This approach also encourages the quality assessment of qualitative studies as a means of avoiding drawing unreliable conclusions, but does not propose excluding studies based solely on the results of the quality assessment, in recognition of the risk of discounting valuable findings. The stages of thematic synthesis can be found in figure 7.3 below.

Thematic synthesis is fundamentally a translation of the thematic analysis approach used for primary research in systematic reviews (Thomas and Harden, 2008). It is similar in approach to the majority of methods of qualitative evidence synthesis, in that it involves constant comparison and re-evaluation of study findings until a comprehensive picture of emerging themes is reached (Paterson et. al, 2001). It seeks to go beyond the original data offered by researchers to offer a new interpretation of the collected findings (Barnett-Page & Thomas, 2009).

1. <i>Line-by-line coding of text in the findings of studies.</i>
2. <i>The development of descriptive codes based on coding, concepts are translated between studies and synthesis begins. Some sentences may have multiple codes applied. At this stage, any similarities or differences between initial codes are identified in order to group them into an interconnected /hierarchical structure.</i>
3. <i>Generation of analytical themes to address the question of the review. Beyond description to interpretation. Using the identified descriptive themes to answer the review question. Inductive themes should explain descriptive themes and their implications.</i>

**Figure 7.3: Three stages of thematic synthesis (Thomas and Harden, 2008)**

## 7.9 Critically appraising qualitative papers

The critical appraisal of qualitative research has provoked a complex and ongoing debate in recent years. On the one hand, the exploratory and subjective nature of qualitative inquiry is fundamentally at odds with a process of assessing validity and reliability in a quantitative fashion. On the other, it could be argued that evidence of a rigorous approach is essential to judge the worth of any piece of research (Aveyard, 2010). As a result, over one hundred qualitative critical appraisal tools have been developed with the intention of addressing these complex issues and assisting those reading qualitative research. Some of the most commonly used tools include the Critical Appraisal Skills Programme tool (CASP, 2018), the ‘Quality Framework’ published by the National Centre for Social Research (2003), and the Joanna Briggs Institute (JBI) tool (2007). There has been considerable discussion and analysis conducted on the use of such tools (Dixon-Woods et al, 2007). However, for the purposes of this research, it was decided that the CASP tool for qualitative research was the most appropriate to be considered in more detail.

The CASP tool is one of the most commonly used critical appraisal tools for qualitative research. This tool, which comprises 10 questions in a ‘checklist’, has been widely used in qualitative systematic reviews as a means of

facilitating judgments on the quality of papers (Dixon-Woods et. al, 2007). The application of a checklist method such as the CASP tool is a useful aide in ensuring that appropriate questions are asked of a paper to ensure its quality. It encourages a systematic approach to appraising the merits of a paper, and is therefore particularly valuable to less-experienced researchers who may not be able to rely heavily on their intuition. The CASP tool also addresses concerns raised previously by those appraising qualitative research regarding the potential to apply quality criteria in an over-rigorous manner (and exclude valuable studies as a result), by including a question on the value of the research.

Despite these merits, it is important to remain vigilant to the limitations of such a 'tick box' approach, and to bear in mind that critical appraisal of qualitative research is fundamentally an interpretive process; requiring reflection and analytical thinking on the part of the reader (Kuper, Lingard and Levinson, 2008).

### **7.9.1 Limitations of the CASP tool**

One of the most striking methodological issues of undertaking critical appraisals of qualitative research using the CASP tool is the potential for subjective variation in answering the questions amongst researchers. There is no guarantee that researchers would answer the questions in the same way (Sandelowski and Barroso, 2002). A study conducted by Dixon-Woods et. al (2007) examined whether the use of structured tools produced more consistent judgements on the quality of a paper than unprompted judgement, (where experienced qualitative researchers rely solely on their own expertise to form a judgement about the quality of the paper). They found that structured approaches did not result in higher levels of agreement amongst a research team about the potential inclusion of a paper in a systematic review than unprompted judgement did. However, the use of critical appraisal tools did appear to make reviewers focus more on research procedures, and to be more explicit concerning the rationale of their judgements (Dixon-Woods et. al, 2007).

Another limitation of using a critical appraisal tool is the inevitable fact that judgements are based solely on the information provided in the research paper. Without access to a full research report it is difficult to judge with absolute certainty if certain elements of research practice have or have not been adhered to. For example, detailed evidence of data analysis processes may not have been included in the article if a restrictive word limit was in place, but that does not necessarily mean the process itself lacked rigour (Atkins et. al; 2008).

Having considered the benefits and limitations of using a critical appraisal tool, it was decided to proceed by reviewing the included papers with cautious use of the CASP tool. However, studies were not excluded on the basis of this quality review, as a means of safeguarding against omitting any valuable insights. Where there were concerns about the methodological quality of a study, these were made explicit in the findings. Once the methodological quality of the papers had been evaluated using the CASP tool, the key components of each article were tabulated to allow for easier comparison (table 7.4). The outcomes of the CASP review can be found in Table 7.5. As only one qualitative systematic review had been identified, this was appraised using the CASP tool for systematic reviews as a means of ensuring a consistent level of assessment for all of the evidence included in this review (CASP, 2018-table 7.6)

**Table 7.4: Results of review of qualitative studies**

<b>Author /date</b>	<b>Aim</b>	<b>Setting/Sample/Exc criteria</b>	<b>Method</b>	<b>Findings</b>	<b>Limitations</b>
<b>Fox and Lantz (1997)</b>	To address the following questions: Do people with brain tumours think about their QoL? What is the meaning of QoL to people with brain tumours? What factors contribute to brain tumour pt's definition of QoL? How does having a brain tumour affect QoL?	Adults with primary or metastatic brain tumours. Significant others included to assist with any communication or cognitive issues. Did NOT exclude poor prognosis pts. Neuro-Oncology clinic in large university medical centre in USA and a brain tumour support group in the same city. Details on how pts were identified or recruited not given. 23 pts and 21 significant others participated.	Described as qualitative, but specific methodology not given. Single semi-structured interviews (although no interview guide). Group interviews undertaken with support group to validate and expand on themes	Identified themes: 1. The stigma of a mind-body illness 2. An invasive disease of the self 3. "My family has a brain tumour" 4. QoL: No substitute for living 5. Dealing with medical diplomats.	Pre-dates combined modality standard of care. Not HGG specific, but included due to depth and relevance of findings. Also one of first attempts to explore QoL in this pt group from a qual perspective. Specific methodological approach not identified-?? Appropriateness of interview technique and validation of findings with group interview. Carers helped when pt had communication difficulties. ?risk of misrepresentation.
<b>Halkett et. al (2010)</b>	To understand pt experiences of HGG and identify and describe support needs along disease trajectory.	Adults with HGG able to participate in interviews. Oncology dept of a tertiary referral centre for neurological tumours in Western Australia. Purposive sampling to ensure representation of a variety of social and clinical situations. 19 recruited.	Grounded theory and constant comparative method for data analysis. Single semi-structured interviews (with carer in first instance).	Four themes identified: 1. Feelings of uncertainty around prognosis and QoL 2. Need for individualised information 3. Dependence on carers 4. Communication with HCP around prognostic uncertainty and disease progression	Carers present at interviews Did not collect longitudinal data from individuals

<b>Author /date</b>	<b>Aim</b>	<b>Setting/Sample/Exc criteria</b>	<b>Method</b>	<b>Findings</b>	<b>Limitations</b>
<b>Lobb, Halkett and Nowak (2010)</b> N.B. same data as Halkett (2010)	Sought the views of HGG pts and their carers on their experience of being diagnosed.	Adults with HGG able to participate in interviews. Oncology dept of a tertiary referral centre for neurological tumours in Western Australia. Purposive sampling to ensure representation of a variety of social and clinical situations. 19 pts and 21 care givers recruited.	Grounded theory and constant comparative method for data analysis. Single semi-structured interviews	Five themes identified: 1. Shock at hearing diagnosis 2. Trying to understand and process prognostic information when still in shock 3. The perception of hope being taken away 4. Individualizing prognostic information 5. Clinicians' lack of communication skills	Interviews took place some months after diagnosis, therefore potential for recall bias.
<b>Cavers et. al (2012)</b>	To understand the multidimensional experiences of pts with glioma as their illness progressed.	Tertiary neuroscience centre in UK. Purposive sample to maximise diversity of pts. Recruited those undergoing investigations for a likely glioma diagnosis. No specific details given on exclusion criteria. 26 pts and 23 relatives participated.	Longitudinal qualitative method. Serial semi-structured interviews with pts and their carers up to 5 times over a period of 2 years. Also interviewed pt's GP around interview 3 to get their perspective on caring for a pt with glioma. Interviews analysed using constant comparative grounded theory approach.	1. Social wellbeing declined alongside the physical. 2. Social isolation worsened as disease progressed. 3. Fluctuations between hope and despair throughout course of illness as pts adapted to their diagnosis. 4. Individual differences in acceptance depending on internal resources, availability of support and prognosis.	Not specifically focused on HGG, although the majority were (18/26). Included as it uniquely focused on wellbeing rather than QoL,, was longitudinal and looked at pre-diagnosis phase. Authors highlighted the difficulty of attrition in terminal phase.

<b>Author /date</b>	<b>Aim</b>	<b>Setting/Sample/Exc criteria</b>	<b>Method</b>	<b>Findings</b>	<b>Limitations</b>
<b>Sterckx et. al (2013) Systematic Review</b>	To explore the experiences and needs of pts with HGG and their caregivers.	<p>Empirical qualitative research published between 2000-2010 (date limitations prompted by significant developments in treatment since 2000) focused on HGG pts and carers. 16 articles included.</p> <p>Included 2 studies from this review: Halkett et. al (2010 and Lobb et. al (2010)</p>	Quality appraisal as per Mays and Pope (2000).	<p>Shock, anxiety and helplessness at diagnosis.</p> <p>Anger at way diagnosis was communicated.</p> <p>Tiredness and loss of autonomy are most significant consequences of symptoms.</p> <p>Some pts experienced anxiety about death, others felt awareness of a near death renewed perspective in life and changed them as a person.</p> <p>Financial impact of HGG caused fear and uncertainty.</p> <p>Importance of hope throughout disease trajectory.</p> <p>Talking is an important source of support.</p> <p>Source, method and timing of info varies between individuals.</p> <p>Importance of hearing a positive message from HCP.</p> <p>Pts and carers value compassion, empathy and trust in HCP, and express need for a dedicated contact person.</p>	<p>Limited evidence of reflexivity.</p> <p>Lack of clarification on tumour classification, pt or caregiver reporting and studied time frame.</p> <p>Attrition a significant issue.</p> <p>Selection bias issues-sample from support groups, exclusion of those with cognitive deficits.</p>

Author /date	Aim	Setting/Sample/Exc criteria	Method	Findings	Limitations
<b>Piil et. al (2015)</b>	To explore the experiences of pts with HGG and their caregivers regarding their needs for rehabilitation and supportive care	30 pts and 33 caregivers. Dept of neurosurgery, University Hospital Copenhagen, Denmark. Adults with newly diagnosed HGG. Able to speak and understand Danish. KPS $\geq$ 60 Anticipated attrition rate of 50%	Prospective longitudinal exploratory design. Individual semi-structured telephone interviews at 5 timepoints along a 1 year trajectory.	Need for prognostic info individual and fluctuates. Some crave info and others avoid it, and they may fluctuate btw the two throughout trajectory. Sense of solidarity with partner-shared experience Importance of hope-either for survival or for a prolonged lifespan, or for wellbeing. HCP could offer hope, which pts appreciated. Benefit of engaging healthy lifestyle as a means of retaining control, but this tended to diminish as disease progressed. Desire to share experiences with other pts. Anxiety about uncertain future evident. Impact on social life/work increased as time progressed.	Attrition rate 27% (lower than expected). PTs experienced serial interviewing as being supportive and having therapeutic value.



<b>Author /date</b>	<b>Aim</b>	<b>Setting/Sample/Exc criteria</b>	<b>Method</b>	<b>Findings</b>	<b>Limitations</b>
<b>Sterckx et. al (2015)</b>	To understand how pts with a HGG experience life with a brain tumour, and to explore their professional care needs.	2 oncology wards in a university hospital, Belgium. Pts with HGG in follow-up phase following chemo-rad. Able to consent and speak Dutch. Pts who were physically, mentally or emotionally unable to participate (according to judgement of dr or nurse) were excluded. Purposive and theoretical sampling. 17 recruited.	Grounded theory Single, semi-structured interviews (no interview guide available)	Shock of diagnosis. Subtle symptoms added to sense of disbelief. Feelings of loss-independence, social life. Living with uncertainty and anxiety. Disregarded/disrespected/ infantilised Loss of control Inner strength, staying positive Importance of hope and retaining a sense of purpose Not wanting to be a burden Need for information Access to professionals. Need to share emotions and concerns	8 interviews terminated by researcher at the point when they appeared burdensome to pt. Pts with severe cognitive impairments could not be included. Presence of caregivers may have influenced answers. Heterogeneous sample in terms of stage in illness trajectory. Authors recommend longitudinal data collection in future studies.
<b>Bennett et. al (2016)</b>	To gain an insight into the impact of headaches on QoL of people with GBM	Purposive sample of 14 pts from a tertiary referral centre in Birmingham, UK. Inc criteria: adults with HGG diagnosis and performance status <2.	Exploratory qualitative methods. One off semi-structured interview undertaken by a senior medical student.	Underlying positivity and determination to live as normally as possible. Reluctance to socialise in a group. Headaches are a worrying reminder of diagnosis. This psychological and emotional impact was more debilitating to their QoL than the physical pain of the headache.	Only 6 pts reported having headaches in the preceding month. ?qualitative interviewing experience and skills of medical student (although topic guide developed by experienced research team). No details of specific qualitative methodology.

<b>Author /date</b>	<b>Aim</b>	<b>Setting/Sample/Exc criteria</b>	<b>Method</b>	<b>Findings</b>	<b>Limitations</b>
<b>Boele et. al (2016)</b>	To explore attitudes and preferences of patients and caregivers towards monitoring symptoms, distress and QoL.	OPD of university medical centre in Amsterdam, Holland. Purposive sample of 15 pts and 15 caregivers. Adults with diagnosis of grade II, III or IV glioma who could communicate in Dutch.	Semi-structured interviews. A variety of paper and electronic monitoring tools were presented to participants.	Cognitive problems may limit ability to comply with monitoring tools. Pts and caregivers felt that feedback and initiation of supportive care should be integral. Pts also like option of face-to-face feedback. Caregivers viewed regular monitoring more favourably than pts.	Mix of low and high grade pts-limited application to HGG.

Author /date	Aim	Setting/Sample/Exc criteria	Method	Findings	Limitations
<b>Piil et. al (2018)</b>	To identify specific needs and preferences for rehabilitation and supportive care in the first year following diagnosis.	Dept of neurosurgery, University Hospital of Copenhagen, Denmark. Adults with HGG diagnosis and KPS score $\geq 60$ who could communicate in Danish. Disease progression was not an exclusion criterion 80 eligible pts identified, 38 excluded due to low KPS. 30 pts and 33 carers participated (sample size based on expected 50% attrition rate).	Longitudinal mixed methods-interviews and questionnaires (physical activity questionnaire; HADS; FACT-G and FACT-Br) 5 times during first year following diagnosis. Semi-structured telephone interviews (with interview guide). Integration of qual and quant data framed by qual findings, with quant data provided additional objective detail.	Needs change dynamically through first year depending on state of disease and individual preferences rather than specific time points.  Need for individualised strategy to prognostic info giving, more desire for info as time passes. Alternate btw seeking and limiting info. Importance of solidarity for EWB-Pts and caregivers joined forces in managing HGG together. Hope is essential for HRQOL. The focus and definition of hope changes throughout disease trajectory. Engaging in health promotion activities fosters hope. Pts reported an ongoing process of adjusting to functional limitations.	278 interviews conducted. A strength of this study is longitudinal data collection with homogenous sample. However, only 18 pts completed all study requirements (therefore potential for bias towards healthier more positive findings). Details on approach to thematic analysis of qualitative data are sparse. ? Did quantitative data contribute much to findings, if not was asking pts to complete 3 questionnaires at 5 timepoints in a year unnecessarily burdensome?

**Table 7.5: Critical appraisal of qualitative studies using CASP tool**

Author/Date	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	Is the research valuable?
Fox and Lantz (1997)	Yes	Yes	Yes (although specific qualitative approach not disclosed)	Unclear	Yes	No	Unclear	Yes	Yes	Yes
Halkett et. al (2010)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes
Lobb, Halkett and Nowak (2010)	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes
Cavers et. al (2012)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes
Piil et. al (2015)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes
Sterckx et. al (2015)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes
Bennett et. al (2016)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Unclear
Boele et. al (2016)	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	Yes	Yes
Piil et. al (2018)	Yes	Yes (mixed methods)	Unclear	Unclear (? Necessity to exclude KPS <sub>≥</sub> 60)	Yes (but ? benefit of quant data)	Unclear	Yes	Yes for quant, can't tell for qual	Yes	Yes

**Table 7.6: Critical appraisal of systematic review using CASP tool**

Author/Date	Did the review address a clearly focused question?	Did the authors look for the right type of papers?	Do you think all the important, relevant studies were included?	Did the review's authors do enough to assess quality of the included studies?	If the results of the review have been combined, was it reasonable to do so?	What are the overall results of the review?	How precise are the results?	Can the results be applied to the local population?	Were all important outcomes considered?	Are the benefits worth the harms and costs?
Sterckx et. al (2013)	Yes	Yes	Yes	Yes	Unclear	See table 5	NA for qual studies	Yes	Yes	NA for qual studies

### **7.9.2 Outcome of the critical appraisal of papers using the CASP tool**

During the process of critically appraising the selected papers using the CASP tool, it was particularly striking to note that none of the studies reported on whether or not the relationship between the researcher and participants had been adequately considered, which is an essential aspect of reflexivity. Reflexivity is a fundamental issue in qualitative research, as it displays recognition of the influence of the researcher on the research process (For example, how might the balance of power in the researcher-research participant relationship have affected any findings?) (Kuper, Lingard and Levinson, 2008). Evidence of reflexivity is one of the most important means of assessing the integrity of qualitative research, yet surprisingly it could not be found in any of the qualitative papers included in this review. That is not to say that it did not happen, but without mention of it in the journal articles it is impossible to know with any certainty. These findings resonate strongly with the work of Newton et. al (2011), who also adopted the CASP tool in their systematic review of qualitative research into the experience of low back pain. They identified a total absence of reflexivity amongst their reviewed papers, and identified that this may well be a result of the word limits placed on journal articles. They also propose that this may be a reflection of a publication culture which still does not prioritise evidence of reflexivity despite it's importance to the integrity of qualitative inquiry (Newton et. al, 2011).

### **7.10 Findings**

Descriptive thematic analysis (as per Thomas and Harden's method) revealed a total of 13 themes relating to the initial question 'What is the impact on wellbeing/quality of life of a diagnosis of high grade glioma?' At the third stage of analysis (the inductive phase), these themes were considered more critically as a means of interpreting their impact and relevance to the research question. It became apparent that these themes generally took the form of 'threats' to the three fundamental domains of SWB (Hope, Sense of Control and Sense of Identity) in a similar way to the themes generated by the study findings. Table 7.7 provides an overview of the

identified themes resulting from this literature review, and their associated SWB domains. Table 7.8 provides details of the sources of evidence from the literature review relating to these domains and threats. Following these tables, each of these threats/themes will be discussed in more detail, followed by an analysis of suggested approaches to preserving SWB in the face of such challenges.

**Table 7.7: Relationship between literature review themes and SWB domains**

<b>SWB domain</b>	<b>Theme/Nature of threat to SWB domain</b>
HOPE	<ul style="list-style-type: none"> <li>• Terminal prognosis</li> </ul>
	<ul style="list-style-type: none"> <li>• Limited information from health professionals</li> </ul>
	<ul style="list-style-type: none"> <li>• Poor communication from health professionals</li> </ul>
SENSE OF CONTROL	<ul style="list-style-type: none"> <li>• Shock and uncertainty at diagnosis</li> </ul>
	<ul style="list-style-type: none"> <li>• Loss of independence/autonomy</li> </ul>
	<ul style="list-style-type: none"> <li>• Difficulty getting information that is individualised.</li> </ul>
SENSE OF IDENTITY	<ul style="list-style-type: none"> <li>• Impact on family role/relationships</li> </ul>
	<ul style="list-style-type: none"> <li>• Symptoms/side effects</li> </ul>
	<ul style="list-style-type: none"> <li>• Lack of individualised care</li> </ul>
	<ul style="list-style-type: none"> <li>• Loss of sense of purpose/meaning</li> </ul>
	<ul style="list-style-type: none"> <li>• Social isolation</li> </ul>
	<ul style="list-style-type: none"> <li>• Loss of 'normality'</li> </ul>
	<ul style="list-style-type: none"> <li>• Burden of treatment schedule</li> </ul>

**Table 7.8: Thematic synthesis – sources of evidence**

SWB DOMAIN	THREAT TO SWB (THEME)	Fox & Lantz (1997)	Halkett et. al (2010)	Lobb et. al (2011)	Cavers et. al (2012)	Sterckx et. al (2013)	Piil et. al (2015)	Sterckx et. al (2015)	Bennett et. al (2016)	Boele et. al (2016)	Piil et. al (2016)
HOPE	Terminal prognosis		✓		✓	✓		✓			
	Limited information from health professionals		✓	✓		✓					
	Poor communication from health professionals			✓	✓	✓	✓	✓		✓	✓
SENSE OF CONTROL	Shock and uncertainty at diagnosis	✓	✓	✓	✓	✓		✓			✓
	Loss of independence/ autonomy		✓			✓		✓			✓
	Difficulty getting information that is individualised.	✓		✓			✓	✓			✓
SENSE OF IDENTITY	Symptoms/side effects	✓	✓		✓		✓				
	Lack of individualised care	✓			✓	✓		✓		✓	
	Loss of sense of purpose/meaning	✓			✓	✓		✓			
	Social isolation	✓					✓	✓			
	Loss of 'normality'	✓			✓			✓	✓		✓
	Burden of treatment schedule	✓	✓								
	Impact on family role/relationships	✓	✓					✓	✓		✓



### **7.10.1 Hope**

Hope was referred to frequently in the literature as being essential to the SWB of people with a diagnosis of HGG, a notion that was also a fundamental aspect of my study. It helped patients to 'keep going' and brought a sense of purpose to their lives (Piil et. al, 2018). Similarly to my findings, the profile of hope changed throughout the disease trajectory. Following diagnosis, it sometimes took the form of hoping to beat the statistics in terms of life expectancy (Lobb et. al, 2010; Sterckx et. al, 2013; Pill et. al, 2015; Pill et al, 2018), but more frequently it was a hope to enjoy and participate in life for as long as possible (Sterckx et. al, 2015; Piil et. al, 2018). Unfortunately, this sense of hope was often undermined, which had a significant impact on SWB. Major threats to maintaining hope included the terminal nature of the prognosis, and limited information and poor communication from health professionals.

#### **7.10.1.1 Terminal prognosis**

As was the case with my study, the literature revealed that the incurable nature of HGG was devastating news for many people and left them feeling hopeless, as if they had 'hit a brick wall' (Halkett et. al, 2010: pg 115). Hope was particularly vulnerable to threat at diagnosis, and also at times of disease progression and treatment failure (Cavers et. al, 2012; Sterckx et. al, 2013). Patients found it difficult to hear when there were no further treatment options, as this led to feelings of despair and futility (Sterckx et. al, 2015).

Many patients reported being able to counteract these feelings of hopelessness in the face of their prognosis by thinking positively (Cavers et. al, 2012). This became easier as they adapted to their diagnosis and recovered from their surgery. The ability to participate in daily activities and regain some of their independence inspired hope, as did entering a new treatment phase and hearing positive news from scans (Sterckx et. al, 2013; Sterckx et. al, 2015). In a longitudinal study conducted with 26 patients and 23 of their relatives over a period of two years by Cavers et. al (2012), hope appeared to fluctuate throughout the disease trajectory. Participants attempted to preserve hope by maintaining a positive attitude, appreciating

elements of their lives such as friendships and the natural world. However, sometimes they struggled to remain hopeful in the light of their prognosis, and experienced sadness and despair.

#### **7.10.1.2 Limited information from health professionals**

Receiving accurate information about their disease is deemed to be extremely important to the SWB of patients with HGG (Sterckx et. al, 2013). Unfortunately, many patients reported that they had only been given vague details about their prognosis, which inhibited any potential they had to make plans and feel hope for the future (Halkett et. al, 2010). In a study conducted by Lobb et. al (2010) further evidence was found of the potential for lack of information, as well as information that was conveyed in as negative and/or inappropriate manner to threaten the hope of people diagnosed with HGG. This qualitative study, conducted with 19 patients and 21 caregivers in a tertiary cancer centre in Australia, found that around half the participants felt their hope was taken away when they were informed of their diagnosis. This was confounded on hearing that their prognosis was terminal, particularly when clinicians used terms such as 'no hope' and 'hopeless'. Being given a specific time frame for their prognosis (e.g. 2 months) was also seen to reduce hope (Lobb et. al, 2010).

Generally, patients were found to seek as much information as possible, although this varied both by individual and by timepoint (Lobb et. al, 2010), and they appreciated when healthcare professionals conveyed this positively, as a lack of positive information to focus on threatened their ability to hope for the future, and induced feelings of uncertainty and anxiety (Sterckx et. al, 2013).

Whilst it is understandable that some people with a diagnosis of HGG would like clear information about their prognosis to enable them to plan for their future, it is important to highlight that health care professionals often cannot predict the rate and nature of disease progression, and therefore may not be able to provide the answers that some patients and their families wish for (Halkett et. al, 2010). Additionally, patients may not know which questions to

ask, or understand some of the medical terminology used, which further hinders their acquisition of appropriate information (Sterckx et. al, 2013), which was also a finding of my study.

### **7.10.1.3 Poor communication from health professionals**

Diagnosis appears to be a particularly vulnerable moment for the SWB of patients and their families, and the way in which prognosis is communicated at this point potentially has a significant and enduring impact on levels of hope. Evidence of this impact was also identified in my study. In Lobb's study (Lobb et. al, 2010), only two out of 40 participants recounted a positive experience in terms of clinician communication of their diagnosis. Sterckx et. al (2013) also found evidence of anger amongst participants at the way in which their diagnosis was conveyed, with some suggesting that they did not feel that the terminal nature of their disease had been communicated to them. Participants in a study conducted in Denmark by Piil et. al (2015) revealed that discussions with clinicians who only offered pessimistic messages eroded hope. Conversely, when interviewees were given positive messages from their clinical teams, this was greatly appreciated and seen to be beneficial. One participant in Lobb's study (2011) was extremely grateful to her doctor, who had encouraged her to believe in a prognosis of at least 6 months. This gave her permission to plan for the future and promoted a sense of hopefulness and positivity. This desire for clinicians to communicate positively as a means of maintaining hope was also identified in other studies (Cavers et. al, 2012; Piil et. al, 2015). Such exemplars emphasise the power healthcare professionals have to control levels of hope in people newly-diagnosed with HGG. The ability to communicate information in a way which preserves hope is undoubtedly challenging in this patient group, yet it appears to be of paramount importance to their ongoing SWB (Piil et. al, 2015). The work of Piil et. al (2018) reinforces this suggestion by recognising that participants had an unmet need from their healthcare team to be supported in maintaining and redefining hope in acknowledgement of its significance to quality of life. When discussions of hope did occur, this appeared to facilitate adaptation to their disease and prognosis (Piil et. al, 2015). Interestingly, evidence of the fundamental role of the Clinical Nurse

Specialist in ensuring effective communication with people with HGG is scarce in the literature. However, this was a key finding of my study.

### **7.10.2 Sense of Control**

In accordance with my study findings, loss of control over numerous aspects of their lives was also widely reported in the literature as having a detrimental impact on the SWB of people with HGG (Halkett, 2010). The prospect and reality of cognitive decline exacerbated feelings of helplessness, as did uncertainty about the disease trajectory (Halkett, 2010; Sterckx et. al, 2013). A sense of control was particularly vulnerable to three major threats; Shock and uncertainty at the time of diagnosis, loss of independence/autonomy and difficulty accessing individualised information about their disease.

#### **7.10.2.1 Shock and uncertainty at diagnosis**

On hearing their diagnosis, everything became unfamiliar and uncertain to many people. Participants reported difficulty processing the reality of having a brain tumour (Lobb et. al, 2011). They felt that they no longer had control over their future. They were unsure how their symptoms would progress, and what impact this would have on the lives of their families as well as themselves (Halkett et. al, 2010; Cavers et.al, 2012; Piil et. al, 2018). As was the case with my study, participants in Sterckx et. al's research (2015) felt that aspects of their lives over which they had always had a degree of control such as work and financial stability were thrown into jeopardy. Participants also experienced a sense of powerlessness relating to decisions about their healthcare and reported feeling as if they were 'on the sidelines of their own life' (Sterckx et. al, 2015 pg 386). Given the prognosis of their disease, they often did not feel that there was a genuine alternative to the treatment proposed by their clinician. This lack of control was intensified when there were cognitive deficits and/or dysphasia present, as these further hampered discussions with healthcare professionals regarding their treatment. Patients sometimes lost the ability to advocate for themselves and resorted to relying on family members to act as surrogates (Fox and Lantz, 1997; Halkett et. al, 2010).

### **7.10.2.2 Loss of independence/autonomy**

Loss of autonomy is highlighted by Sterckx et. al (2013) as having a fundamental impact on the lives of those with HGG. The inability to perform previous roles, earn a living or go out independently caused considerable distress, humiliation and loss of self-esteem (Sterckx et. al, 2013; Sterckx et. al, 2015). Being unable to drive as a result of their diagnosis was felt to be particularly detrimental to SWB (Halkett et. al, 2010; Sterckx et. al, 2013; Sterckx et. al, 2015). This was associated with a loss of independence and subsequent forfeiture of control over their everyday activities. This inability to drive was highlighted by patients in Halkett et. al's study as major issue, with comments such as 'we have got a driving issue' and 'it is frustrating having to rely on other people' being made (Halkett et. al, 2010 pg 117).

Preservation of independence for as long as possible was a priority for many participants. Piil et. al (2018) revealed that some patients managed to achieve this through an ongoing process of adapting both psychologically and practically to accommodate neurological deficits. Although these findings were similar to mine, the literature did not appear to make the same connection to between loss of autonomy and the impact on sense of identity and sense of control as my study did. There was also a lack of evidence on longitudinal changes to loss of autonomy, whereas my study highlighted the shifting profile of this aspect of SWB depending on the stage of disease journey.

### **7.10.2.3 Difficulty getting information that is individualised**

Individualised information appeared to enable people to take back a degree of control over their lives. For example, practical information about treatment schedules allowed them to plan their days, and guidance on managing symptoms promoted a degree of autonomy, which was seen to be highly beneficial (Sterckx et. al, 2013; Piil et. al, 2018). The presence of a constant contact professional allowed them to access information as and when it was individually appropriate, and reduced feelings of uncertainty and helplessness (Halkett et. al, 2010; Sterckx et. al, 2013; Sterckx et. al, 2015). Participants in my study also highlighted the value of this individualised support to SWB.

Unfortunately, some interviewees reported difficulties in accessing the information they needed to understand and take control of their illness (Fox and Lantz, 1997). Lobb et. al (2011) emphasised the responsibility of health professionals to deduce how much information patients and their families would like, and to respect this preference as a means of supporting them to retain a sense of control over their lives. This theory of the potential for health professionals to help patients regain power through honest and appropriate information-giving is supported by Sterckx et. al (2015), who also found this to be highly beneficial to the wellbeing of people with HGG.

### **7.10.3 Sense of Identity**

The literature highlighted a particularly detrimental impact of being diagnosed with a brain tumour on an individual's sense of identity. This appears, at least partly, related to the fact that the brain controls aspects such as personality and intellect, which define personal identity (Boele et. al, 2016). There was a prevailing sense that people with HGG felt that they were 'just a shell of who they once were' (Sterckx et. al, 2015: pg 385). As was also revealed by my study, the prospect of surgery on the brain was seen to be particularly alarming, with many patients expressing anxiety as to how they would be afterwards. Some were concerned about whether or not they would be able to perform such fundamental tasks as speaking, walking and eating (Halkett et. al, 2010). Longitudinal data on the changing perceptions of their sense of identity according to stages in the disease and treatment journey was not found in the literature, but was an important aspect of my findings.

Another example of the negative impact of a HGG diagnosis on a person's sense of identity was offered by the research of Fox and Lantz (1997), with some participants insinuating that memory loss felt like 'losing track of who you really were' (pg 247). Interviewees revealed that they had lost the connection with the person they used to be. They attempted to retain their sense of identity by maintaining previous roles wherever possible. For example, one patient highlighted the benefit to his SWB of being able to continue with seemingly simple tasks such as mowing the lawn.

Such anxieties regarding the threats posed to sense of identity are strikingly similar to my study findings, as are the attempts to preserve identity by continuing to undertake roles which had previously defined their identity, such as household tasks and caring for dependents.

A number of issues appeared to threaten the sense of identity of people following a diagnosis of HGG, and subsequently harmed their SWB. These included: The impact on family role/relationships, symptoms and side-effects, lack of individualised care, loss of sense of purpose/meaning, social isolation, loss of normality and burden of the treatment schedule.

#### **7.10.3.1 Impact on family role/relationships**

Five studies reported on the significant impact a diagnosis of HGG had on family life, and in particular on an individual's role within the family unit (Fox and Lantz, 1997; Halkett, 2010; Piil, 2015; Sterckx, 2015; Piil, 2016). In Fox and Lantz's study (1997), participants and their families implied that HGG was a 'family disease, because it affects everybody' (pg 247). Some carers reported feeling as if they had become a single parent with the additional significant burden of caring for their spouse. They had also taken on roles that had historically been performed by their partners, such as preparing meals or managing family finances (Halkett et. al, 2010). Patients reported their distress at this increased dependence on their spouse, and the sense that their relationship had become one of carer and patient rather than that of equal partners (Halkett et. al, 2010). However, there was limited discussion on the impact this change in role had on their sense of identity.

Participants in Halkett et. al's study (2010) expressed concern about the impact their diagnosis would have on their family. In particular, anxieties around how family members should manage seizures were articulated. It was clear that the potential for children to witness their parent having a seizure was understandably an extremely distressing prospect for some participants.

There was particular mention of the effect their diagnosis had on relationships with partners, and how this affected their self-esteem (Piil et al,

2015; Sterckx et. al, 2015; Piil et al, 2016). Interviewees talked of a loss of connection and sexual attraction with their partners. They also discussed undesirable role changes in their relationships as they became increasingly dependent on their spouse for support. In addition, partners expressed dismay at the realisation that they could no longer hold a conversation or exchange views with their partner in the way that they were used to (Sterckx et. al, 2015), in a strikingly similar way to some of the respondents in my study.

Despite these negative effects on participants' sense of identity within their families, it was clear that there were some perceived benefits. For example, Piil et. al's study (2015) revealed that some participants and their partners felt an improvement in their relationship as they had developed a shared solidarity with their partner in the face of their disease and prognosis. Piil et al (2015) suggested that patients and their partners felt that they had joined forces in the face of the disease. Admiration and gratitude for the commitment and support of their partner was also seen as a positive outcome, which subsequently enhanced wellbeing (Sterckx et. al, 2015).

#### **7.10.3.2 Symptoms/side effects**

Patients in seven studies reported significant symptoms and side effects resulting from their disease and treatment, and it appeared that these generally seemed to worsen over time (Cavers et. al, 2012). This trend is strikingly different to my findings, which instead emphasised a general improvement in SWB once chemotherapy and radiotherapy were completed and side effects began to subside. Some participants experienced disabilities that left them unable to fulfil the work and social activities that had previously defined their sense of identity (Halkett et. al, 2010; Piil et. al, 2016). These included cognitive deficits such as loss of vision and balance, headaches and seizures as well as side effects of treatment such as personality changes, nausea and weight gain resulting from steroid therapy (Bennett et. al, 2016; Boele et. al, 2016). Issues with memory and speech were particularly distressing and led to feelings of frustration and anguish



when trying to hold conversations or follow instructions (Cavers et. al, 2012; Piil et. al, 2015; Piil et. al, 2016).

Tiredness and fatigue were reported as having a significant impact on the ability of participants to take part in activities that had previously defined their sense of identity, and this appeared to worsen along the disease trajectory (Sterckx et. al, 2013). As was the case with my study, seizures were also widely reported in the literature as a symptom which caused participants significant anxiety and threatened their confidence to live their lives as before, hence activities which may have been beneficial to SWB such as social engagements and exercise being avoided (Fox and Lantz, 1997; Halkett et. al, 2010; Cavers et. al, 2012; Piil et. al, 2015).

A particularly interesting exemplar offered by Fox and Lantz (1997) involved a participant who reported significant physical disability, having to use a wheelchair to mobilise. Despite these limitations, he reported this did not impact on his wellbeing as negatively as might be expected, as he could still communicate and was mentally aware. Such an insight offers a crucial reminder that not all domains of SWB rank equally. Each individual will have a different perspective on what the most important issues are for their sense of identity. To make generalised assumptions on what the most fundamental concerns might be does not endorse the individualised care that participants have reported to be so valuable.

### **7.10.3.3 Lack of individualised care**

The notion of being treated as a medical case rather than as a person was prevalent throughout the studies, and echoed the experiences of some participants in my study (Fox and Lantz, 1997; Sterckx et. al, 2013; Sterckx et. al, 2015; Boele et. al, 2016). Evidence of this could be found in a study conducted by Boele et. al (2016), in which participants expressed concern that they did not think that their physicians paid enough attention to 'the person behind the disease' (pg 3013). Sterckx et. al (2015) also identified that when patients were not given time with clinicians to discuss concerns of a more existential or psychological nature, they felt that they were being

treated as 'the disease' rather than as an individual. Participants reported feelings of disregard as healthcare professionals and insurance companies focused on the results of the medication and box-ticking exercises over the participant's sense of wellbeing (Sterckx et. al, 2015). In scenarios where care was offered from a more holistic viewpoint this was much appreciated, and helped participants to feel valued as individuals, thus enhancing their self-esteem and reported wellbeing (Sterckx et. al, 2013).

In terms of the need for information about their diagnosis, there was considerable evidence in support of my findings that the form that this should take was highly subjective. Some wanted as much information as possible at the time of diagnosis, others felt that this was inappropriate and did not enable them to process the facts. Some felt that written information was the most useful format, whereas others needed verbal communication, particularly if they had cognitive impairments. Some wanted to hear all the facts about their disease and prognosis, others could only handle minimal information that had a positive focus. Information needs also changed over time, as participants appeared to fluctuate between information seeking and avoidance (Halkett et. al, 2010). Such individual information needs are undoubtedly extremely challenging for healthcare professionals to predict and manage, yet it appears that succeeding in addressing differing information needs is fundamental to the preservation of SWB in people with HGG.

#### **7.10.3.4 Loss of sense of purpose/meaning**

Such a devastating diagnosis led a number of interviewees to re-evaluate the purpose of their lives. When they had difficulty finding a sense of meaning, this often resulted in distress and a reduction in SWB (Cavers et. al, 2012). However, not all patients experienced a detrimental impact on their sense of purpose. Indeed, some reported an unexpected benefit of intensifying their focus on the meaning of life, as it promoted an appreciation of every day, which helped them to adapt psychologically to their prognosis. Sterckx et. al (2013) identified the potential for a HGG diagnosis to prompt people to make positive changes in their lives and to look at things from a new perspective.

Additionally, finding a sense of meaning was cited as an important means of drawing strength and maintaining a sense of wellbeing and positivity in the face of their prognosis (Sterckx et. al, 2015). Such positive outcomes were also identified in my study, as participants re-evaluated what was important to their lives and reflected on changes they wished to make or had made as a result of their diagnosis.

#### **7.10.3.5 Social isolation**

There was a suggestion that the particular stigma of having a neurological illness may lead to intensified feelings of social isolation. This was often worsened by visible consequences of the disease such as seizures and changes in appearance. On the other hand, this isolation could also be consolidated earlier on in the disease trajectory when people may still look and feel well, making it difficult for others to understand the ‘invisible’ impact of having received a HGG diagnosis. There was the potential for a sense of ‘feeling alone’, as few people could relate to the experience of participants and their families (Fox and Lantz, 1997). Sterckx et al. (2015) reinforced this suggestion of social isolation, with the revelation that some interviewees felt that certain friends avoided them, and particularly avoided talking about their diagnosis.

In addition to these emotional burdens on their social lives, some reported that the amount of time taken up with hospital visits left little opportunity to socialise. They also felt that they were no longer able to participate in their social lives as before as a result of fatigue and diminishing cognitive and physical abilities (Cavers et. al, 2012; Piil et. a, 2015). Similarly, Bennett et. al (2016) found that anxieties around the unpredictable onset of headaches prevented some participants from engaging in social activities, mainly as they worried that people would be concerned and anxious if they started experiencing symptoms in their company. Evidence from the literature concerning fluctuations in attitudes towards working and socialising throughout the disease journey could not be found, but was an important aspect of my study findings.

### **7.10.3.6 Loss of 'normality'**

The terms 'normal' and 'normality' were used on numerous occasions in the literature, and it was clear that there was an overwhelming desire amongst participants to maintain a normal life for as long as possible as a means of preserving their sense of identity and wellbeing (Cavers et. al, 2012; Bennett et. al, 2016; Pill et. al, 2016). When individuals felt uncertain about their potential to continue with activities that they considered to be central to their normal lives such as working and socialising, this led to feelings of despondency and a loss of identity (Halkett et. al, 2010). Despite this risk, a number of interviewees reported the positive benefits to their sense of identity of being able to maintain as many aspects of their normal lives as possible. This was particularly prevalent in the work of Sterckx et. al (2015), who found that participants gained considerable satisfaction from being able to do 'the little things' in life such as domestic tasks, which significantly helped them to maintain a sense of purpose and identity in a similar way to the participants in my study.

### **7.10.3.7 Burden of treatment schedule**

As was the case in my study, participants in two studies felt that their lives had become determined by medication schedules, and many relied heavily on their carers to manage complex treatment regimes. The amount of time spent at hospital during treatment also significantly disrupted the every day lives of both participants and their carers (Cavers et. al, 2012; Halkett et. al, 2010). In addition, navigating the intricacies of the medical system was cited by many as a burdensome task, which dominated their thoughts and left little time for more personal issues (Fox and Lantz, 1997). Discussion on the varying impact of the treatment schedule on SWB depending on the stage of disease trajectory could not be found in the literature. However, this was found to be a fundamental factor in the temporal nature of SWB in my study.

## **7.11 Evidence for strategies which preserve SWB**

These findings have highlighted a considerable number of potential threats to the SWB of people diagnosed with HGG. Whilst these are daunting in their nature and scope, there was some evidence in support of strategies that were

reported to help manage these threats and preserve a sense of SWB, which was also the case in my study. These included: fostering healthy lifestyle choices, maintaining a positive outlook, sharing experiences and receiving individualised care from health professionals.

#### **7.11.1 Fostering healthy lifestyle choices**

Fostering healthy lifestyle choices appeared to offer considerable benefits to the wellbeing of people with a diagnosis of HGG. Not only in terms of their physical health, but also in the sense that it facilitated feelings of both hope and control (Piil et. al, 2018). Participants in Piil et. al's study (2015) displayed an increased drive to become engaged in health promotion activities, particularly in the post-operative and early treatment phases. Such activities included adopting a healthier diet, reducing alcohol and cigarette consumption and participating in yoga. In a strikingly similar finding to my study, taking regular exercise was seen to have multiple advantages. Not only did it improve physical health and perceived ability to tolerate cancer treatment, it also promoted a feeling of empowerment, as participants felt that this was an aspect of their health over which they could retain some control. The potential to engage socially with others during exercise (at the gym for example) was also cited for its positive contribution to SWB (Piil et. al, 2015).

#### **7.11.2 Maintaining a positive outlook**

Participants in four studies referred to the importance of fostering a positive mental attitude as a means of preserving their wellbeing (Fox and Lantz, 1997; Cavers et. al, 2012; Sterckx et. al, 2015; Bennett et. al, 2016). For example, the principle aim of Bennett et. al's study (2016) was to investigate the impact of headaches on the quality of life of people with a HGG. However, their results identified a consistent and overriding theme relating to the importance of maintaining an inner strength and positivity. One participant described feeling 'thankful for what you've still got' (pg 4), and there was a perceived sense of determination not to focus on the negative aspects of their diagnosis. This suggestion of the importance of 'staying optimistic' was also identified by Sterckx et. al (2015), who reasoned that a positive attitude empowered patients to cope with their cancer more confidently. Similarly,

Cavers et. al (2012) found remarkable resilience and a determination to remain positive amongst participants, despite the fact that this was sometimes extremely difficult to maintain. Some reported that every day felt more valuable, and that this renewed appreciation for life encouraged feelings of hope and enhanced SWB.

Whilst it is gratifying to hear of the positive outlook maintained by some participants despite their prognosis, there is potential for this positivity to be overstated. It could be suggested that both the nature of data collection and the cultural tendency to favour a 'fighting spirit' against cancer may have had an impact on these findings. For example, in the study conducted by Cavers et. al (2012), caregivers were included in the interview process, which may have led to participants feeling the need to display an attitude of strength and positivity as a means of reassuring their partners.

### **7.11.3 Sharing experiences with peers**

There was a suggestion in the literature that sharing experiences with others who they could relate to may have a positive impact on SWB. Sterckx et. al (2015) reported that having contact with other patients was a source of hope for some of their participants. They suggested that talking to others who have endured similar experiences at organisations such as support groups encouraged positivity. It appeared that sharing experiences of symptoms and how to manage them helped participants to cope, and potentially led to improved levels of confidence and autonomy (Sterckx, 2013). This desire to connect with other people with a HGG diagnosis was also emphasised by Piil et. al (2018), who identified a wish to exchange experiences with peers amongst their participants. However, this appeared to be an unmet need for some (Piil et. al, 2015). It is important to highlight that this finding is at odds with my study, which in fact found that sharing experiences had the potential to be counterproductive if the participant felt that they were not relevant to them. This disparity emphasises the idea that sharing experiences with peers is a highly subjective form of support. Whilst it may prove to be beneficial to some, it can also be detrimental to others.

#### **7.11.4 Provision of individualised care**

The significant benefits of receiving information, support and communication that is personalised to the individual were highly prevalent amongst the identified studies as well as in my research, suggesting that this has a fundamental impact on the SWB of people with HGG and their ability to adapt to illness (Halkett et. al, 2010; Lobb et. al, 2011; Cavers et. al, 2012; Sterckx et. al, 2013; Piil et. al, 2015; Sterckx et. al, 2015; Piil et. al, 2018). In particular, the importance of timing when it came to communicating diagnosis appeared to be a highly emotive and subjective matter. Whilst some participants sought detailed information as soon as possible as a means of taking control of their situation (Halkett et. al, 2010; Sterckx et. al, 2015), others could not process extensive detail early on in the disease trajectory. A number of participants deliberately avoided asking about prognosis as a means of retaining hope for the future, and felt shocked to be presented with the stark reality of their disease (Halkett et. al, 2010; Lobb et. al, 2011; Sterckx et. al, 2013; Piil et. al, 2015).

Tailoring information and communication about their disease to the individual appears to offer the best strategy for maintenance of hope and the preservation of SWB. Lobb et. al (2011) propose one strategy for clinicians may be to ascertain the level of information desired on an individual level, and revisit this on a regular basis rather than expecting the communication of prognostic information to be conducted in a one-off conversation. Such an approach acknowledges the fact that patients' information needs are dynamic and may change over time, and that information must be communicated in an empathetic and sensitive manner, a suggestion that also resulted from my findings (Cavers et. al, 2012; Piil et. al, 2015; Piil et. al, 2018). Lobb et. al (2011) also stress the need for specific communication skills training for healthcare professionals caring for people with HGG, with a particular emphasis on the specific challenges of cognitive deficits and the difficulties of discussing terminal prognoses. The importance of identifying the format in which people prefer to receive information is also essential as a means of meeting the differing needs of individuals. Whilst some sought written information, others much preferred to have a conversation with a

professional who understood their individual circumstances (Halkett et. al, 2010; Pill et.al, 2015).

Halkett et. al (2010) suggested that a key component of individualised care is maintaining lines of communication with a professional who is knowledgeable, accessible and knows the individual. Care that offers stability, compassion and a holistic approach is widely claimed to be beneficial to patients (Sterckx et. al, 2013; Sterckx et. al, 2015). Such support encourages feelings of empowerment and control, which are crucial to the SWB of people with HGG. There appeared to be an unmet need for professional care that allowed participants to discuss their emotions and concerns on an existential level. This was deemed to be essential to care that was individualised and holistic. However, Sterckx et. al (2015) reported that participants felt that they were often denied the opportunity to have such discussions. Findings from my study suggested that the CNS has a crucial role to play in providing such individualised care and addressing this unmet need. However, further evidence on the importance of the CNS role to the SWB of people with HGG could not be found in the literature.

### **7.12 Conflicting findings**

There were a number of contradictory findings in the literature, particularly relating to the nature of healthcare provision. Whilst some participants felt well-supported by their clinicians and appreciated access to compassionate and knowledgeable experts, others highlighted poor experiences and unmet needs. Another example of conflicting evidence involved the prevalence of fatigue. Piil et. al (2015) identified fatigue as being the most debilitating symptom experienced by people with HGG. On the other hand, Bennett et. al (2016) found that although fatigue was present for many, it was not associated with negative connotations as participants found it easy to manage by incorporating daytime naps.

Such contradictory findings are unsurprising given the diversity of the studies included. Data was collected from a variety of countries, all of which have differing healthcare systems. The dates of publication also span a period



of 21 years, over which time approaches to care have evolved and awareness of the holistic needs of patients has increased. It is fundamental that the specific context of each study is taken into account when considering relevance to a local population. Whilst it may seem preferable to draw firmer conclusions from the literature search, it is more important to remain true to the evidence and highlight conflicting findings rather than make inaccurate assumptions (Aveyard, 2010).

### **7.13 Limitations of the qualitative studies reviewed**

Whilst this review of the qualitative literature has generated a number of interesting insights into the SWB of people diagnosed with HGG, there are some important limitations that must be taken into account when considering the trustworthiness and transferability of the findings. Firstly, two of the papers were not exclusively focused on people with a diagnosis of HGG. Fox and Lantz (1997) recruited participants diagnosed with any primary or metastatic brain tumour. However, it was decided that this paper should be included in the review as it was the first to begin exploring quality of life issues in the brain tumour population using qualitative methodology, and was therefore considered to be a seminal work. Similarly, as Cavers et. al (2012) recruited patients with a suspected brain tumour, not all of these proceeded to be diagnosed with a HGG (9 out of 26 were not HGG). However, this paper offered a unique insight into the impact of awaiting a formal diagnosis on SWB, and as the majority of participants did have a HGG it was felt that it was both important and appropriate for this paper to be included. The fact that it adopted a longitudinal approach was also highly relevant to the current study.

It is important to mention the fact that all of the participants involved in these studies were willing to discuss their experiences. The exclusion of those who were either not willing or not able to discuss these issues may have biased findings. Whilst this is an unavoidable issue for the majority of qualitative research, including my own, it is particularly pertinent in this patient group. Those who were unable to participate due to debilitating cognitive symptoms may well have reported a significantly different impact

of a HGG diagnosis on their SWB. However, this data could not be captured by researchers as a result of both ethical and practical issues.

Finally, it was realised on closer inspection of the two papers written by Piil et. al in 2015 and 2018 that these were in fact discussing the same data. However, the 2018 paper had incorporated a mixed methods approach. Again, the relevance of the findings was deemed to be particularly high in relation to this study, and it was therefore decided that both papers would be included in the review, but only the qualitative findings would be taken into consideration.

### **7.14 Implications for this study**

During the last decade there has been an exponential increase in the volume of research undertaken to explore the wellbeing and quality of life of people diagnosed with brain tumours. On consideration of the findings of this qualitative literature review, there were some apparent 'gaps' in the evidence, which this study addressed as follows:

1. It focused specifically on people with a diagnosis of HGG rather than brain tumours in general.
2. It offered a longitudinal perspective by including data collected at different stages in the disease and treatment journey.
3. It explored the experiences and perceptions of the impact of a diagnosis of HGG on SWB using a phenomenological methodology.

These characteristics are supported by the proposals of Sterckx et. al (2013), who identified with many of these deficiencies in their systematic review. It is hoped that incorporating these details has helped to ensure that this study results in a unique and valuable contribution to the body of available literature.

### **7.15 Conclusion**

This literature review has sought to explore the evidence relating to the research question 'What is the impact on wellbeing/quality of life of a

diagnosis of high grade glioma?’ The initial scoping review of relevant quantitative research identified a number of studies that had used validated questionnaires to collect data on the impact of a HGG diagnosis on QoL. Whilst this resulted in a useful overview of prevalent issues, the identification of which factors were most important from the patient’s perspective was absent.

The ensuing review of qualitative literature suggested that in the past decade researchers have begun to address this omission. Three of the key domains of SWB that appear to be most relevant to participants have been identified by my study as Sense of Control, Hope and Sense of Identity. The literature supports this assertion, and suggests that these domains are threatened by a diagnosis of HGG as a result of issues such as loss of independence and normality, social isolation, poor communication and lack of information from health professionals. There is some evidence of strategies that have proved to assist individuals in preserving their SWB following diagnosis. These include maintaining a positive outlook, sharing experiences with peers and the provision of individualised care. This study has enhanced the body of literature available in this area by undertaking a uniquely longitudinal phenomenological approach to exploring the SWB of people with HGG in greater depth from the perspective of the participants. The similarities and differences between the findings of this study and the outcomes of the literature review will now be discussed in more detail in the discussion chapter.

## **Chapter 8: Discussion**

## **8.1 Introduction and structure of chapter**

The aim of this chapter is to discuss in detail the findings of this study in relation to the initial aims and objectives for the project. In particular, the evidence for proposing Sense of Identity, Hope and Sense of Control as key domains of the SWB of people with HGG will be explored in depth. This will involve examination of similarities and differences between the study findings and the findings of the literature review for each of these domains, and will highlight the significant and unique insights from this study. This chapter then reconsiders the definition of SWB derived from the concept analysis in the light of these new findings, before offering reflections on conducting longitudinal research and analysis, unexpected findings, and study limitations. Recommendations for future research and implications for practice are also considered for each SWB domain.

## **8.2 The conceptual model of SWB for people with HGG, and the relationship between the three domains**

Interpretive analysis of the research findings resulted in the development of an innovative conceptual model of the SWB of people with HGG (Figure 8.1). This model portrays Sense of Identity, Hope and Sense of Control as the fundamental domains of SWB, and also demonstrates how they relate to each other throughout the disease trajectory. At the time of diagnosis and surgery, as well as throughout chemotherapy and radiotherapy, Sense of Identity, Hope and Sense of Control were all diminished, and SWB was severely impaired.

An improvement was seen in all three SWB domains when chemotherapy and radiotherapy were completed. The increased availability of time, as well as the general easing of side effects allowed individuals to regain a degree of control over their daily lives, participate in activities that enhanced their sense of identity and allow themselves to hope for the future.

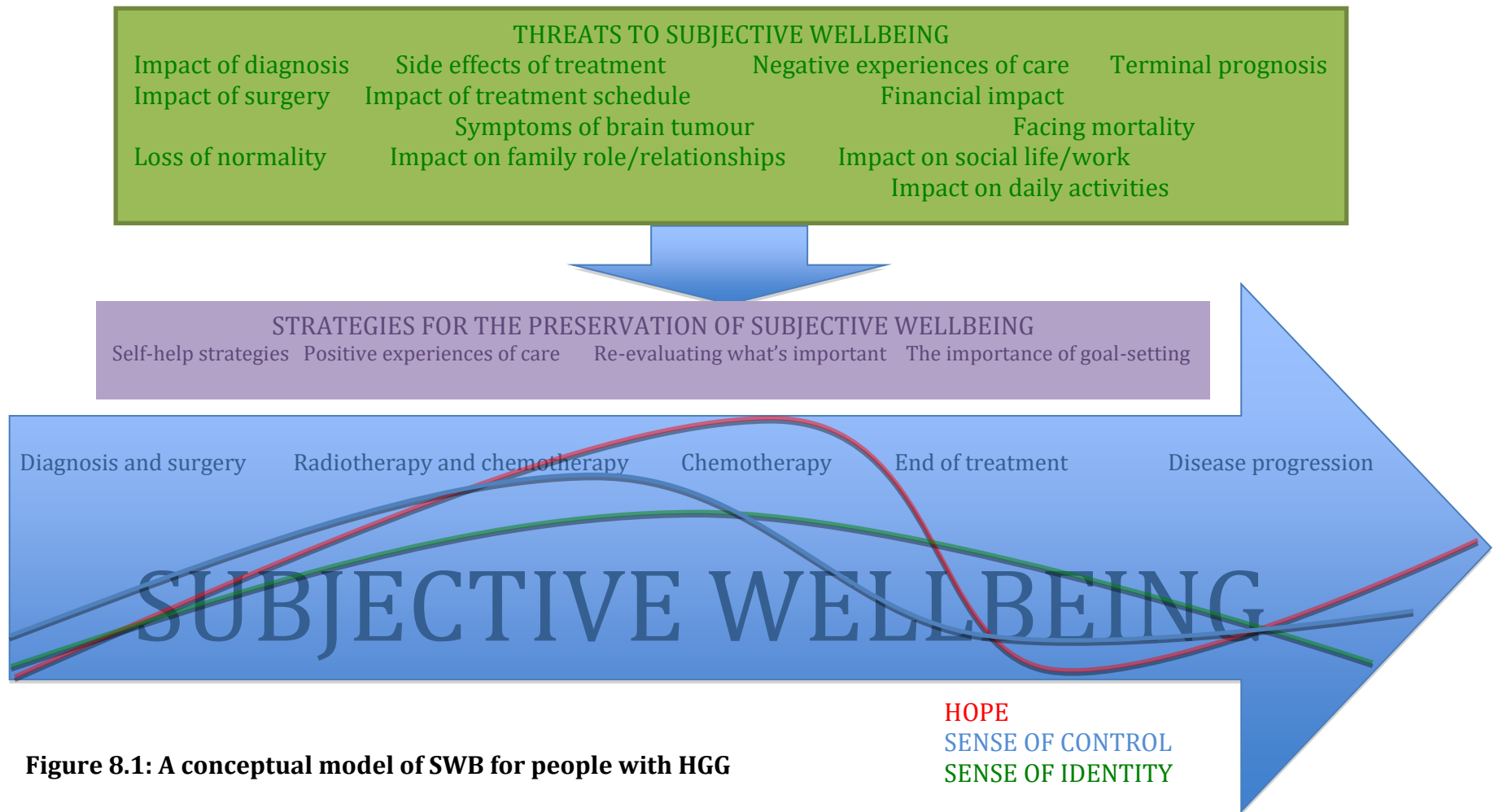
As treatment came to an end, participants spoke of their hopes to begin spending more time on leisure activities. However, the end of treatment also

presented a threat to hope, as a realisation dawned that they were unlikely to return to their pre-HGG health, and had a greater awareness of their mortality. As their HGG journey progressed, there was evidence of a redefining of hope. Participants expressed a determination to retain a positive outlook, and focused their hopes on spending more time with family, making changes to their work lives and the ongoing welfare of their families after their death.

The 'Sense of Control' domain followed a similar longitudinal profile to the 'Hope' domain, and was also detrimentally affected during the initial periods of diagnosis, surgery and combined chemotherapy and radiotherapy. The two domains were closely related, as it appeared difficult to hope for the future when life felt unpredictable and out of control. A sense of control appeared to return towards the end of treatment as participants had adapted to their schedules and became accustomed with approaches to managing symptoms and side effects. They also experienced a boost to their SWB at the end of treatment as they regained control over their time. However, the end of treatment also triggered feelings of uncertainty about how their disease would progress and feelings of abandonment as contact with health professionals reduced, both of which contributed to a loss of control that did not recover to the extent that their feelings of hopefulness did.

Similarly to the other two domains, Sense of Identity was most vulnerable at the time of initial diagnosis and surgery, and during combined chemotherapy and radiotherapy treatment. The shock of their diagnosis, and the loss of independence following surgery were particularly damaging to their self-image. Sense of Identity also followed a similar trajectory to Hope and Sense of Control in the sense that participants experienced significant improvements at the end of treatment when their lives were no longer dictated by a medication schedule and they were able to feel a degree of normality returning. A noticeable longitudinal pattern in this domain which distinguished it from the others was that it did not appear to recover later on in the disease trajectory, as disease burden and symptoms worsened, the threat to sense of identity increased.

It is important to note that this model only applies to the phases of the illness trajectory captured during the interviews. Had it been possible to include data from more participants at the later stages of their disease (in either the stable disease or palliative phases), the model may have evolved differently. Its transferability to these later stages is therefore restricted.



**Figure 8.1: A conceptual model of SWB for people with HGG**



### 8.3 Objectives of the study revisited

The following objectives were established at the outset of the study, and were addressed in the following ways:

*Objective 1: To explore the lived experiences and perceptions of people with high grade gliomas in terms of their SWB at various points throughout their illness.*

The findings indicate that SWB comprised three key domains: Hope, Sense of Identity and Sense of Control. These domains of wellbeing were threatened in a variety of ways over the course of their illness trajectory as participants adapted to living with HGG. These findings will be discussed in greater detail later in this chapter.

*Objective 2: To investigate the lived experiences and perceptions of people with high-grade gliomas regarding the assessment tools currently used to monitor their wellbeing.*

Whilst not all participants had experience of using these tools, there were mixed reports on the use and value of the assessment tools administered by the hospital. These generally took the form of QoL questionnaires or Holistic Needs Assessments. Some found the tools to be a useful prompt for discussions with their CNS, whereas others thought that some of the questions seemed irrelevant, and felt they would rather have a conversation with someone who knew them. Indeed, talking with a key worker on a regular basis was cited as one of the most positive aspects of their care for participants. The suggestion arising from this research is that people with HGG preferred informal monitoring of their wellbeing with someone who they felt they could trust, and who knew them well.

This finding has implications for the increasing trend of digital and remote monitoring systems in cancer services. Such systems offer a number of benefits such as preventing unnecessary hospital visits and releasing clinic capacity. Despite these benefits, it is important to have an awareness of the

value of a personal relationship with a key worker to the care of people with cancer. However, as the number of people with a diagnosis with cancer increases, this may not always be possible. There is potential for future research into the nature of monitoring the SWB of people with cancer. The potential stratification of those with the highest support needs (such as those with terminal prognoses like HGG) could offer a means of ensuring that monitoring systems are appropriately allocated.

*Objective 3: To clarify the differences between wellbeing and quality of life.*

The differences between the terms wellbeing and quality of life were examined through the process of conducting a concept analysis of subjective wellbeing, the details of which are in Chapter 2. Whilst the terms are often used interchangeably in the literature, wellbeing (which is often referred to in two parts: objective and subjective wellbeing) is only one aspect of QoL, which also includes components such as living conditions, education, health and the environment.

Interestingly, it became clear during the data collection phase that many participants did not understand the meaning of the terms 'wellbeing' and 'subjective wellbeing', and often used 'day-to-day life' or 'quality of life' as surrogate terms. It would be useful to consider the impact of this discrepancy in understanding of the terms 'wellbeing' and 'subjective wellbeing' between health professionals and service users in more detail. Improved clarity and understanding could potentially enhance patient care by minimising miscommunication. Objective 3 sought to address this lack of clarity, but further investigation is needed to increase understanding of such terminology on a broader scale.

## **8.4 The relationship between study findings and the broader literature**

Following analysis of the themes identified in this study, it was important to identify any relationship between the study findings, the outcomes of the

literature review and the broader knowledge base in this field. This allowed for the interpretation of any similarities and differences between the study findings and the extant literature on the subject, as well as identifying original insights resulting from my research that offer a significant contribution to the knowledge base. The identified themes will now be discussed within the context of the three SWB domains, including the findings relating to strategies for the preservation of SWB, and will also take into account evidence collated from wider reading that offers a valuable contribution to the discussion.

## **8.5 Domain 1-Hope**

This study identified hope as a key domain of the SWB of people with HGG. However, the existence of hope is jeopardised following diagnosis because of the terminal nature of the prognosis, facing mortality and negative experiences of care. In order to analyse in more detail the importance of hope to SWB, the broader literature available concerning the concept of hope in terminal disease was taken in to consideration.

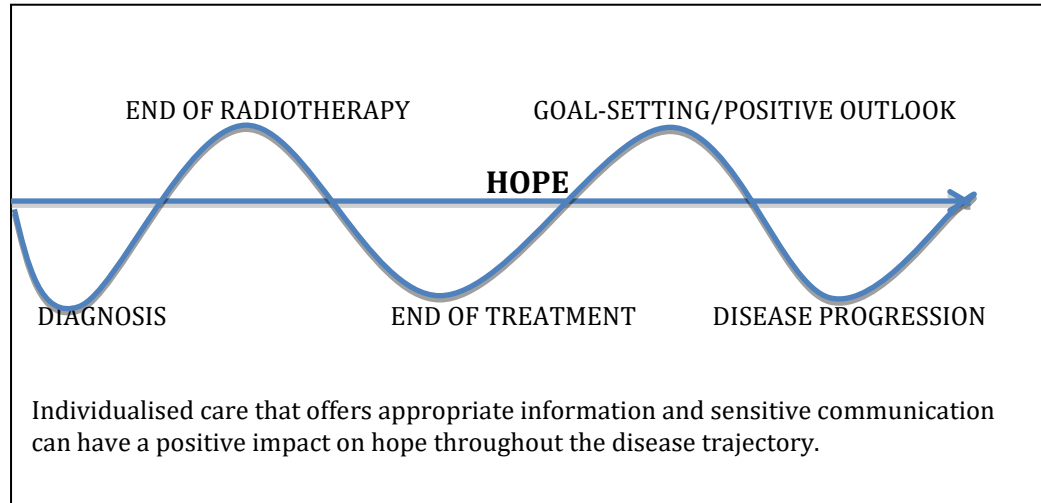
### **8.5.1 What is hope?**

In recent decades, many attempts have been made to define the term 'hope' (Herth, 1990). This is particularly the case in the field of palliative care, where practitioners have long recognised the value of hope in terms of its therapeutic value, but struggled to convey this in tangible terms (Herth and Cutcliffe, 2002). In an attempt to delineate hope more specifically in relation to illness and healthcare, Stephenson (1991) undertook a concept analysis based on literature from the fields of theology, philosophy, psychology and nursing in response to claims that although hope was widely recognised as an essential component of human life, the concept of hope itself remained ill-defined and poorly understood. As an outcome of this concept analysis, Stephenson (1991) proposed that hope is associated with '*anticipation, desire and expectation...of a positive possible future*' (pg 1457) and that it is an essential component of human development and meaning of life. In his conclusion, Stephenson (1991) identified the key attributes of hope. These

included: being a process involving thoughts, feelings, behaviours and relationships; having a meaningful objective; having an element of anticipation; and a positive future orientation. On analysing these attributes in relation to the current study, they appear to offer a useful summary of the participants experiences of hope in the face of their HGG diagnosis, despite the nature of hope evolving, and being threatened at various points throughout their disease journey.

### **8.5.2 The vulnerability and temporality of hope**

This study revealed that the shortened life expectancy of people with HGG often resulted in feelings of hopelessness. Hope was particularly vulnerable at key points in the disease and treatment journey, such as at diagnosis, disease progression and the end of treatment, as participants felt anxious and uncertain about their future. Whilst this was a general trend, it must be acknowledged that there were individual variations within it. Figure 8.2 portrays the fluctuating longitudinal nature of the hope domain.



**Figure 8.2: The fluctuating longitudinal profile of hope following a diagnosis of HGG**

At interview one, participants spoke of their initial shock of the diagnosis, and the threatening impact this had on their ability to hope for the future. Participants also demonstrated their sense of hope at this time, when the intensity of the treatment schedule dominated their time, by discussing how they planned to spend more time on leisure activities such as travelling, reading and visiting museums and galleries in the future. By the time of interview two, hope was threatened by a realisation that they were unlikely to return to normal health and had a greater awareness of their mortality. In interview two, Joan generated hope for her family's future by organising their home life as much as possible to make it easier for them to carry on living normally after her death. Herth's study (1990) supports this identification of temporal changes in hope for people with advanced cancer. Similarly to this study, she found that as disease progressed, goals were re-evaluated, and tended to change focus onto the immediate future and a desire for serenity and peace. Examples offered by Herth (1990) included hoping to be well enough to see visitors or to be pain-free, as well as hopes for the future after their death such as the ongoing welfare of their children.

### **8.5.3 The preservation of hope**

My study has revealed that participants managed to retain a sense of hope for the future by using strategies such as maintaining a positive outlook and

setting themselves goals for the future. Hopes for the future often revolved around spending more time with family or making changes to their work lives. Similar findings in the broader literature on terminal cancer have also suggested that levels of hope appear to remain stable throughout the cancer trajectory (Herth, 1990; Ozen, et. al, 2019). This concept of preserving hope in the face of terminal cancer was explored in depth by Benzein and Saveman (1998). They used a phenomenological hermeneutic method to explore hope among cancer patients receiving palliative care. They found that as long as patients were able to find meaning in life and maintain a positive attitude despite their prognosis, they remained hopeful. This hope appeared to facilitate an inner strength and energy, which enabled them to cope with their disease and subsequently enhanced their SWB. Whilst this resonates with findings from my study, it must be reiterated that Benzein and Saveman's work differs in the sense that it explored the concept of hope amongst palliative cancer patients from the perspective of nurses rather than the patients themselves (1998).

Many researchers have identified the potential of maintaining hope in facilitating an individual's ability to cope with and adapt to their diagnosis (Herth, 1992; Herth and Cutcliffe, 2002; Guclu, 2007) and it is frequently cited as an important coping strategy in accordance with the findings of this study. However, it could be argued that hope emerges as a consequence of successful coping (Rusteon, 1995). A causal relationship is therefore difficult to identify. However, a strong association between levels of hope and coping is widely evident. For example, a Norwegian study conducted by Rusteon et. al (2010) exploring the importance of hope as a mediator of psychological distress and life satisfaction suggested that hope was an important resource for cancer patients as a means of limiting psychological distress. It also concluded that individuals with lower levels of hope were less able to adjust to their disease and consequently reported higher levels of distress. However, any comparisons between Rusteon et. al's work (2010) and the current study should be made with caution, as participants in the Norwegian study were largely identified to be well-educated women with breast cancer. The potential transferability of these findings is therefore limited.

Despite these limitations, it appears that maintaining hope is considered to be a fundamental principle of caring for people with terminal diagnoses, as it enables patients and their families to maximise their wellbeing during their remaining lives, and promotes an optimistic outlook based on anticipating enjoyable future events despite their prognosis (Scanlon, 1989; Benzein and Saveman, 1998).

#### **8.5.4 The importance of goal-setting**

This study found that goal-setting was a highly individual, and often very important aspect of preserving hope. Some participants focused on future milestones, which they found to offer hope for the future and a distraction from their disease and treatment. Others felt safer limiting their aspirations to the short-term. This finding is supported by other available literature on the value of short-term goal-setting and its relevance to the preservation of hope and SWB. For example, Benzein and Saveman (1998) revealed that many patients in their study appeared to focus on specific events such as making a journey, going to the hairdressers or witnessing the academic achievements of loved ones. As their disease progressed, goals were re-evaluated, and changed to focus on the immediate future and a desire for serenity and peace (Herth, 1990). Examples offered by Herth (1990) included hoping to be well enough to see visitors or to be pain-free, as well as hopes for the future after their death such as for the ongoing welfare of their children.

A finding of my study, which does not appear to be identified elsewhere in the literature, indicates that as well as those who felt that limiting their goals to the short-term was the best way to cope, others found aspiring towards physical challenges such as triathlons or exciting holidays helped them to feel positive and hopeful for the future. Such disparities serve as a useful reminder that personal goal setting is both highly individual and fundamentally important to the SWB of people with HGG, and may also reflect a trend towards living longer with a cancer diagnosis since much of the available literature on this subject was written at least 10-20 years ago.

My study proposes that, although the nature of hope changes along the disease trajectory and is threatened at various time points, its preservation is fundamental to the SWB of people with HGG. This can be achieved by fostering an optimistic outlook based on anticipating enjoyable future events, regardless of prognosis, and setting individual goals (Scanlon, 1989; Benzein and Saveman, 1998).

### **8.5.5 The impact of care on hope**

This study identified that poor communication, lack of information and individualised care pose significant threats to maintaining hope (and subsequently SWB) throughout the disease trajectory.

The point of diagnosis was identified in the study as being a high-risk period for the potential erosion of hope as a result of poor communication and lack of information from health professionals. Participants in my study revealed that a lack of information about their prognosis and potential mortality resulted in feelings of uncertainty about how their disease might progress, and what they might expect to experience as they neared death. Evidence from the literature supports this view and reveals that feelings of hopelessness are heightened on hearing the prognosis is terminal. The use of terms such as 'no hope' and 'hopeless' by clinicians exacerbated their despair. Likewise, Lobb et. al, (2010) found being given a specific time frame for the prognosis (e.g. 2 months) also reduced hope. Lack of information about prognosis inhibited their potential to make plans and feel hope for the future, an indicator of the impact that lack of information can have on individual SWB.

The evidence from this study suggests health professionals can have a significant impact on levels of hope in people with HGG. The ability to communicate effectively and sensitively, to offer tailored and accurate information and to provide individualised care is of paramount importance to the preservation of hope and SWB and facilitates adaptation to disease and treatment.



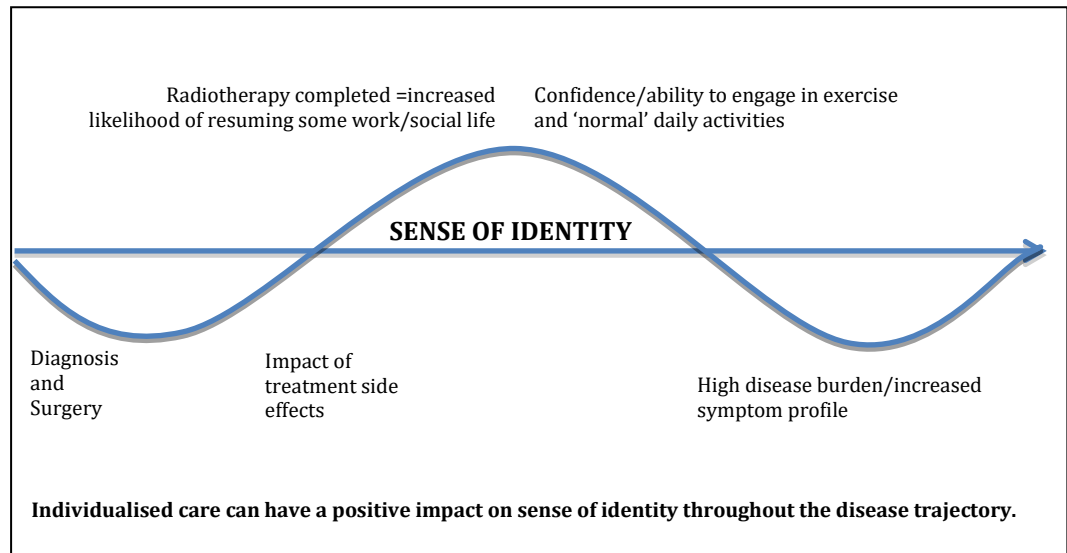
My study has contributed in numerous ways to the knowledge base regarding the nature of hope in people with HGG. It has not only emphasised that hope is a fundamental aspect of SWB, but also revealed that it is threatened by factors such as disease progression and end of treatment. My study has identified the value of goal-setting in preserving hope, and highlighted the varied and subjective nature of these goals. Additionally, the findings of this study acknowledge the crucial role that health care professionals can play in the preservation of hope by offering personalised communication, information and individualised care.

## **8.6 Domain 2 – Sense of Identity**

This study identified sense of identity as a crucial element of SWB for people with HGG. Sense of identity may be threatened following diagnosis as a result of experiencing a loss of normality due to the impact of symptoms and side effects on daily activities, work, family and social life. The longitudinal profile of sense of identity following a diagnosis of HGG can be seen in figure 8.3.

### **8.6.1 What is ‘sense of identity’?**

The concept of ‘sense of identity’ is interchangeably referred to in the literature as ‘identity’, ‘self-identity’, ‘personal identity’ ‘sense of self’ and ‘self’. It is fundamentally concerned with existential concepts concerning the person we think we are, the self we know, a way of differentiating self from others, and a framework for making meaning from experience (Charmaz, 1995; Hubbard, 2010; Gokler-Danisman, 2017).



**Figure 8.3: Longitudinal profile of sense of identity following a diagnosis of HGG**

### **8.6.2 The nature and temporality of 'sense of identity' domain**

The findings of this study reveal that the sense of identity of people with HGG was most vulnerable to threats at the time of initial diagnosis and surgery, during combined chemotherapy and radiotherapy treatment and when disease burden and symptoms were at their most severe.

This study offers unique testimony regarding experiences of surgery, which is noticeably lacking elsewhere in the literature. The results highlight the anxiety some participants felt about the prospect of brain surgery and how they would feel afterwards, particularly in terms of their ability to perform activities of daily living. Loss of independence and dignity in the aftermath of surgery, and the challenge of going to the toilet were offered as examples of how autonomy was threatened at the most fundamental level. One participant reported finding this unprecedented level of dependency damaging both physically and psychologically, as he felt anxious that he might not return to functioning as the person he was pre-operatively.

Furthermore, after surgery participants were vulnerable to multiple threats to their identity resulting from their treatment, particularly during the first treatment phase of both radiotherapy and chemotherapy. The study findings

revealed having to take regular pills threatened their sense of normality. Participants looked forward to a time when their daily lives were no longer dictated by a medication schedule and expressed determination to maintain a normal life. Three studies identified in the literature review similarly reported that participants felt unable to participate in many of their usual daily activities as a result of both time taken up with hospital visits and the onset of symptoms such as fatigue, headaches, seizures and diminishing cognitive and physical abilities (Cavers et. al, 2012; Piil et. al, 2015; Bennett et. al, 2016). Although it is important to highlight that these studies included a broader population of people with brain tumours, rather than focusing specifically on HGG. They also did not identify this disruption to daily activities as a threat to sense of identity in the way my study has.

Longitudinal analysis of my data revealed unique insights into the fluctuating impact of the treatment schedule on a sense of normality and identity. There was evidence of a return to what many felt was a degree of normality by the time radiotherapy had finished. There was relief at being able to perform simple household tasks at this stage, which represented a welcome return to normality, independence, and a sense of the person they used to be.

Longitudinal analysis of the 'importance of normality' theme in the study findings also offered new insight into the impact of a HGG diagnosis on daily activities. It revealed that participants felt less able to participate in activities such as exercising, socialising and going to art galleries and cinemas during the combined chemotherapy/radiotherapy phase of their treatment, and spent more time resting at home. Once radiotherapy was completed, participants reported an increase in free time and energy levels, which allowed them to engage in daily activities more freely, and subsequently enhanced their sense of identity.

Both the literature review and the study findings make repeated mention of the importance of maintaining as 'normal' a life as possible as a means of preserving SWB (Cavers et. al, 2012; Bennett et. al, 2016; Pill et. al, 2016.) When individuals felt uncertain about their potential to continue with activities that they considered to be central to their normal lives such as

working and socialising, this led to feelings of despondency and a loss of identity (Halkett et. al, 2010).

My study findings generally agree with findings from the literature review that for many participants, their diagnosis and treatment left them unable to fulfil the work and social activities that previously contributed to their sense of identity (Halkett et. al, 2010; Piil et. al, 2016). The unpredictable onset of symptoms, such as seizures and headaches, were widely reported in both the literature and the study findings as threatening the confidence of participants to engage in activities which previously contributed to their sense of identity such as social engagements, work and exercise (Fox and Lantz, 1997; Halkett et. al, 2010; Cavers et. al, 2012; Piil et. al, 2015; Bennett et. al, 2016).

There were additional thought-provoking insights from my study about the effect of living with a HGG diagnosis on the work and social lives of participants and the impact this had on their sense of identity. For example, some participants reflected on how their working lives had previously defined their sense of identity, and that this had prompted a desire to make some changes to how they might spend their time in the future. It was clear that for some, work had offered a sense of purpose and satisfaction, and was crucial to their sense of identity.

The longitudinal nature of this study resulted in a unique revelation of the changes to social life and work along the disease trajectory. At the time of interview one, many participants discussed feeling isolated and 'stuck at home'. However, by the time of interview two (once radiotherapy had finished) many felt motivated to be more sociable and to return to some level of working, which appeared to contribute positively to sense of identity and enhance SWB. This may relate to reduced treatment burden, both physically and in terms of available time. It may also be linked to a boost in self-confidence as the length of time that they had lived with their diagnosis increased.

There were several similarities between the literature review and the study findings in terms of daily activities, which are thought to be important to retaining a sense of identity and preserving SWB. The study findings revealed that daily activities largely revolved around exercising, spending time with family, resting, being outdoors, listening to music and reading. As with the literature review findings, participants reported their ability to engage in such activities was threatened by both the symptoms of their HGG and the side effects of treatment.

### **8.6.3 The importance of family role and relationships to sense of identity**

There was widespread evidence both in the study findings and the literature review about the significant impact a diagnosis of HGG had on an individual's role and sense of identity within the family unit (Fox and Lantz, 1997; Halkett, 2010; Piil, 2015; Sterckx, 2015; Piil, 2016). Both in my study and Halkett et al's study (2010), participants described relinquishing roles such as preparing meals or managing family finances. Some felt distressed at this increased dependence on partners, and the subsequent perception that their relationship had become one of carer and patient rather than that of equal partners (Halkett et. al, 2010). In my study, participants highlighted how their sense of identity had been threatened by the fact that they felt they could no longer make basic contributions to family life. Being 'fussed over', was acknowledged for its good intentions, but ultimately served to reinforce a sense of futility and loss of role.

The study findings revealed particularly interesting insights from participants who were mothers, which echoed findings from the literature regarding sense of identity (Kuswanto et. al, 2018). For some women, their role as a mother remained intrinsic to their sense of identity. They were committed to safeguarding the wellbeing of their children above all else. My study found that those who were mothers felt a significant benefit to their SWB when they could continue to perform their maternal role, even when they felt unwell, and they expressed a determination to maintain as much normality as possible for their children.

The importance of this maternal role was analysed by Kuswanto et. al (2018), who conducted a systematic review to explore the impact of a cancer diagnosis on the psychological wellbeing, roles and identity of mothers. Similarly to this study, they found that mothers faced a significant threat to their sense of identity as they struggled to meet both their own and society's expectations around caring for their children. Mothers reported ongoing difficulty in balancing their desire to continue taking responsibility for childcare and the need to care for themselves as they experienced side effects such as fatigue and nausea. Many felt forced to take on a new identity as 'cancer patient' and relinquished aspects of their previous identity by delegating parenting responsibilities to others. This often resulted in feelings of guilt, shame and anxiety, which detrimentally impacted their sense of maternal identity (Kuswanto et. al, 2018). On a more optimistic note, it was also proposed that their diagnosis had in some senses consolidated their sense of identity as mothers, as they re-evaluated their priorities and concentrated their focus on home and family life above all else. They also identified that maintaining a daily routine was a beneficial strategy for preserving their sense of self, as it offered emotional reassurance to their children and maintained a link with their pre-cancer identity. These findings resonate with those from my study, which highlighted the desire of participants to maintain as normal a life as possible for their children. Participants in my study also cited the benefits they felt to their SWB when they could perform activities with their children such as shopping for their favourite foods and watching television together.

#### **8.6.4 Illness perceptions**

My study argues that sense of identity is a fundamental aspect of SWB for people with HGG, which is threatened by various aspects of the disease and its treatment. It could be argued that loss of identity is an unavoidable aspect of serious illnesses, such as cancer (Gokler-Danisman, 2017). Depending on the nature of the disease and treatment, fundamental aspects of identity such as physical wellbeing, cognition and ability to perform daily activities may be significantly affected (Gillies, 2004). However, the reality proposed by my

study does not appear to be this straightforward. Identity may be transformed by a diagnosis of cancer, but the nature of this transformation appears to depend on numerous individual factors. Findings from this study have revealed some negative consequences of HGG on sense of identity, but it has also proposed that these negative consequences are temporal in nature.

Evidence from the literature suggests that some people are determined not to let their diagnosis affect their identity and wish to return to their lives as they were prior to diagnosis, whereas others aim to incorporate their experience of disease and treatment into a new sense of self (Charmaz, 1995; Shapiro, 1997; Kumar and Schapira, 2013). A review undertaken by Bury (1991) exploring the sociology of chronic illness supports the notion that not all people with cancer feel it changes their identity. He found that whilst some people experienced cancer as a fundamental threat to their identity, others saw it as a disruption in life that did not have any long-term implications for their sense of self. This suggestion resonates with findings from this study, which found that not only did some participants demonstrate the ability to implement strategies to help preserve their sense of identity, but that in fact some reported benefits to their identity as they re-evaluated fundamental aspects of their lives, such as time spent at work and with family.

A possible explanation for this disparity in the impact cancer makes on sense of identity is offered by the concept of 'illness perception'. Illness perception is concerned with a person's subjective understanding of their illness and the impact it may have on their sense of self, depending on how much importance they place on it in relation to their identity (Gokler-Danisman, 2017). Some may adopt a new role as 'a cancer patient', whereas others refuse to allow their diagnosis to define them (Gokler-Danisman, 2017). The reality for people with HGG may not be so clear-cut. As was revealed in this study, symptoms such as seizures and cognitive changes can have an irrefutable impact on sense of identity. Palmer-Wackerly (2018) proposes that illness perceptions are constantly re-evaluated by people with cancer, depending on the stage of their disease trajectory. This is certainly the case in

this study, where participants reported feeling more defined by their illness during phases of intensive treatment and increased disease burden, but felt a degree of normality and their sense of identity returned once they completed radiotherapy and they could participate more in daily activities such as exercise, work, household tasks and socialising.

### **8.6.5 Reference to sense of identity in the cancer literature**

It is interesting to note that the majority of identifiable literature regarding the impact of a cancer diagnosis on sense of self is generally focused on the breast cancer population. Whilst this literature offers some useful insights into the perceptions of threats to identity following cancer treatment, its application to the population of this study (i.e. those diagnosed with HGG) is limited. The prognostic outlook for someone diagnosed with breast cancer may be more positive than for those diagnosed with a high-grade brain tumour. Indeed, there is the potential for breast cancer patients to be cured, which is not the case for HGG. It is imperative that this significant difference in disease profile is taken into account when considering the impact of HGG on sense of identity, hope, control and wellbeing in general. Only one paper could be identified which specifically explored the impact of brain cancer on sense of identity. Anderson-Shaw et. al (2010) presented three case studies which demonstrated the impact of Glioblastoma Multiforme diagnosis on self-identity. These patients exhibited neuropsychiatric manifestations, which significantly altered their identity. Whilst these were extreme cases, a degree of cognitive change (including memory loss, seizures and personality changes) is a commonly reported symptom of HGG, and was certainly a factor in the findings of my study. These symptoms epitomise the unique threats to identity faced by people diagnosed with a brain neoplasm in comparison to the cancer population as a whole. Their sense of self may be altered so dramatically that they no longer resemble the person they were prior to diagnosis (Anderson-Shaw et. al, 2010). Despite this potentially catastrophic impact, alterations to sense of identity are not always discussed with people with HGG, and research available on the subject remains scarce. (Anderson-Shaw et. al, 2010).



### **8.6.6 Strategies for preserving identity**

The exploratory nature of this study offers an interesting and unique insight into the self-help strategies that participants felt helped them to retain a sense of identity. They discussed approaches they had found, which helped them to manage symptoms, such as taking a rest and making dietary changes. The most important approach for many appeared to be retaining independence and control over aspects of their life wherever they could, either through continuing with household jobs such as cooking, cleaning and shopping, or making time to exercise. In the case of exercise, Piil et. al, (2015) suggest that not only does this improve physical health, but it also promotes feelings of empowerment and provides an opportunity for social interaction. These factors were identified in my study as beneficial both to sense of identity and to SWB in general.

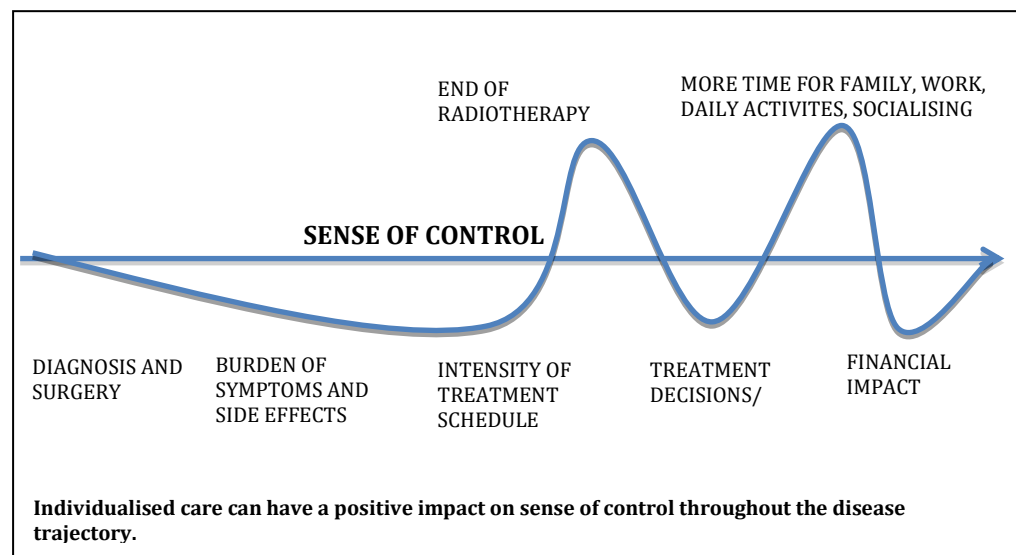
Evidence from the literature review supports the finding that people can be successful in identifying and implementing strategies as a means of preserving a sense of identity, thereby enhancing their own SWB despite a cancer diagnosis. These include continuing to undertake daily activities such as work, gardening and socialising (Bury, 1991). Sterckx et. al (2015) also found that participants gained considerable satisfaction from being able to do 'the little things' in life, such as domestic tasks, which significantly helped them to maintain a sense of identity and normality. As disease progresses and the goals of identity preservation need to be adjusted, strategies such as remaining in the home environment for as long as possible and being surrounded by personal memorabilia, such as photographs, offer an effective method of preserving both identity and hope (Maersk, 2018).

This study has provided a unique contribution to the cancer literature of the impact of a HGG diagnosis on sense of identity. The terminal nature and symptom profile of a high-grade brain tumour has a unique and undeniable impact on sense of identity and self-perception. Whilst the impact of intensive treatment and the value of retaining a degree of normality has been previously reported, this study has also highlighted temporal changes in

sense of identity during different treatment phases, as well as the positive impact that individualised care can have on the preservation of sense of identity and SWB in general.

### 8.7 Domain 3-Sense of Control

This study proposes that a person’s sense of control is threatened by HGG on many levels. From the point of diagnosis, the future feels uncertain and uncontrollable. Aspects of life that were important to SWB such as the ability to work, have a social life and a role within their family unit may feel insecure, and the intensity of a multi-modality treatment schedule leaves little opportunity to dictate one’s own daily activities. Additionally, symptoms of their disease such as seizures and cognitive changes can lead to feelings of vulnerability and powerlessness for some participants, which worsened when they felt they had little say in any treatment decisions. Figure 8.4 demonstrates the fluctuating longitudinal profile of the sense of control domain following a diagnosis of HGG as identified by this study.



(N.B. factors above the line represent a strong sense of control, and factors below the line represent a weak sense of control).

**Figure 8.4: The fluctuating longitudinal profile of Sense of Control following a diagnosis of HGG**

### **8.7.1 The nature and temporality of the Sense of Control domain**

From the moment of diagnosis, sense of control was threatened for participants in numerous ways. The future became uncertain and unfamiliar, and aspects of life they had previously controlled, such as work, finances and social life, were thrown into jeopardy. The fact that many felt powerless about their treatment decisions potentially intensified this sense of helplessness, a finding which echoed the work of Sterckx et. al (2015). The study findings add unique insights into the impact of diagnosis and treatment on a person's sense of identity and control over life through the experiences of participants where they had felt infantilised. For Christopher, this occurred during his post-operative recovery period. Having to re-learn how to dress himself and tie his own shoelaces led to feelings of lost independence and helplessness. Similarly, Len's wife Sam recalled how an experience of being asked to categorise pictures by a health professional resulted in Len feeling frustrated and deflated, as though he was being treated 'like a little boy'. Both of these experiences fundamentally altered the identities of two adult men who now felt like children. As a result of their disease and treatment they had lost control over their life course as well as their minds and bodies. They felt that their sense of control had been taken from them and was now in the hands of the health professionals.

The study identified a variety of symptoms and side effects resulting from HGG diagnosis and treatment that left participants unable to fulfil the work and social activities that had previously defined their sense of identity and control over their lives. Similar experiences and interpretations were also identified in the available literature (Halkett et. al, 2010; Piil et. al, 2016). Side effects of treatment such as personality changes, nausea, weight gain, cognitive deficits, loss of vision and balance, headaches and seizures often led to feelings of powerlessness. As a consequence of these symptoms, participants felt they had lost control over aspects of their lives such as their appearance and their ability to interact socially.

In line with findings from other studies, seizures were emphasised in this study for their potential impact on sense of control. Seizures were a source of extreme anxiety, and undermined confidence in taking part in activities that had previously defined their sense of self, such as socialising, driving and exercising (Fox and Lantz, 1997; Halkett et. al, 2010; Cavers et. al, 2012; Piil et. al, 2016). Participants could not control when seizures might happen, and therefore tended to avoid situations where they might occur such as going to the supermarket and work. Not only were they concerned about how to manage the physical manifestations of a seizure in public spaces, but they also expressed anxiety about how a seizure might look to others, and did not want to risk such a perceived indignity and threat to their sense of identity. This threat to their ability to continue everyday life as before had a significant impact on their sense of control over their daily lives and their sense of independence, as activities were limited by their diagnosis. My study also echoed the findings of others in the sense that issues with memory and speech resulted in frustration and anguish when trying to hold conversations or follow instructions (Cavers et. al, 2012; Piil et. al, 2015; Piil et. al, 2016).

This study suggested that the intensity of the treatment schedule left little opportunity for participants to determine the structure for their daily lives. This loss of control was intensified on days when participants experienced delays and long periods of waiting at the hospital. The literature review findings support the suggestion that intensive, multi-modality treatment schedules place a significant burden on the SWB of participants and their families. For example, Fox and Lantz (1997) reported that patients relinquished control over complex medication regimens to their carers, and that this in combination with navigating the intricacies of the medical system dominated both their thoughts and their time.

Despite the significant threat to a sense of control engendered by the treatment schedule, longitudinal analysis of the study data revealed that this burden reduced significantly at interview two (once radiotherapy was completed). By this stage participants regained control over their daily schedules, and had more time to spend on activities that enhanced their SWB such as exercise and spending time with family.

### **8.7.1.1 'Locus of Control' (LOC) and it's relevance to the study findings**

LOC is a phenomenon initially described by Rotter (1966), which classifies a person's perception of the influences of various forces over their life outcomes (Brown et. al, 2017). LOC is defined as being either *internal* (the result of one's own behaviour) or *external* (controlled by the actions of others and/or uncontrollable forces such as 'fate', 'chance' and 'luck') (Rotter, 1966; Marks et. al, 1986; De Valck and Vinck, 1996; Brown et. al, 2017). It is reasonable to think of LOC as a continuum, as most people tend to believe that both internal and external elements are relevant to their LOC (Brown et. al, 2017). However, a tendency to prioritise one extreme or the other may have a role to play in beliefs, attitudes and behaviours.

LOC theory is particularly relevant to the field of health, where it has been proposed that an individual's perception of their LOC may have an impact on their health-related quality of life and wellbeing (Brown et. al, 2017). It has been suggested that a high internal LOC is linked to improved psychological outcomes and positive health behaviours, whereas a high external LOC is associated with feelings of powerlessness and despondency (Brown et. al, 2017). However, the reliability of this hypothesis has been questioned (Watson et. al, 1990). A counter argument has been proposed that those with a high external LOC display a better ability to cope with their diagnosis as they see it as a result of luck or fate, and the outcome as being in the hands of their physicians and treatment, therefore they do not bear a psychological burden of responsibility for their situation (Brown et. al, 2017; Broers et. al, 2000). Conversely, in some studies, those with a high level of internal LOC have been associated with decreased functioning, perhaps as the responsibility they place on themselves for their disease and outcomes detrimentally affects their wellbeing (Cheng et. al, 2013; Brown et. al, 2015).

Further distinctions can be made when considering the disease stage of the individuals reporting their LOC beliefs. As was previously mentioned, Watson et. al, (1990) highlighted the important distinction between internal control

over the *cause* of the illness and internal control over the *course* of the illness. Patients with high internal locus of control regarding the course of their illness reported less loss of control, higher self-esteem and less anxiety, whereas patients, with high internal locus of control regarding the cause of the illness, reported a greater loss of control. Detailed analysis of their data revealed that the association between a high level of internal LOC regarding the course of their illness and a positive adjustment to their diagnosis was limited to those with early stage and good prognosis cancer types. Those with a poorer prognosis were understandably less able to maintain a high level of internal LOC regarding their disease outcomes.

Participants in this study demonstrated widespread beliefs that both internal and external LOC were relevant to their current situation. They felt that their internal LOC was threatened when they could no longer dictate their daily routine or have a say in their treatment decisions. They also acknowledged that external forces had a considerable role to play in their diagnosis and wellbeing. Participants felt that being diagnosed with HGG was the 'worst possible luck' (Mateo, I1) and their future was no longer something they had control over. They reported that their lives were now in the hands of the clinical teams treating them. The case of Tom (I1), who was told he was not eligible for a clinical trial in which he had placed considerable hope, offers an exemplar of the potential for external forces to significantly threaten internal LOC.

This study has contributed to the broader knowledge base regarding the significance of sense of control to people with terminal cancer by revealing its' fundamental importance to their SWB, as well as the crucial role that healthcare professionals may play in its' preservation. A lack of individualised care can result in feelings of futility and powerlessness. My study findings have shown that appropriate and individualised communication from the healthcare team regarding their disease and treatment, as well as involvement in treatment decisions, contribute

positively to sense of control, and appear to facilitate a sense of empowerment and confidence.

As was the case with the sense of identity domain, this study suggests that health professionals can facilitate the preservation of sense of control following diagnosis by supporting patients to participate in activities such as exercising, socialising, working and spending time with family wherever possible as a means of enhancing their SWB. Encouraging them to set either short or long-term goals relating to such activities may be beneficial to some individuals as a means of promoting feelings of autonomy, control and hope.

### **8.7.2 Financial impact**

This study has revealed that concerns about money had a significant impact on the SWB of the participants. This is relevant to both sense of identity and sense of control domains. This has been reported elsewhere in the literature, whereby the inability to earn a living caused considerable distress, humiliation, loss of self-esteem and sense of control for some participants (Sterckx et. al, 2013; Sterckx et. al, 2015). The study findings offer more detail about the nature of these concerns by revealing that confusion about benefits and where to seek help and advice regarding finances significantly threatened the sense of control of participants and their families. Money and finances were aspects of their lives which many participants had controlled throughout their adult lives, but which now appeared to be in the hands of people responsible for benefits and advice who often proved difficult to access. Conversely, the study findings also highlighted that for those fortunate to be on paid sick leave from work this was a great relief, and ensured participants could retain a degree of control over their financial situation.

### **8.7.3 Lack of information**

The study findings highlight that when participants could not access information about practical issues, such as treatment schedules and symptom management, their sense of autonomy was jeopardised, as they

were unable to plan their own time, which subsequently had a negative impact on their overall SWB. Additionally, a lack of information regarding their prognosis and the course of their disease left some participants feeling that they had little control over their future, resulting in significant frustration and anxiety. The key role that limited provision of appropriate and individualised information from health professionals plays in threatening people's sense of control was also identified by Sterckx et. al (2013) who found a lack of information about both practical issues and disease progression had the potential to result in feelings of anxiety, uncertainty and chaos for patients.

#### **8.7.4 The importance of individualised care to SWB**

The significant benefits of receiving information, support and communication that is personalised to the individual were identified by the study findings and supported elsewhere in the literature. Care that offers stability, compassion and a holistic approach is widely claimed to be beneficial to patients' wellbeing (Sterckx et. al, 2013; Sterckx et. al, 2015), and was supported by findings from my study. Many participants offered a resounding message on the importance to wellbeing of being cared for in a way that helped them to feel like a person rather than a number.

This study emphasises the fundamental role the Clinical Nurse Specialist played in terms of ensuring personalised care, with eight participants expressing how crucial they found their support in terms of managing the impact of the cancer diagnosis and treatment on their SWB. Despite the overwhelmingly positive reports of the care they had received, the study findings exposed some novel suggestions for improvements in care that may further help with the preservation of SWB following diagnosis and treatment for HGG. These include improved availability of counselling services for patients and their families, and the need for increased contact with the CNS once radiotherapy was complete.



## **8.8 Relationship between the study findings and the concept analysis**

Chapter two of this thesis provided details of a concept analysis undertaken to define the meaning of SWB for people with cancer. The purpose was to clarify the concept prior to undertaking research exploring the perceptions of people with HGG in terms of their SWB. The following definition resulted from the concept analysis:

*“Wellbeing is an all-encompassing term which conceptualises an ideal state of existence. The idea of wellbeing during illness is more closely linked to subjective/individual wellbeing rather than objective/societal wellbeing. It is concerned with the experiences of individuals, and can only be assessed from a person’s own perspective. During periods of illness, subjective aspects of wellbeing may take precedence for the individual. These include life satisfaction, having control and independence when making life choices, a sense of purpose and fulfilment, positive relationships with family and friends, being happy and calm, having faith and a relationship with God, setting and achieving challenges and goals, not being defined by illness, reciprocating care, altruism and feeling capable, engagement in leisure activities, being free from pain, the ability to sleep, and having positivity and hope for the future.”*

*(chapter 2, page 44)*

Having undertaken the research, analysed the findings and conducted a literature review on this subject, I decided it was important to reconsider the initial definition offered by the concept analysis to ensure that the entirety of the identified evidence in this study are incorporated into the findings.

The concept analysis identified a number of antecedents (situations or phenomena that precede an example of the concept) (Rodgers, 1993) that appeared to have a strong impact on the SWB of people with cancer. These include personality factors, will to live, sense of control (an identified domain of this study’s conceptual framework of SWB), support networks, distress,

the nature of cancer and its treatment and demographic factors. Noticeable similarities to the current study findings include the positive association identified between SWB and having a sense of purpose, will to live, an optimistic outlook and life satisfaction. Those who felt that they had adequate social and emotional support were also more likely to report higher levels of SWB according to the concept analysis, a suggestion that is supported by the findings of this study.

Defining attributes, according to Rodgers (1993), are essential components that combine to produce a definition of the concept (Rodgers, 1993). In the concept analysis of SWB, defining attributes are identified as life satisfaction, happiness and optimistic factors, such as feeling calm, happy and full of life, as well as having a sense of peace, joy and excitement. These attributes bear numerous similarities to the findings of both this study and the literature findings, particularly in terms of their contribution to retaining a sense of hope and its subsequent effect on SWB.

It is interesting to note that very little evidence from the concept analysis discussed the importance of sense of identity to SWB, even though this was a significant finding of both the study findings and the literature review. Although life satisfaction and sense of purpose were mentioned, more specific factors such as the importance of normality and the impact on social life and family role were not. This was perhaps a result of the fact that the concept analysis did not stipulate diagnosis or prognostic factors. Such a broad population encompasses a variety of experiences in terms of impact on SWB. On reflection, the findings of this study reveal the importance of distinguishing a person's prognosis when considering their SWB. For example, the impact of a cancer diagnosis on SWB may mean something entirely different for a person who receives curative treatment for early stage breast cancer to another who has been diagnosed with terminal cancer such as HGG. This difference was not highlighted in the initial concept analysis. However, it is proposed that it is an essential distinction to make in future research concerning the SWB of people with cancer.

Interestingly, the concept analysis, literature review and study findings all identified a tendency for people to maintain their reported SWB despite their diagnosis. The concept analysis revealed that the reported level of SWB of people with cancer was similar to that of the general population. Similarly, both the literature review and study findings reveal a perhaps surprising maintenance of wellbeing, even towards the end of life, although the nature and interpretation of wellbeing may adjust over time. My study has identified that key domains of SWB include retaining hope, sense of identity and sense of control. Whilst individual interpretations of these may require adaption as their disease progresses, it is proposed that they are still attainable (and may even become more pertinent) when living with cancer.

## **8.9 Researcher reflections**

Throughout the course of this study, reflective notes were maintained on pertinent aspects of the research process as a means of ensuring quality and evidence of reflexivity. These reflections will now be discussed in more detail.

### **8.9.1 Reflections on conducting longitudinal research**

One of the fundamental aims of this study was to explore the perceptions of people with HGG in terms of their SWB at different points in their disease trajectory by using a longitudinal approach. Particular challenges of conducting this research longitudinally resulted from the poor prognosis of people with HGG. Initially, I aimed to conduct three interviews with participants over a one-year time frame. However, this was only achieved with one participant (Yulia). The others were unable to participate for a variety of reasons, including transfer of care to a different area, disease progression to the extent to which they could no longer participate, or death.

Of 15 participants, only four did not manage a second interview: two because of time constraints on completing data collection, one (Mateo) returned to his home country (Spain) and another (Tom) experienced significant disease

progression which meant that approaching him to participate in a second interview would have been ethically inappropriate.

On reflection, I felt that the approach of maintaining a relatively short time frame between interviews one and two (between 3-6 months) was a key factor in reducing attrition at this time. This allowed regular contact to be maintained with the participants as they were regularly seen in clinic. Conducting the interviews within a short time frame also reduced the possibility of inaccurate recall of events (Robinson and Marshland, 1994).

Attrition rates in longitudinal studies conducted with people with advanced cancer is recognised to be a considerable issue, largely due to declining physical health and death (Applebaum et. al, 2012). And my study was no exception. This issue may explain why there is limited research conducted longitudinally with such populations, and therefore evidence regarding their experiences at different points in the disease trajectory remains limited. This study has attempted to address this knowledge gap by offering a unique insight into the fluctuating nature of patient experience regarding the impact of HGG on SWB. The longitudinal approach has also generated proposals for future research to enhance the knowledge base in this area.

### **8.9.2 Reflections on the term 'wellbeing', and what this meant to participants**

As revealed by the concept analysis, the term 'wellbeing' is subject to a number of interpretations and is often used interchangeably in the literature with terms such as 'quality of life'. The practical implications of this disparity of understanding became evident early in the data collection phase of this study when using the term 'wellbeing' during interviews. When conversations started with open-ended questions such as *'Tell me about how you think your diagnosis has affected your wellbeing?'* many participants asked for further clarification on what the term wellbeing meant. I therefore quickly realised that using terms such as 'day-to-day life' or 'quality of life' rather than 'wellbeing' or 'subjective wellbeing' appeared to have more meaning for interviewees. This was also the experience of Fox and Lantz

(1997), who similarly used 'day-to-day life' with participants in their study exploring the impact of brain tumours on quality of life as a means of avoiding language that may have appeared meaningless to interviewees. It would be interesting to consider the impact of this discrepancy in understanding of the terms 'wellbeing' and 'subjective wellbeing' between health professionals and service users in more detail. Perhaps wellbeing is a concept that is still generally restricted to the domain of health professionals, and if so should they be adopting more commonly understood terminology such as 'day-to-day life'? Alternatively, the general public may become more familiar with the ideas of wellbeing and SWB as their use becomes more commonplace. This could be an extremely valuable area to research further as a means of ensuring successful communication between healthcare providers and their patients and families in the future.

### **8.9.3 Reflections on the emotional burden of conducting longitudinal research with people with a terminal illness**

The longitudinal nature of this study meant that I, inevitably, developed certain degree of personal connection with participants. In many ways, this was a positive outcome, as it made the process of data collection (including my regular attendance at clinic) an enjoyable and sociable experience. It also allowed for the development of a rapport with participants, which is seen as being beneficial to qualitative research (Kemp et. al, 2018). However, as Saldana (2003) highlights, the longer a researcher spends on a study, the more likely they are to feel personally involved in each case. Due to the poor prognosis of HGG, eleven of the fifteen participants died within 24 months of commencing data collection. This was distressing to hear, particularly when reflecting on conversations discussing participants' hopes for the future, which some did not manage to realise. The recording of reflective notes and regular discussions with my PhD supervisors proved to be an effective strategy for managing this emotional burden, but it cannot be denied that there is a risk of distress for researchers working in emotionally-sensitive areas, and that this should be anticipated and prepared for within research teams (Kemp et. al, 2018).

## **8.10 Implications for practice**

This study has generated a number of important implications for the practice of caring for people with HGG. These are summarised below by domain, followed by specific recommendations for service development.

### Hope Domain

This study has revealed that hope is often threatened as a result of lack of information and poor communication from health professionals. However, when participants had confidence and trust in their clinical team (particularly their CNS) and were positive about the communication and information they received this significantly enhanced their ability to plan ahead and enhanced their SWB. Evidence from other research conducted on the importance of hope to the SWB of people with terminal prognoses reinforces the suggestions of this study that nurses are well positioned to support their patients in fostering hope. Stephenson (1991) identified a connection between nurses and the preservation of hope, suggesting that encouraging hope through support and confidence in a person's treatment is an essential element of the nursing role. Such evidence serves as a powerful reminder to nurses that maintaining a positive attitude, treating people with terminal cancer as individuals and supporting them to find ways to feel hopeful (such as promoting goal-setting) despite their prognosis may significantly impact on their SWB.

### Sense of Identity Domain

Evidence from the study findings suggests numerous opportunities for health professionals to support people with a HGG to preserve their sense of identity as a means of enhancing their SWB. Encouraging and supporting individuals to make healthy lifestyle choices such as participating in regular exercise and eating a healthy diet appears to promote sense of identity, as does engaging in work and social events. However, it is vital to remember that such activities are highly subjective, and their contribution to sense of identity may depend largely on how important they were to an individual prior to diagnosis.

Both the study findings and the literature identified the importance of the maternal role to the sense of identity of mothers diagnosed with cancer. Conducting research that may in turn lead to heightened awareness amongst health professionals of the significance of this component of identity to the SWB of women with children, and the prioritisation of supporting them to continue fulfilling this role both practically and emotionally may assist in the preservation of their SWB following diagnosis.

#### Sense of Control Domain

In order to support people with a diagnosis of HGG to retain a sense of control over their lives, it is imperative that health professionals provide care that feels personalised to an individual. Evidence from this study revealed that when participants had a perception that they were 'just a number' this could result in feelings of futility, detachment and powerlessness, which can significantly threaten their sense of control. Equally, when people trust their health care team and know whom to contact with any questions or concerns appears to facilitate a sense empowerment and confidence. Appropriate and individualised communication from the healthcare team regarding their disease and treatment, as well as involvement in treatment decisions, also contribute positively to sense of control, and should be a priority for health professionals.

As was the case with the sense of identity domain, this study suggests that health professionals can facilitate the preservation of sense of control following diagnosis by supporting patients to participate in activities such as exercising, socialising, working and spending time with family wherever possible as a means of enhancing their SWB. Encouraging them to set either short or long-term goals relating to such activities may be beneficial to some individuals as a means of promoting feelings of autonomy, control and hope.

#### Recommendations for service development based on the findings

- The SWB of patients benefits from having regular contact with a healthcare professional who knows them, and whom they can trust and access easily. The findings of this study support the importance of

a named CNS being allocated to everyone with HGG from the point of diagnosis.

- Participants reported a sense of detachment from their clinical team once they had completed radiotherapy. It is recommended that CNSs contact patients more regularly during the later stages of their disease and treatment as this reassurance enhances their sense of control and subsequent wellbeing.
- This study has revealed that goal-setting is a key aspect of the preservation of hope and subsequently SWB. It is suggested that the setting of goals is discussed with patients at various points throughout their disease and treatment journey. These goals will be highly individual in nature, must be realistic and achievable, and may be either short or long-term. Further research is required to determine the format of this goal-setting intervention.
- It would be interesting to explore in more detail the applicability of the conceptual model of SWB of people with HGG to practice such as its potential value to the communication training of healthcare staff caring for people with HGG. However, this practice development would require further discussion and evaluation of the model with the clinical teams involved. It is also important to emphasise that the potential transferability of this model to people in the terminal stages of their disease is limited, as it can only be regarded as a reflection of the timepoints captured in the interviews.

### **8.11 Suggestions for future research**

Numerous interesting and valuable opportunities for future research have arisen from the study findings and a subsequent evaluation of the relevant contextual literature. These will now be discussed according to each SWB domain .



### Hope Domain

Despite the increasing recognition that hope plays an important role in SWB and adaptation to illness, there is a lack of instruments specifically designed to assess and monitor levels of hope, particularly in clinical settings where health professionals traditionally rely on their intuition as a means of determining levels of hopefulness in their patients (Herth, 1992). This issue was addressed by the creation of the Herth Hope Index (HHI-see appendix) (Herth, 1992), which was designed as a straightforward tool for the assessment of hope in clinical settings. It offers a means for nurses to assess levels of hope quickly and easily, and to use findings as prompts for ongoing discussions regarding strategies for the preservation of hope (Herth, 1992). There is also the potential to use the HHI to evaluate both longitudinal changes in levels of hope and the effectiveness of any strategies implemented, thus offering the potential for novel future research into the nature of hope and its contribution to SWB in people with terminal diagnoses such as HGG.

### Sense of Identity Domain

An interesting finding of my study concerns the reported improvement in sense of identity and SWB once the radiotherapy treatment finished. Although participants were still receiving chemotherapy, this was considerably less of a burden on them both physically and practically. Being able to return to a degree of normality, including working, exercising and engaging more socially, was an extremely positive transition for participants. Longitudinal research exploring fluctuations in sense of identity and illness perception along the cancer trajectory would result in a more accurate understanding of the patient experience, and allow health professionals to target supportive interventions to episodes when sense of identity may be most under threat.

Most research conducted into the impact of a cancer diagnosis on sense of identity has been undertaken with the breast cancer population. As has been previously discussed, HGG often results in particular symptoms and side effects such as seizures and cognitive changes which do not occur with other

cancers which did not affect the brain It would therefore be interesting to conduct further research into the specific experiences of people with HGG in terms of the impact of their diagnosis on sense of identity.

Finally, this study identified the importance of the maternal role as a significant factor in the sense of identity of women with children. The majority of available literature on this issue has again been conducted with women with breast cancer, most of whom had early stage and curative disease. Further research into the specific impact of a poor prognosis cancer such as HGG on maternal identity is warranted.

#### Sense of Control Domain

It would be valuable to further explore the importance of sense of control beliefs to people with terminal cancer diagnoses, such as HGG, as the findings may be very different from the evidence investigating sense of control and cancer in people with early stage and low grade diagnoses (Brown et. al, 2017). With the exception of Watson et. al (1990), there is a paucity of research examining the nature of control in those with more advanced cancers . Further research examining longitudinal changes in sense of control through the HGG disease trajectory would offer a more accurate insight, on which health professionals may base appropriate supportive measures. (Brown et. al, 2017).

### **8.12 Wellbeing monitoring and assessment tools for people with cancer**

One finding of this research is that people with HGG preferred their wellbeing and/or QoL to be monitored informally, by someone they could trust and who knew them well, with the questionnaire acting as a prompt for their discussions. This finding has implications for the current tendency towards the use of digital and remote monitoring systems. It is important to have an awareness of the value of this personal relationship to the care of people with cancer. However, as the number with a diagnosis of cancer increases, this is

not always possible. There is potential for future research into the nature of monitoring the wellbeing of people with cancer, and whether this should be face-to-face or remote, using a validated tool or more of an informal discussion. The potential stratification of those with the highest support needs (such as those with terminal prognoses) could potentially offer a means of ensuring that monitoring systems are appropriately allocated.

### **8.13 Strengths and limitations of the study**

This study offers a unique insight into the perceptions and experiences of people with HGG in terms of the impact of their diagnosis on SWB. The fact that it has involved participants with this specific type of brain tumour, as well as its longitudinal phenomenological approach has resulted in original findings, which will contribute, positively to the body of knowledge in this area. Despite its potential value, it is important to highlight the limitations of the study as a means of ensuring transparency and trustworthiness.

One of the major limitations of this study was that second and third interviews could not be conducted with all participants as a result of both attrition due to disease progression and time restraints on the data collection period. Longitudinal findings may have been strengthened had more data been collected in these later stages of disease and treatment. Only one participant (Yulia) managed to attend a third interview. This was an extremely interesting interaction as she discussed her feelings of returning to a degree of normalcy and enhanced SWB once her treatment had finished and her disease was defined as stable. Unfortunately, the majority of people with HGG experience more rapid disease progression, and Yulia's situation did not reflect that of most participants.

Five of the study participants had family members present during their interviews. The presence of carers during interviews was allowed in this study following discussion with the medical team, as they felt it would offer reassurance and reduce anxiety for those who may have had difficulty communicating as a result of cognitive changes brought on by their diagnosis. Whilst this decision was made in the best interests of the participants, it may

have impacted participant responses. For example, they may have been conscious of protecting their family members from information or feelings that might have caused distress. Similarly, they may have felt the need to portray positivity and optimism as a means of reassuring family members.

Both Len's wife (Sam) and Brian's wife (Ann) became actively involved in the discussions, and often spoke on behalf of their husbands. This appeared to be a natural and comfortable situation for them, and may have been particularly helpful as both Len and Brian were experiencing cognitive impairment. However, it cannot be assumed that Len and Brian would have responded in exactly the same way as their wives, and it is not possible to tell if this would have affected the study findings.

Whilst the presence of carers was necessary for ethical issues in this study, transparency regarding the impact this may have had on the study findings is essential for the overall trustworthiness of the study.

Another limitation of this study is its potentially limited transferability to other groups. The setting for this research was a large brain tumour service at a London teaching hospital. It therefore had a significant number of patients with complex and aggressive diagnoses, many of whom had been referred from smaller centres. The high proportion of HGG patients with high-grade disease, combined with the demographic and cultural diversity of the group is unlikely to be replicated at many other cancer centres. However, the diversity of the sample may also be considered a strength of the study, as over-representation of a certain group was not an issue. Additionally, hermeneutic phenomenologists acknowledge and value the unique nature of each study and believe it is the responsibility of the reader to assess transferability to his or her own context (Holloway and Wheeler, 2002).

Finally, an important limitation of this study results from the relatively small sample size of fifteen participants. This sample size allowed for the fact that I intended to conduct multiple interviews with each participant. It also facilitated in depth analysis in accordance with a hermeneutic phenomenological approach, whilst at the same time being sufficient to gain

a new and varied insight into the experience of people with HGG and to allow for anticipated levels of attrition (Sandelowski, 1995).

Only those deemed well enough to participate by the medical team could be included in the study for ethical reasons. However, this may have resulted in a degree of selection bias, which may have impacted upon the results. Had people with significant cognitive impairment participated, it could be hypothesized that they would have reported a greater detrimental impact of their diagnosis on SWB. Although this recruitment issue was unavoidable (and essential on ethical grounds), it is imperative that its potential impact on the findings is discussed transparently as a means of ensuring confirmability (Holloway and Wheeler, 2002).

### **8.14 Summary**

This chapter has discussed in more detail the findings of this study in relation to the initial aims and objectives for the project. In particular, the evidence for proposing Sense of Identity, Hope and Sense of Control as key domains of the SWB of people with HGG, and the potential threats to these has been elaborated on. Longitudinal fluctuations within each domain have also been examined, as well as the identified strategies for preserving them. This chapter has offered reflections on various aspects of the study, discussed its strengths and limitations, and offered suggestions for research and practice. The unique findings of this study are summarised below:

- The SWB of people with HGG comprises three major domains. These are: Sense of Identity, Hope and Sense of Control. These domains are susceptible to multiple threats resulting from diagnosis and treatment.
- For many, the emotional burden of HGG is harder to bear than the physical impact of the disease. It can be difficult to remain hopeful in such circumstances, but some try hard to remain positive.
- Sharing other people's cancer stories as a way of offering hope has the potential to be counterproductive for this group, as they may lack relevance to their own situation and can consolidate feelings of futility.

- Whilst clinical trials may have the potential to help people with HGG to feel hope in an otherwise hopeless situation. There is a possible threat to hope which may arise should people discover they are ineligible, particularly if this is not communicated in a sensitive manner.
- The setting of goals is both highly individual and fundamentally important to the SWB of people with HGG as a means of preserving Sense of Identity, Hope and Sense of Control. However, this is an entirely personal endeavour. Whereas some participants felt that limiting goals to the short-term was the best way to cope, others found aspiring towards longer-term aims helped them feel positive and hopeful for the future. Healthcare professionals can support people with HGG to set appropriate goals as a means of enhancing their SWB.
- This study offered unique testimony on the impact of surgery on sense of identity and SWB of people with HGG. Participants reported anxiety at the prospect of brain surgery. However, this anxiety was predominantly concerned with potential loss of independence and dignity in the aftermath of their surgery, rather than the procedure itself.
- The longitudinal nature of this study resulted in a unique insight into the fluctuating impact of the treatment schedule on a sense of normality and identity. There was evidence of a return to what many felt was 'more normal' by the time radiotherapy had finished.
- The impact of work on sense of identity and SWB is a highly individual phenomenon. Although being unable to continue working had a significant effect on sense of identity, some viewed their diagnosis as a positive opportunity to reflect on their future and re-evaluate how they might spend their time. Some participants found not going to work had a positive impact on their SWB. Whereas it was clear that for others work offered a sense of purpose, feelings of satisfaction and was crucial to their sense of identity.
- The longitudinal nature of this study resulted in a unique revelation into the changes in impact on social life and work along the disease

trajectory. At interview one, many participants discussed feeling isolated and 'stuck at home'. However, by interview two (once radiotherapy had finished) there was an increased suggestion that some people felt motivated to be more sociable and to return to some level of working, which appeared to enhance SWB and contribute positively to sense of identity.

- The sense of control of people with HGG is threatened by the intensity of their treatment schedule. However, this burden reduced significantly at interview two (once radiotherapy was completed) as participants regained control over their daily schedules and had more time to spend on activities which enhanced their SWB such as exercise and spending time with family.

The concluding chapter will offer a final overview of the importance of this study, and reflections on the future of research in this area.

## **Chapter 9: Conclusion**



## 9.1 Conclusion

This is the first study to explore the perceptions and experiences of the SWB of people with a HGG diagnosis using a longitudinal phenomenological approach. As a result of the findings, an innovative conceptual model of SWB has been developed, which demonstrates that SWB consists of three fundamental domains: Sense of Identity, Hope and Sense of Control. The nature of these domains fluctuates over time as a result of threats arising from a HGG diagnosis and treatment. Strategies have been identified which may help to preserve a sense of SWB despite the devastating nature of the diagnosis.

The nature of hope changes along the disease trajectory and is threatened at various time points. Hope is particularly vulnerable at certain stages in the disease and treatment journey, such as at the points of diagnosis, disease progression and the end of treatment, when participants felt particularly anxious and uncertain about their future. During intensive treatment phases, participants hoped to have more time to spend on activities that enhanced their SWB, such as spending time with family and exercising. Strategies for the preservation of hope included fostering an optimistic outlook and the setting of individual goals.

Poor communication, lack of information and individualised care pose significant threats to levels of hope (and subsequently SWB) at various points throughout the disease trajectory. Healthcare professionals can have a significant impact on levels of hope in people with HGG by communicating effectively and sensitively, offering tailored and accurate information and providing individualised care.

This study has also identified sense of identity as a crucial element of SWB for people with HGG. Sense of identity may be threatened following diagnosis as a result of experiencing a loss of normality associated with the impact of symptoms and side effects on daily activities, work, family and social life. The sense of identity of people with HGG was most vulnerable at the time of initial diagnosis and surgery, during combined chemotherapy and

radiotherapy treatment, and when disease burden and symptoms were at their most severe. Participants attempted to preserve their sense of identity by maintaining as much normality as possible, and by retaining independence and control over their lives wherever they could.

This study has proposed that a person's sense of control is threatened by a diagnosis of HGG on many levels. From the point of diagnosis, the future feels uncertain and uncontrollable. Aspects of life that were important to SWB, such as the ability to work, have a social life and earn a living may feel insecure, and the intensity of a multi-modality treatment schedule leaves little opportunity to dictate one's own daily activities. Additionally, symptoms of their disease such as seizures and cognitive changes lead to feelings of vulnerability and powerlessness for some participants, which was worsened when they felt they had little say in any treatment decisions.

Healthcare professionals can support and encourage people with a diagnosis of HGG to retain a sense of control by providing care that feels personalised to an individual. Evidence from this study has revealed that when participants had a perception that they were 'just a number' this could result in feelings of futility, detachment and powerlessness, which can significantly threaten their sense of control. Conversely, when people trust their health care team and know whom to contact with any questions or concerns this appears to facilitate a sense empowerment and confidence. Appropriate and individualised communication from the healthcare team regarding their disease and treatment, as well as involvement in treatment decisions also contributes positively to their sense of control.

A diagnosis of HGG is a life-altering event, which has a significant impact on SWB. However, this study has identified strategies that patients, their families and healthcare professionals may implement as a means of preserving a sense of SWB. Further research into the SWB of people with HGG, particularly in terms of how the domains of Sense of Identity, Hope and Sense of Control can be safeguarded, will inform the continued improvement of care for people with HGG.

## **References**

- Allen, D. (2010) *Fieldwork and Participant Observation* in Bourgeault, I, Dingwall, R and de Vries, R (eds.) (2010) *The SAGE Handbook of Qualitative Methods in Health Research*. London: Sage.
- Anderson-Shaw, L, Baslet, G and Villano, J.L. (2010) Brain Neoplasm and the Potential Impact on Self-Identity *AJOB Neuroscience* 1 (3): 3-7.
- Applebaum, A.J., Lichtenthal, W.G., Pessin, H.A. et. al (2012) Factors associated with attrition from a randomized controlled trial of meaning-centered group psychotherapy for patients with advanced cancer. *Psycho-Oncology* [1057-9249] vol:21 iss:11 pg:1195
- Asselin, M (2003) Insider research: issues to consider when doing qualitative research in your own setting. *Journal for Nurses In Staff Development*. 19, 2, 99-103.
- Atkins, S et al. (2008) Conducting a meta-ethnography of qualitative literature: Lessons learnt. *BMC Medical Research Methodology* 8:21 <https://doi.org/10.1186/1471-2288-8-21>
- Avant, K.C. (1993) The Wilson Method of Concept Analysis. In: Rodgers, B.L. and Knafl, K.A. (1993) *Concept Development on Nursing. Foundations, Techniques, and Applications*. Philadelphia: W.B. Saunders Company
- Aveyard, H. (2010) *Doing a Literature Review* (second edition) Maidenhead: Open University Press.
- Bailey, R. (2013a) Cerebral Cortex. (online) Available at: <http://biology.about.com/od/anatomy/a/aa032505a.htm>. (accessed 15/1/2013)
- Bailey, R. (2013b) Brainstem. (online) Available at: <http://biology.about.com/od/anatomy/p/Brainstem.htm>. (accessed 15/1/2013)
- Baker, C., Wuest, J. and Stern, P.N. (1992) Method slurring: the grounded theory/phenomenology example. *Journal of Advanced Nursing*. 17: 1355-1360.
- Baldwin, M.A., Rose, P. (2009) Concept analysis as a dissertation methodology. *Nurse Education Today* 29:780-783.
- Barnett-Page, E and Thomas, J (2009) Methods for the synthesis of qualitative research: a critical review. *BMC Medical Research Methodology* 9:59 <https://doi.org/10.1186/1471-2288-9-59>
- Baumstarck K, Leroy T, Hamidou Z, et al. (2016) Coping with a newly diagnosed high-grade glioma: Patient-caregiver dyad effects on quality of life. *J Neurooncol*. 129(1):155-164.

Beckwith, S., Dickinson, A. And Kendall, S. (2008) The “con” of concept analysis. A discussion paper which explores and critiques the ontological focus, reliability and antecedents of concept analysis frameworks. *International Journal of Nursing Studies*. 45: 1831-1841.

Bell, H, Ownsworth, T, Lloyd, O, Sheeran, N, Chambers, S. (2018) A systematic review of factors related to children's quality of life and mental health after brain tumor. *Psycho Oncology*. 27: 2317– 2326.

Benner, P. (1994) The tradition and skill of interpretive phenomenology in studying health, illness and caring practices. In: Benner, P. (1994) (ed) *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness*. Thousand Oaks: Sage.

Bennett SR, Cruickshank G, Lindenmeyer A, Morris SR. Investigating the impact of headaches on the quality of life of patients with glioblastoma multiforme: A qualitative study. *BMJ Open*. 2016;6

Benzein, E and Saveman, B I (1998) Nurses' perception of hope in patients with cancer: a palliative care perspective. *Cancer Nursing* 21(1): 10-16

Bloom, J.R., Stewart, S.L., Johnston, M., Banks, P., & Fobair, P. (2001). Sources of support and the physical and mental well-being of young women with breast cancer. *Social Science & Medicine*,53, 1513–1524.

Boele, F.W., van Uden-Kraan, C.F., Hilverda, K et. al (2016) Attitudes and preferences toward monitoring symptoms, distress, and quality of life in glioma patients and their informal caregivers. *Supportive Care in Cancer* 24: 3011-3022

Bosma I, Reijneveld JC, Douw L, et al. (2009) Health-related quality of life of long-term high-grade glioma survivors. *Neuro-oncology*. 11(1):51-58

Brain Tumour UK (2012) High-grade glioma. (online) Available at: <http://www.braintumouruk.org.uk/high-grade-glioma> (accessed 30/1/2013)

Brain Tumour Research (2016) Report on National Research Funding: Addressing the historic underfunding of brain tumour research. (online) Available at: <https://www.braintumourresearch.org/docs/default-source/default-document-library/public-affairs-and-campaigning-documents/brain-tumour-research---report-on-national-research-funding---2016.pdf> (accessed 19.8.2020)

Braun, V and Clarke, V. (2013) *Successful Qualitative Research. A Practical Guide for Beginners*. London: SAGE publications Ltd.

Broers S, Kaptein AA, Le Cessie S, Fibbe W, Hengeveld MW (2000) Psychological functioning and quality of life following bone marrow transplantation: a 3-year follow-up study. *J Psychosom Res* 48(1):11-21

Brown, A, Thaker, P, Sun, C et. al (2017) Nothing left to chance? The impact of locus of control on physical and mental quality of life in terminal cancer patients.

[Supportive Care in Cancer](#) 25 (6) 1985-1991

Bury, M (1991) The sociology of chronic illness-a review of research and prospects. *Sociology of health and Illness* 13 (4) 451-468.

Calman, L., Brunton, L. and Molassiotis, A. (2013) Developing longitudinal qualitative designs: lessons learned and recommendations for health services research. *BMC medical research Methodology*. 13 (14)

Cancer Research UK (2010) Statistics and outlook for brain tumours (online) Available at: <http://cancerhelp.cancerresearchuk.org/type/brain-tumour/treatment/statistics-and-outlook-for-brain-tumours#glioma>. (accessed 14/1/2013)

Cancer Research UK (2019) research into brain tumours (online) Available at: <https://www.cancerresearchuk.org/about-cancer/brain-tumours/research-clinical-trials/research-into-brain-tumours> (accessed 6.6.20)

Cancer Research UK (2012) Tests for Brain Tumours (online) Available at: <http://www.cancerresearchuk.org/cancer-help/type/brain-tumour/diagnosis/tests-for-brain-tumours> (accessed 14.1.13)

Carver, C. S., Smith, R. G., Antoni, M. H., Petronis, V. M., Weiss, S., Derhagopian, R. P. (2005) Optimistic personality and psychosocial well-being during treatment predict psychosocial well-being among long-term survivors of breast cancer. *Health Psychology*. 24 (5) 508-516.

Cavers D, Hacking B, Erridge SE, et al. Social, psychological and existential well-being in patients with glioma and their caregivers: A qualitative study. *CMAJ*. 2012; 184(7):373

Charalambous, A. (2010) Interpreting patients as a means of clinical practice: Introducing nursing hermeneutics. *International Journal of Nursing Studies* 47: 1283-1291

Charmaz, K. (1995) The body, identity and self: Adapting to impairment. *Sociological Quarterly* 36 (4) 657-680

- Charmaz, K. (2006) *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. London: Sage.
- Chen, HC and Teherani, A (2016) Common Qualitative Methodologies and Research Designs in Health Professions Education. *Academic Medicine*. 91(12):e5
- Cheng, S.F. Cheung, J.H. Chio, M.P. Chan (2013) Cultural meaning of perceived control: a meta-analysis of locus of control and psychological symptoms across 18 cultural regions. *Psychol. Bulletin* 139 (1)152-188
- Chinn, P.L., and Kramer, M.K., (1995) *Theory and Nursing: A Systematic Approach*. 4<sup>th</sup> edition. St. Louis: Mosby.
- Clancy M (2013) Is reflexivity the key to minimising problems of interpretation in phenomenological research? *Nurse Researcher*. 20, 6, 12-16.
- Clavarino, A. M., Najman, J. M., Beadle, G. (2003) The impact of will to live and belief in curability on the subjective well-being of patients with advanced cancer. *Mortality*. 8 (1) 3-19.
- Colaizzi, P.F. (1978) Psychological Research as the Phenomenologist Views It. In: Valle, R.S. and King, M. (eds) (1978) *Existential Phenomenological Alternatives for Psychology*. New York: Oxford University Press.
- Corbin, J. and Strauss, A. (2008) *Basics of Qualitative Research: Techniques and procedures for developing grounded theory (3<sup>rd</sup> edition)*. Los Angeles: Sage.
- Cornwell J. (1994) *Hard-earned Lives. Accounts of Health and Ill-ness from East London*. Tavistock, London.
- Cooley, M.E. (1998) Quality of life in persons with non-small cell lung cancer: a concept analysis. *Cancer Nursing*. 21(3):151-61.
- Costs, P.T. and McCrae, R.R. (1992) *Revised NEO and personality inventory (NEO PI-R) and NEO five factor inventory professional manual*. Odessa, Florida: Professional Assessment Resources.
- Courneya, K.S., Bobick, T.M., Rhodes, R.E., Jones, L.W., Friedenreich, C.M. and Arthur, K. (2000) Personality Correlates of Patients' Subjective Well-Being After Surgery for Colorectal

Cancer. An Application of the Five-Factor Model. *Journal of Psychosocial Oncology*. 18 (4) 61-72.

Crist, J. and Tanner, C. (2003) Interpretation/Analysis Methods in Hermeneutic Interpretive Phenomenology *Nursing Research* 52:3.

Critical Appraisal Skills Programme (2018). CASP Qualitative Checklist. [online] Available at: <https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf>

Culos-Reed S, Leach HJ, Capozzi LC, Easaw J, Eves N, Millet GY. (2017) Exercise preferences and associations between fitness parameters, physical activity, and quality of life in high-grade glioma patients. *Supportive Care in Cancer*.25(4):1237-1246.

Cutcliffe, J. (2003) reconsidering reflexivity in the case for intellectual entrepreneurship. *Qualitative Health Research* 13: 136-148.

DeNeve, K.M., and Cooper, H. (1998) The happy personality: A meta-analysis of 137 personality traits and subjective well-being. *Psychological Bulletin* 124:197-229.

Deiner, E. (1996) Traits can be powerful, but are not powerful enough: Lessons from subjective well-being. *Journal of Research in Personality*. 30:389-399.

Deiner, E. (2005) *Guidelines for National Indicators of Subjective Well-Being and Ill-Being*. Chicago: University of Illinois.

De Valck, C and Vinck, J. (1996) Health locus of control and quality of life in lung cancer patients. *Patient education and counseling* 28 (2) 179

Dixon-Woods M, Shaw RL, Agarwal S, et al. (2004). The problem of appraising qualitative research. *Quality and Safety in Health Care*, 13(3): 223-225.

Dixon-Woods et. al (2007) Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. *Journal of Health Services Research & Policy* Vol 12 No 1, 2007: 42-47

Dowling, M. (2005) From Husserl to Van Manen: A review of different phenomenological approaches. *International Journal of Nursing Studies* 44:131-142.

Dowling, M (2006)<sup>[1]</sup>Approaches to reflexivity in qualitative research *Nurse Researcher*; 13 (3)



- Duncan, C., Duff Cloutier, J. And Bailey, P.H. (2009) In response to: Risjord, M. *Journal of Advanced Nursing*. 65 (9): 1985-1986.
- Edmondson, D., Park, C. L., Blank, T. O., Fenster, J. R. and Mills, M. A. 2008. Deconstructing spiritual well-being : existential well-being and HRQOL in cancer survivors. *Psycho-Oncology*, 17, 2, 161–9.
- Flechl B, Sax C, Ackerl M, et al. (2017) The course of quality of life and neurocognition in newly diagnosed patients with glioblastoma. *Radiotherapy and Oncology*. 125(2):228-233.
- Fox S, Lantz C. The brain tumor experience and quality of life: A qualitative study. *The Journal of neuroscience nursing: journal of the American Association of Neuroscience Nurses*. 1998; 30(4):245-252.
- Gagnon, M, Jacob, J and McCabe, J (2015) Locating the qualitative interview: reflecting on space and place in nursing research. *Journal of Research in Nursing* 20(3) 203–215
- Gale, N.K, Heath, G., Cameron, E., Rashid, S., and Redwood, S. (2013) Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*. 13:117
- Ganz, P. A., Desmond, K. A., Leedham, B., Rowland, J. H., Meyerowitz, B. E., & Belin, T. R. (2002). Quality of life in long-term, disease-free survivors of breast cancer: A follow-up study. *Journal of the National Cancer Institute*. 94, 39–49
- Gately L, McLachlan SA, Dowling A, Philip J, McLachlan SA. (2017) Life beyond a diagnosis of glioblastoma: A systematic review of the literature. *J Cancer Survivorship*. 11(4):447-452.
- Gilbert, E. ;Ussher, J. M. ;Perz, J. (2011) Sexuality after gynaecological cancer: a review of the material, intrapsychic, and discursive aspects of treatment on women's sexual-wellbeing. *Maturitas* 70 (1) 42-57
- Gillies, B and Johnston, G (2004) Identity loss and maintenance: commonality of experience in cancer and dementia. *European Journal of Cancer Care*. 13(5):436-42
- Gokler-Danisman, I. (2017) Experience of grief by patients with cancer in relation to perceptions of illness: The mediating roles of identity centrality, stigma-induced discrimination, and hopefulness. *Journal of psychosocial oncology* 35(6) 776

Goldman, B. (2009) The brain's silent majority. *Stanford Medicine Magazine*. 2009 Fall. Stanford University School of Medicine. (online) Available at: <http://stanmed.stanford.edu/2009fall/article6.html> (accessed 15/1/2013)

Goldzweig, G., Hasson-Ohayon, I., Alon, S., and Shalit, E. (2016) [Perceived threat and depression among patients with cancer: the moderating role of health locus of control](#). *Psychology Health & Medicine*. 21(5):601-7.

Green, J. and Thorogood, N. (2014) *Qualitative Methods for Health Research (3rd ed)* London: Sage.

Grossoehme, D. and Lipstein, E. (2016) Analyzing longitudinal qualitative data: the application of trajectory and recurrent cross-sectional approaches. *BMC Research Notes*. 9 (136).

Guclu, Y.A. (2007) [A Hope-enhancement Instrument for Palliative Care Cancer Patients](#). *Cureus*. 11(8): e5342

Halkett GK, Lobb EA, Oldham L, Nowak AK. (2010) *The information and support needs of patients diagnosed with high grade glioma*. *Patient Educ Couns*. 79(1):112-119.

Halkett GKB, Lobb EA, Rogers MM, et al. (2015) Predictors of distress and poorer quality of life in high grade glioma patients. *Patient Educ Couns*. 98(4): 525-532.

Harper, M. And Hartman, N. (1997) *Research Paradigms* In: Smith, P. (ed) *Research Mindedness for Practice: An Interactive Approach for Nursing and Healthcare*. New York: Churchill Livingstone.

Hecht, M. (1993) A research odyssey: Towards the development of a communication theory of identity. *Communication Monographs*, 60, 76–82. doi:10.1080/03637759309376297

Heidegger, M. (1962) *Being and Time* (trans) Maquarrie, J. & Robinson, E. Oxford: Basil Blackwell.

Herth, K. (1990) *Fostering hope in terminally-ill people*. *Journal of Advanced Nursing*. 15: 1250-1259

Herth, K. (1992) *Abbreviated instrument to measure hope: development and psychometric evaluation*. *Journal of Advance Nursing* 17(10): 1251-9.

Herth, K and Cutcliffe, J (2002) *The concept of hope in nursing 3: hope and palliative care nursing. British Journal of Nursing* 11 (14).

Holland J: Qualitative Longitudinal Research: Exploring ways of researching lives through time. Real Life Methods Node of the ESRC National Centre for Research Methods Workshop held at London South Bank University 2007. Retrieved from <http://www.reallifemethods.ac.uk/training/workshops/qual-long/documents/ql-workshop-holland.pdf>.<sup>[1]</sup><sub>SEPP</sub>

Holloway, I. and Wheeler, S. (2002) *Qualitative Research in Nursing*. 2<sup>nd</sup> Edition. Oxford: Blackwell.

Hou, W and Lam, J. (2014) Resilience in the year after cancer diagnosis: a cross-lagged panel analysis of the reciprocity between psychological distress and well-being. *Journal of Behavioral Medicine*; 37 (3): 391-401.

HSCIC (Health and Social Care Information Centre) (2013) *A guide to confidentiality in health and social care*. Available at: <file:///Users/katiesutton/Downloads/hscic-guide-to-confidentiality-2013.pdf> Accessed: 17.06.2020

Hubbard, G. (2010) Disrupted lives and threats to identity: the experiences of people with colorectal cancer within the first year following diagnosis. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*. 14(2)131

Hughes, C, Knibb, W and Allan, H. (2010) Laparoscopic surgery for endometrial cancer: a phenomenological study. *Journal of Advanced Nursing*. 66(11): 2500-9, 2010 Nov.

Jesson, J.K., Matheson, L and Lacey, F.M. (2011) *Doing Your Literature Review; Traditional and Systematic Techniques*. London: SAGE.

Joanna Briggs Institute. (2007). SUMARI: The Joanna Briggs Institute system for the unified management, assessment and review of information. Adelaide, Australia. Available at: <http://www.joannabriggs.edu.au/services/sumari.php>

Jones, C and Chapman, Y. (2000) The lived experience of seven people treated with autologous bone marrow/peripheral blood stem cell transplant. *International Journal of Nursing Practice*. 6(3):153-9.

Jung, E., and Hecht, M. L. (2004) Elaborating the communication theory of identity: Identity gaps and communication outcomes. *Communication Quarterly*, 52, 265–283.

- Kedde, H; van de Wiel, H B; M; Weijmar Schultz, W C; M; Wijzen, C. (2013) Subjective sexual well-being and sexual behavior in young women with breast cancer. *Supportive Care in Cancer* 21(7) 1993-2005.
- Kemp CL, Ball MM, Morgan JC, et al.( 2017) *Exposing the Backstage: Critical Reflections on a Longitudinal Qualitative Study of Residents' Care Networks in Assisted Living*. *Qual Health Res*. 27(8): 1190–1202. doi:10.1177/1049732316668817
- Klein M, Taphoorn MJB, Heimans JJ, et al. (2001) Neurobehavioral status and health-related quality of life in newly diagnosed high-grade glioma patients. *Journal of Clinical Oncology*. 19(20): 4037-4047.
- Koch, T. (1994) Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing* 19:976-986.
- Koch, T. (1995) Interpretive approaches in nursing research: The influence of Husserl and Heidegger. *Journal of Advanced Nursing*. 21 (5) 827-836.
- Kornblith, A. B., Herndon, J. E., II, Weiss, R. B., Zhang, C., Zuckerman, E. L., & Rosenberg, S., et al. (2003). Long-term adjustment of survivors of early-stage breast carcinoma, 20 years after adjuvant chemotherapy. *Cancer*, 98, 679–689.
- Kumar, A.R and Schapira, L (2013) The impact of intrapersonal, interpersonal, and community factors on the identity formation of young adults with cancer: a qualitative study. *Psycho-Oncology* [1057-9249] 22 (8) 1753
- Kuper, A; Lingard, L & Levinson, W (2008) Critically appraising qualitative research *BMJ* 2008;337:a1035. doi:10.1136/bmj.a1035
- Kuswanto, C.; Stafford, L.; Sharp, J and Schofield, P. (2018) Psychological distress, role, and identity changes in mothers following a diagnosis of cancer: A systematic review. *Psycho-Oncology* 27(12) 2700
- Laverty, S.M. (2003) Hermeneutic Phenomenology and Phenomenology: A Comparison of Historical and Methodological Considerations. *International Journal of Qualitative Methods*. 2(3).
- Leslie, H and McAllister, M (2002) The benefits of being a nurse in critical social research practice. *Qualitative Health Research*. 12, 5, 700-712.

Lia, C., Forda, E.S., Zhaoa, G. and Mokdadab, A.H. (2009) *Associations of health risk factors and chronic illnesses with life dissatisfaction among U.S. adults: The Behavioral Risk Factor Surveillance System, 2006*. Preventive Medicine. 49 (2-3): 253-259

Lincoln, Y.S. and Guba, E.G. (1986) But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *N Dir Eval.* (30):73-84.

Lo, C; Lin, J, Gagliese, L; ;Zimmermann, C; Mikulincer, M; Rodin, G. Lo, Christopher (2010) Age and depression in patients with metastatic cancer: The protective effects of attachment security and spiritual wellbeing. *Ageing & Society* 30 (2) 325-336.

Lobb EA, Halkett GKB, Nowak AK. (2011) Patient and caregiver perceptions of communication of prognosis in high grade glioma. *J Neurooncol.* 104(1):315-322.

Lopez, K.A. and Willis, D.G. (2004) Descriptive Versus Interpretive Phenomenology: Their contributions to Nursing Knowledge. *Qualitative Health Research.* 14(5):726-735.

Lyon, J. and Walker, C. (1997) *Ethical Issues*. In: Smith, P. (ed) *Research Mindedness for Practice: An Interactive Approach for Nursing and Healthcare*. New York: Churchill Livingstone.

Lynn, P. (2009) *Methods for Longitudinal Surveys*. In: Lynn, P. (ed) (2009) *Methodology of Longitudinal Surveys*. Chichester: John Wiley and Sons Ltd.

Mackey, S. (2004) Phenomenological nursing research: methodological insights derived from Heidegger's interpretive phenomenology. *International Journal of Nursing Studies.* 42: 179-186.

Macmillan (2012a) Symptoms of brain tumours. (online) Available at: <http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Brain/Aboutbraintumours/ Causes.aspx> (accessed 14/1/2013)

Macmillan (2012b) Risk factors and possible causes of brain tumours. (online) Available at: <http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Brain/Aboutbraintumours/ Causes.aspx> (accessed 14/1/2013)

Macmillan (2012c) Intensity-modulated radiation therapy (online) Available at: <http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Radiotherapy/IMRT.aspx> (accessed 21/1/2013)

Macmillan (2017) PCV (online) Available at: <https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/pcv> (accessed 27/1/2020)

Macmillan (2019) The Recovery Package: Sharing Good Practice. Available at: [https://www.macmillan.org.uk/images/recovery-package-sharing-good-practice\\_tcm9-299778.pdf](https://www.macmillan.org.uk/images/recovery-package-sharing-good-practice_tcm9-299778.pdf) accessed: 31.1.2020

Mackey, S. (2004) Phenomenological nursing research: methodological insights derived from Heidegger's interpretive phenomenology. *International Journal of Nursing Studies*. 42: 179-186

Maersk, J.L. (2018) Identity and home: Understanding the experience of people with advanced cancer. *Health and place* [1353-8292] 51: 11

Marks G; Richardson JL; Graham JW; Levine A. (1986) Role of health locus of control beliefs and expectations of treatment efficacy in adjustment to cancer. *Journal of Personality & Social Psychology*. 51(2):443-50

Mauer, M.E., Bottomley, A, and Taphoorn, M.J.B. (2008) Evaluating health-related quality of life and symptom burden in brain tumour patients: instruments for use in experimental trials and clinical practice. *Current Opinion in Neurology*. 21: 745-753

McCance T.V., McKenna H.P., and Boore J.R. (1997) Caring: dealing with a difficult concept. *International Journal of Nursing Studies*. 34(4):241-8.

McDonough, M. H., Sabiston, C. M., and Wrosch, C. (2014) Predicting changes in posttraumatic growth and subjective well-being among breast cancer survivors: the role of social support and stress. *Psycho-Oncology*. 23 (1) 114-120.

McNaught, A. (2011) Defining Wellbeing. In: Knight, A. and McNaught, A. (eds) *Understanding Wellbeing. An Introduction for Students and Practitioners of Health and Social care*. Banbury: Lantern.

McWilliam, C.L., (2010) Phenomenology. In Bourgeault, I, Dingwall, R. and de Vries, R. (Eds) (2010) *The SAGE handbook of qualitative methods in health research*. London: Sage.

Melia, K (2010) Recognising Quality in Qualitative Research. In Bourgeault, I, Dingwall, R. and de Vries, R. (Eds) (2010) *The SAGE handbook of qualitative methods in health research*. London: Sage.

Miles, M.B., Huberman, A.M. and Saldaña, J. (2014) *Qualitative Data Analysis. A Methods Sourcebook*. (3<sup>rd</sup> ed) London: Sage

Mount, B.M., Boston, P.H. and Cohen, S.R. (2007) Healing Connections: On Moving from Suffering to a Sense of Well-Being. *Journal of Pain and Symptom Management* 33(4) 372-388.

Murdoch, B (2009) The cerebellum and language: Historical perspective and review. *Cortex*. 46 (7) :858-868

National Centre for Social Research (2003) *Framework for Assessing Qualitative Evaluation*. London: Crown Copyright.

National Brain Tumor Society (2011) Tumor Types. (online) Available at: <http://www.braintumor.org/patients-family-friends/about-brain-tumors/tumor-types/> (accessed 14/1/2013)

National Centre for Social Research (2003) *Quality in Qualitative Evaluation: A Framework for Assessing Research Evidence*. London: National Centre for Social Research/UK Cabinet Office.

Neil, E., McCabe, M, and Carver, A et. al (2016) Ethical Conflicts at the End of Life in Patients with Malignant Brain Tumors 86 (16) S17.002

Nelson, J. (1996) Struggling to gain meaning: living with the uncertainty of breast cancer. *Advances in Nursing Science*. 18(3): 59-76.

Newton, BJ, Rothlingova, Z and Gutteridge, R et. al (2011) No room for reflexivity? Critical reflections following a systematic review of qualitative research *Journal of Health psychology* 17 (6): 866-885

NHS Specialised Services (2012) Proton Beam Therapy. (online) Available at: <http://www.specialisedservices.nhs.uk/info/proton-beam-therapy>. (accessed 21/1/2013)

NHS (2019) The NHS Long Term Plan. Available at: <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf> accessed: 31.1.2020

Noble H, Smith J (2015) Issues of validity and reliability in qualitative research *Evidence-Based Nursing* 18:34-35.

Office for National Statistics (ONS) (2015) *Personal Well-being in the UK, 2014/15*. Available at: [http://www.ons.gov.uk/ons/dcp171778\\_417216.pdf](http://www.ons.gov.uk/ons/dcp171778_417216.pdf). Accessed 23.09.2015

Office for National Statistics (ONS)(2018) *Personal well-being user guidance*. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/methodologies/personalwellbeingsurveyuserguide> Accessed 13.06.2020.

Owen, D.C. (1989) *Nurses' perspectives on the meaning of hope in patients with cancer: a qualitative study*. *Oncol Nurs Forum*: 16(1): 75-9

Ozen, B, Ceyhan, O and Buyukcelik, A. (2019) [Hope and perspective on death in patients with cancer](#). *Death Studies*. 1-7, Jun17

Palgi, Y; Ben-Ezra, M; Hamama-Raz, Y; Shacham Shmueli, E; Shrira, A. (2014) The Effect of Age on Illness Cognition, Subjective Well-being and Psychological Distress among Gastric Cancer Patients. *Stress & Health: Journal of the International Society for the Investigation of Stress* 30 (4): 280-6.

Palmer-Wackerly, A.L. (2018) Patient Perceptions of Illness Identity in Cancer Clinical Trial Decision-Making. *Health communication* [1041-0236] 33(8) 1045

Parahoo, K (2006) *Nursing Research-Principles, Process and Issues* (2<sup>nd</sup> ed) Basingstoke: Palgrave Macmillan.

Paterson, B et. al (2001) *Metastudy of Qualitative Health Research*. Thousand Oaks: SAGE.

Persoskie, A., Ferrer, R., Nelson, W. L., Klein, W. M. P., (2014) Precancer Risk Perceptions Predict Postcancer Subjective Well-Being. *Health Psychology* 33 (9) 1023-1032.

Peters KB, West MJ, Hornsby WE, et al. (2014) Impact of health-related quality of life and fatigue on survival of recurrent high-grade glioma patients. *J Neurooncol*. 120(3):499-506.

[Phillips-Pula, L, Strunk, J](#) and [Pickler, RH](#) (2011) Understanding phenomenological approaches to data analysis. *Journal of Pediatric Health Care*; 25(1):67-71

Pickard, A. S., & Knight, S. J. (2005). Proxy evaluation of health-related quality of life: a conceptual framework for understanding multiple proxy perspectives. *Medical care*, 43(5), 493–499.

Piil K, Juhler M, Jakobsen J, Jarden M. (2015) Daily life experiences of patients with a high-grade glioma and their caregivers: A longitudinal exploration of rehabilitation and supportive care needs. *J Neurosci Nursing* 47(5): 271-284.



- Piil K, Juhler M, Jakobsen J, Jarden M. (2016) Controlled rehabilitative and supportive care intervention trials in patients with high-grade gliomas and their caregivers: A systematic review. *BMJ supportive & palliative care*. 6(1): 27-34.
- Piil K, Jakobsen J, Christensen KB, et al. (2018) Needs and preferences among patients with high-grade glioma and their caregivers – A longitudinal mixed methods study. *European Journal of Cancer Care*. 27(2): 1.
- Pinquart, M., Hoffken, K., Silbereisen, R.K., & Wedding, U. (2007). Social support and survival inpatients with acute myeloid leukaemia. *Supportive Care in Cancer*, 15, 81–87.
- Pinquart, M. and Frohlich, C. (2009) Psychosocial resources and subjective well-being of cancer patients. *Psychology & Health*. 24 (4) 407-421.
- Plager, K.A. (1994) Hermeneutical Phenomenology: A methodology for family health and health promotion study in nursing. In: Benner, P. (ed) (1994) *Interpretive Phenomenology: Embodiment, caring and ethics in health and illness*. Thousand Oaks: Sage.
- Reimer, Y. and Gerber, B. (2010) Quality-of-life considerations in the treatment of early-stage breast cancer in the elderly. *Drugs & Ageing* 27 (10): 791-100.
- Risjord, M. (2009) Rethinking concept analysis. *Journal of Advanced Nursing*. 65 (3); 684-691.
- Ritchie, J and Spencer, L. (1994) Qualitative data analysis for applied policy research. In Bryman, A. and Burgess, R.G. (eds) *Analyzing qualitative data*. London: Routledge.
- Robinson S, Marsland L (1994) Approaches to the problem of attrition in a longitudinal panel study of nurses' careers. *Journal of Advanced Nursing* 20:729-741
- Rodgers, B.L. (1993) Concept Analysis: An Evolutionary View. In: Rodgers, B.L. and Knafl, K.A. (1993) *Concept Development on Nursing. Foundations, Techniques, and Applications*. Philadelphia: W.B. Saunders Company.
- Rotter, J.B. (1966) Generalized expectancies for internal versus external control of reinforcement *Psychol. Monograph* 80 (1) 1-28
- Russell B, Collins A, Dally M, et al. (2014) Living longer with adult high-grade glioma: Setting a research agenda for patients and their caregivers. *J Neurooncol*. 120(1):1-10.
- Rustoen T. (1995) *Hope and quality of life, two central issues for cancer patients: a theoretical analysis*. *Cancer Nurs*.18 (5): 355-361.

Rusteon, T., Cooper, B. and Miaskowski, C. (2010) *The Importance of Hope as a Mediator of Psychological Distress and Life Satisfaction in a Community Sample of Cancer Patients*. *Cancer Nursing* 33(4).

Rustoen, T., Lerdall, A., Gay, C. and Kottorp, A (2018) Rasch analysis of the Herth Hope Index in cancer patients. *Health and Quality of Life Outcomes* 16:196

Sacher M, Meixensberger J, Krupp W. (2018) Interaction of quality of life, mood and depression of patients and their informal caregivers after surgical treatment of high-grade glioma: A prospective study. *J Neurooncol.* 140(2): 367-375.

Sagberg LM, Solheim O, Jakola AS. (2016) Quality of survival the 1st year with glioblastoma: A longitudinal study of patient-reported quality of life. *J Neurosurg.* 124(4):989-997.

Saldaña, J. (2003) *Longitudinal Qualitative Research: Analyzing Change through Time*. Walnut Creek: AltaMira Press.

Shapiro, S (1997) Identity and meaning in the experience of cancer: three narrative themes. *Journal of Health Psychology* [1359-1053] 2 (4) 539

Sharif, P.S. (2017) Locus of control, quality of life, anxiety, and depression among Malaysian breast cancer patients: The mediating role of uncertainty. *European Journal of Oncology Nursing.* 27:28-35

Sivell S, Prout H, Hopewell-Kelly N, et al (2019) Considerations and recommendations for conducting qualitative research interviews with palliative and end-of-life care patients in the home setting: a consensus paper *BMJ Supportive & Palliative Care* 9:14.

Stephenson, C. (1991) The concept of hope revisited for nursing. *Journal of Advanced Nursing.* 16(12):1456-61

Sterckx W, Coolbrandt A, Dierckx de Casterle B, et al. (2013) The impact of a high-grade glioma on everyday life: A systematic review from the patient's and caregiver's perspective. *European Journal of Oncology Nursing.*17(1): 107-117.

Sterckx W, Coolbrandt A, Clement P, et al. (2015) Living with a high-grade glioma: A qualitative study of patients' experiences and care needs. *European Journal of Oncology Nursing.* 19(4):383-390.

- Sandelowski, M. (1995) Sample Size in Qualitative Research. *Research in Nursing & Health*.18: 179-183.
- Sandelowski, M (1998) The call to experts in qualitative research. *Research in Nursing and Health*. 21: 467-71.
- Sandelowski, M and Barroso, J (2002) Reading Qualitative Studies. *International Journal of Qualitative Methods* 1(1). <https://doi.org/10.1177/160940690200100107>
- Scanlon C (1989) *Creating a vision of hope: the challenge of palliative care*. *Oncology Nursing Forum* 16(4): 491-6
- Schickler, P. (2005) Achieving health or achieving wellbeing? Learning in Health and Social Care.4 (4) 217-227.
- Shapiro, S (1997) *Identity and meaning in the experience of cancer: three narrative themes*. *Journal of Health Psychology* [1359-1053] 2 (4) 539
- Sharif, P.S. (2017) *Locus of control, quality of life, anxiety, and depression among Malaysian breast cancer patients: The mediating role of uncertainty*. *European Journal of Oncology Nursing*. 27:28-35
- Simon, A. E.; Wardle, J. (2008) Socioeconomic disparities in psychosocial wellbeing in cancer patients. *European Journal of Cancer*. 44 (4) 572-8.
- Sin, S (2010) Considerations of Quality in Phenomenographic Research. *International Journal of Qualitative Methods* 9 (4): 305-319
- Starks, H and Trinidad, S (2007) Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory. *Qual Health Research*: 17(10):1372-80.
- Stephenson, N. and Corben, V. (1997) *Phenomenology*. In: Smith, P. (ed) *Research Mindedness for Practice: An Interactive Approach for Nursing and Healthcare*. New York: Churchill Livingstone.
- Sutton, K. (2012) The impact on quality of life for people with brain tumours of entering a research trial involving new anti-cancer agents. *European Journal of Oncology Nursing*.(online) Available at: <http://dx.doi.org/10.1016/j.ejon.2012.12.003>. (accessed 28.1.13)

Taphoorn, M.J.B, Sizoo, E.M. and Bottomley, A. (2010) Review on Quality of Life Issues in Patients with Primary Brain Tumors. *The Oncologist*. 15(6): 618-626

Thomas, J and Harden, A (2008) Methods for the thematic synthesis of qualitative research in systematic reviews<sup>[1]</sup><sub>SEP</sub>. *BMC Medical Research Methodology* 8:45

Tinkler, L. and Hicks, S. (2011) Measuring Subjective Well-being. Newport: Office for National Statistics.

Tobin, G. and Begley, C. (2008) Receiving bad news: a phenomenological exploration of the lived experience of receiving a cancer diagnosis. *Cancer Nursing*. 31(5): E31-9.

VanderZee, K. I.; Buunk, B. P.; DeRuiter, J. H.; Tempelaar, R.; VanSonderen, E; et al. (1996) Social comparison and the subjective well-being of cancer patients. *Basic and Applied Social Psychology* 18 (4): 453-468.

Walker, L.O. and Avant, K.C. (1995) *Strategies for Theory Construction in Nursing (Third Edition)*. Norwalk: Appleton and Lange.

Walsh D, and Downe S. (2006) Appraising the quality of qualitative research. *Midwifery*; 22:108-19.

Watson, M., Pruyn, J., Greer, S. and van den Borne, B. (1990) *Locus of control and adjustment to cancer*. *Psychol. Reports* 66(1):39-48

Whitehead, L. (2004) Enhancing the quality of hermeneutic research: decision trail. *Journal of Advanced Nursing*, 45: 512–518

Wilson, J. (1963) Thinking with concepts. Cambridge; Cambridge University Press.

Wimpenny, P and Gass, J. (2000) Interviewing in phenomenology and grounded theory: is there a difference? *Journal of Advanced Nursing*. 31 (6) 1485–1492.

World Health Organisation (WHO) (2016) The 2016 World Health Organization Classification of Tumors of the Central Nervous System: a summary. Available at: <https://braintumor.org/wp-content/assets/WHO-Central-Nervous-System-Tumor-Classification.pdf> Accessed: 02.06.2020

World Health Organisation (WHO) (1946) *Constitution*. Geneva: WHO. Available at: [http://apps.who.int/gb/bd/pdf\\_files/BD\\_49th-en.pdf#page=7](http://apps.who.int/gb/bd/pdf_files/BD_49th-en.pdf#page=7) Accessed: 09.02.2020

Yavas C, Zorlu F, Ozyigit G, et al. (2012) Health-related quality of life in high-grade glioma patients: A prospective single-center study. *Supportive Care in Cancer*. 20(10): 2315-2325

# **Appendices**

## Appendix 1: Ethical approval letter



### Health Research Authority

NRES Committee South East Coast - Brighton & Sussex  
Health Research Authority  
Ground Floor, Skipton House  
80 London Road  
London  
SE1 6LH

Telephone: 020 797 22551

10 December 2014

Dr Jo Armes  
Florence Nightingale School of Nursing & Midwifery King's College London  
Room 3.21 James Clerk Maxwell Building  
London  
SE1 8WA

Dear Dr Armes

**Study title:** Perceptions and experiences of wellbeing in people with a diagnosis of high grade glioma, and their impressions of how this is evaluated by healthcare professionals.  
**REC reference:** 14/LO/1898  
**IRAS project ID:** 153686

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Hayley Fraser [NRESCommittee\\_SECoast-BrightonandSussex@nhs.net](mailto:NRESCommittee_SECoast-BrightonandSussex@nhs.net) Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the*

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The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Ethical review of research sites**

##### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

##### Non-NHS sites

#### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [cover letter]		09 October 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [KCL indemnity letter]		01 August 2014
GP/consultant information sheets or letters [GP letter]	1.2	04 June 2014
Interview schedules or topic guides for participants [Interview guide]	2	24 July 2014
Other [clinical information form]	1	24 July 2014
Other [demographic information form]	2	08 August 2014

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the National Patient Safety Agency and Research Ethics Committees in England



Other [clinical director authorisation]		
Other [consent form for carers]	1.3	05 December 2014
Other [info sheet for carers]	1.0	05 December 2014
Other [response to REC letter]		05 December 2014
Participant consent form [Participant consent form]	1.3	25 November 2014
Participant information sheet (PIS) [PIS with tracked changes]	6.1	25 November 2014
REC Application Form [REC_Form_09102014]		09 October 2014
Research protocol or project proposal [Research Protocol]	3	25 November 2014
Summary CV for Chief Investigator (CI) [Jo Armes CV]		
Summary CV for student [Katie Sutton CV]		
Summary CV for supervisor (student research) [CV Jaqualyn Moore]		

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

##### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

#### HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

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the National Patient Safety Agency and Research Ethics Committees in England

14/LO/1898

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



Simon Walton  
Chair

Email: [NRESCommittee.SECoast-BrightonandSussex@nhs.net](mailto:NRESCommittee.SECoast-BrightonandSussex@nhs.net)

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

## **Appendix 2: Participant information sheet**

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Perceptions and experiences of people with a diagnosis of high grade glioma and their impressions of how this is evaluated by healthcare professionals.

**You are being invited to take part in a research study. Before you decide whether or not to participate, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and ask if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part.**

### **1. What is the purpose of the study?**

To explore the views of people with high grade gliomas in terms of their wellbeing at various points throughout their illness, including surgery, chemotherapy and radiotherapy and to investigate their views on the assessment tools used to monitor wellbeing.

This research is being undertaken by the principal researcher as part of a PhD in Nursing Research at King's College London.

### **2. Why have I been invited?**

You have been invited because you are an adult receiving treatment for a high grade glioma at [REDACTED]

### **3. Do I have to take part?**

No - participation is voluntary. The Principal Researcher will discuss the study with you and you will be given this information sheet to take away. We will also provide you with a copy of the interview guide, so that you know what kind of questions to expect. It is entirely up to you whether or not you would like to take part and you are free to withdraw at any time, without giving a reason. This will not affect the care that you receive.

Version 6.3  
15/04/2016

#### **4. What are the next steps if I agree to take part?**

You will be asked to participate in an interview with the Principal Researcher on up to three separate occasions over a maximum period of two years. The interviews will take place shortly after your diagnosis and/or initial surgery, and again during or shortly after your first and any subsequent treatments. These interviews can occur whilst you are attending the hospital (in a private clinical room) , at a time that is convenient for you.

Each interview will last no longer than one hour and will be audio-recorded with your permission. If you feel too unwell to attend an interview, you will be given the option to re-schedule. You are welcome to have a friend or family member with you during the interview.

#### **5. What are the possible benefits of taking part?**

You may not personally benefit from this study but the information you provide will help to improve care provision for patients with high grade gliomas in the future. We hope that all participants will find taking part in the study and helping to shape future services a valuable experience.

#### **6. What are the potential risks of taking part in this study?**

We do not foresee any risks in being involved in this study other than the potential distress you may feel at discussing your experiences. The content of the interview is entirely up to you, and you do not have to talk about anything that makes you feel uncomfortable, but professional help will be available for you should you find any of the issues raised distressing.

#### **7. What will happen if I don't want to carry on with the study?**

You can withdraw from further involvement in the study at any time and we will destroy all of your identifiable data if you wish. However, once the final interview has been completed, data that has already been given cannot be withdrawn as analysis of the findings will have begun.

#### **8. Will my participation in this study be kept confidential?**

All information collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital will have your name and address removed and will be given a numerical code, so that you cannot be identified. Interviews will be audio-recorded, but all digital recordings and written transcriptions will remain anonymous and will be stored in a secure environment. Only the Principal Researcher will have access to identifiable data. Once the study has been completed and reviewed, all identifiable data will be destroyed.

The Principal Researcher will only disclose confidential data when it is felt that withholding relevant information may risk the safety of yourself or others.

**9. What will happen to the results of the study?**

Once data collection has been completed, it is intended that results from the study will be published in a scientific journal. It is hoped that the results will help to improve care provision for patients with high grade gliomas in the future. If you would like to see a copy of the final study report and any published findings, please inform the Principal Researcher, who can send them to you.

**10. Who has reviewed the study?**

This study has been reviewed and given favourable opinion by the Brighton and Sussex NRES Committee (study code: 14/LO/1898).

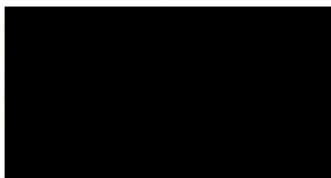
**11. Who can I contact during the course of the study?**

Should you have any questions about the study, please contact the Principal Researcher:

**Principal Researcher:** 

**12. What if I have any problems or concerns?**

Please contact the Principal Researcher on the details above, or:



If you have a complaint, you should talk to the Principal Researcher, who will do their best to answer your questions. If you remain unhappy, you may be able to make a formal complaint through the NHS complaints procedure.

This trial is sponsored by King's College London. The sponsor will at all times maintain adequate insurance in relation to the study independently. Kings College London, through its own professional indemnity (Clinical Trials) and no fault compensation and the Trust having a duty of care to patients via NHS indemnity cover, in respect of any claims arising as a result of clinical negligence by its employees, brought by or on behalf of a study patient.

If you need a large print, audio or translated copy of this document, please contact us on [REDACTED]. We will try our best to meet your needs.

Version 6.3  
15/04/2016

First published: September 2014  
Date last reviewed: December 2014  
Date next review due: April 2017  
Leaflet code: N/A

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## **Appendix 3: Information sheet for carers**

1



Florence Nightingale Faculty  
of Nursing and Midwifery  
King's College London  
James Clerk Maxwell Building  
57 Waterloo Road  
LONDON SE1 8WA  
Email: [Katie.sutton@kcl.ac.uk](mailto:Katie.sutton@kcl.ac.uk)

### **Perceptions and experiences of people with a diagnosis of high grade glioma and their impressions of how this is evaluated by healthcare professionals.**

Your friend/family member has agreed to be involved in the above study, and would like you to be present during the interview.

#### **1. What is the purpose of the study?**

To explore the views of people with high grade gliomas in terms of their wellbeing at various points throughout their illness, including surgery, chemotherapy and radiotherapy and to investigate their views on the assessment tools used to monitor wellbeing. This research is being undertaken by the principal researcher as part of a PhD in Nursing Research at King's College London.

#### **2. How will the interviews be done?**

Participants will be asked to attend an interview with the Principal Researcher on up to three separate occasions over a maximum period of two years. These interviews can occur whilst they are attending the hospital (in a private clinical room), at a time that is convenient for them. Each interview will last no longer than one hour and will be audio-recorded with permission. If the participant feels too unwell to attend the interview, they will be given the option to re-schedule.

#### **3. What will my involvement in the interview be?**

You will be present during the interview because your friend/family member has said that they would like you to be there. You will not be asked any questions directly during the interview, but you are welcome to contribute if you feel it would be helpful. The interviews will be audio-recorded and transcribed, and you will be asked to sign a consent form beforehand stating that you are happy for any contributions you make to the interview to be recorded and referred to in the research.

**4. Where can I find out more about the study?**

You can find out more about the study from the Participant Information Sheet, which can be provided to you by the Principal Researcher. You are also welcome to ask the Principal Researcher any questions you may have.

**5. Who has reviewed the study?**

This study has been reviewed and given favourable opinion by ...

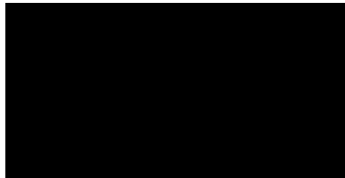
**6. Who can I contact during the course of the study?**

Should you have any questions about the study, please contact the Principal Researcher:

**Principal Researcher: Katie Sutton**  
**Telephone: 020 3447 8827**  
**E-mail: [katie.sutton@kcl.ac.uk](mailto:katie.sutton@kcl.ac.uk)**

**7. What if I have any problems or concerns?**

Please contact the Principal Researcher, or:



If you have a complaint, you should talk to the Principal Researcher, who will do their best to answer your questions. If you remain unhappy, you may be able to make a formal complaint through the NHS complaints procedure.

This trial is sponsored by King's College London. The sponsor will at all times maintain adequate insurance in relation to the study independently. Kings College London, through its own professional indemnity (Clinical Trials) and no fault compensation and the Trust having a duty of care to patients via NHS indemnity cover, in respect of any claims arising as a result of clinical negligence by its employees, brought by or on behalf of a study patient.



## Appendix 4: Consent form

### CONSENT FORM

Perceptions and experiences of the wellbeing of people with a diagnosis of high grade glioma, and their impressions of how this is evaluated by healthcare professionals.

Initial Box

1. I confirm that I have read and understood the information sheet dated.....for the above study and have had the opportunity to ask questions.
2. I confirm that I have had sufficient time to consider whether or not I want to be included in the study.
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
4. I understand that I am free to ask for my data to be withdrawn from the study at any point up until completion of the final interview, after which time data cannot be withdrawn as analysis of the findings will have begun.
5. I understand that I am welcome to have a relative/friend with me during the interview, and that they may contribute to the discussion if I want them to.
6. I am happy for the principal researcher to contact me to inform me of the outcome of the study
7. I agree to interviews being audio-recorded.
8. I agree to the principal researcher having access to my medical records for the purposes of this study only.
9. I am happy for my GP to be informed of my participation in this study.
10. I agree to my anonymised quotes being included in the research findings.
11. I agree to take part in the above study.

-----  
Name of Patient                      Date                      Signature

-----  
Name of Researcher                      Date                      Signature

## Appendix 5: Consent form for carers

### CONSENT FORM FOR CARERS

Perceptions and experiences of the wellbeing of people with a diagnosis of high grade glioma, and their impressions of how this is evaluated by healthcare professionals.

Initial box

1. I confirm that I have read and understood the information sheet dated.....for the above study and have had the opportunity to ask questions.
2. I understand that I will be present during the interview as my friend/family member has requested this.
3. I acknowledge that I will not be asked any questions directly, but that I am welcome to contribute to the discussion if appropriate
4. I understand that I am free to ask for my data to be withdrawn from the study at any point up until completion of the final interview, after which time data cannot be withdrawn as analysis of the findings will have begun.
5. I agree to interviews being audio-recorded.
6. I agree to my anonymised quotes being included in the research findings.

-----  
Name

-----  
Date

-----  
Signature

-----  
Name of Researcher

-----  
Date

-----  
Signature

## **Appendix 6: Interview guide**

### **INTERVIEW GUIDE**

Perceptions and experiences of the wellbeing of people with a diagnosis of high grade glioma, and their impressions of how this is evaluated by healthcare professionals.

Principal Researcher: Katie Sutton

#### **Proposed topics to be covered during the interviews:**

##### **During the first interview:**

- Introduce self and offer a brief summary of the aims of the research and the format of the interview.
- Reiterate to the participant the option of terminating the interview at any point if they wish to do so.
- Experience so far of diagnosis and treatment.
- What was wellbeing like before diagnosis (lifestyle, family, social life, work) and what has been the effect of diagnosis and treatment on wellbeing.
- The meaning of wellbeing to the participant at this point in time.
- Experiences of having wellbeing assessed through the use of tools such as questionnaires. Perceptions of the appropriateness of these assessments.
- Thoughts/suggestions on how participants would like their wellbeing to be monitored.
- Anything else to add in terms of experiences of the impact of disease and treatment on wellbeing, or impressions of how this is evaluated by healthcare professionals.
- Thank the participant for agreeing to be involved.

##### **During subsequent interviews:**

- Reiterate to the participant the option of terminating the interview at any point if they wish to do so.
- What has happened since the previous interview.
- The meaning of wellbeing to the participant at this point in time.
- Experiences of having wellbeing assessed through the use of tools such as questionnaires. Perceptions of the appropriateness of these assessments.
- Thoughts/suggestions on how participants would like their wellbeing to be monitored.
- Anything else to add in terms of experiences of the impact of disease and treatment on wellbeing, or impressions of how this is evaluated by healthcare professionals.
- Thank the participant for agreeing to be involved.

## **Appendix 7: Demographic information form**

### **Demographic Information Form**

Perceptions and experiences of the wellbeing of people with a diagnosis of high grade glioma, and their impressions of how this is evaluated by healthcare professionals.

Principal Researcher: Katie Sutton

The following information will be collected from the patient's medical notes once they have signed the consent form:

Name:	Date of Birth:
Hospital Number:	Gender:
Address:	Contact phone number:
Numerical code allocated to patient for data confidentiality purposes:	

## **Appendix 8: Clinical information form**

### **Clinical Information Form**

Perceptions and experiences of the wellbeing of people with a diagnosis of high grade glioma, and their impressions of how this is evaluated by healthcare professionals.

Principal Researcher: Katie Sutton

The following information will be collected from the patient's medical notes once they have signed the consent form:

Numerical code allocated to patient for data confidentiality purposes:	Diagnosis:
Date of diagnosis:	
Any co-morbidities and treatments for these:	
Any symptoms resulting from diagnosis and treatments:	
Any significant factors in social background:	
Surgery dates and details:	

--

Chemotherapy dates and details:

--

Radiotherapy dates and details:

--

Other treatments:

--

## **Appendix 9: GP letter**

Date:

Dear Dr.....

Re: [Patient Name], DOB: [dd/mm/yy], Hospital Number:

I am writing to inform you that the above named patient has consented to participate in the following qualitative research study:

‘Perceptions and experiences of the wellbeing of people with a diagnosis of high grade glioma, and their impressions of how this is evaluated by healthcare professionals.’

This research study is being conducted as a component of the PhD studies of the Principal Researcher at King’s College London. I enclose a copy of the participant information sheet for your information. Please do not hesitate to get in touch on the contact details above if you require any further information.

Yours sincerely

Katie Sutton (Principal Researcher)

**Appendix 10: List of abbreviated tools included in scoping review literature**

<b>Abbreviation</b>	<b>Full name of tool</b>
BCM	Brain Cancer Module
BRCS	Brief Resilience Coping Scale
BrTSCNS	Brain Tumour Specific Supportive Care Needs Scale
CES-D	Center for Epidemiological Studies-Depression Scale
EORTC BN-20	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire - Brain Cancer Module
EORTC QLQ C30	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire
EQ-5D-3L	EuroQol 5 dimension 3 levels
FACT-Br	Functional Assessment of Chronic Illness Therapy-Brain
FACIT-F	Functional Assessment of Chronic Illness Therapy-Fatigue
FACT-G	Functional Assessment of Chronic Illness Therapy-General
HADS	Hospital Anxiety and Depression Scale
KPS	Karnofsky Performance Score
MDMQ	Multidimensional Mood State Questionnaire
MMSE	Mini Mental State Examination
NeuroCogFX	Computer-based neuropsychological assessment battery for the follow-up examination of neurological patients
SCNS-34	Supportive Care Needs Survey-short form 34
SF-12	Short Form Health Survey-12 item
SF-36	Short Form Health Survey-36 item



## Appendix 11-Example of interview transcript

TRANSCRIPT-BILL INTERVIEW 2

For:

[REDACTED]

Title:

[REDACTED]

Type:

Interview

Convention:

Verbatim

Audio Length:

49 minutes

Transcriber:

[REDACTED]

Completion Date:

27.07.2016

Transcriber's Notes:

Any difficulties experienced, accents and general comments

number of unclears

23

number of inaudibles

0

spell check performed

Yes

proofing performed

Yes

audio quality

Good

speaker related issues

Mumbling

equipment related issues

Echoing

terminology issues

N/A

other comments

N/A

Please find attached your completed transcript.

Whilst every effort is made to ensure that the attached transcript is an accurate record of your audio recording, sometimes difficulties are encountered in understanding technical words, people speaking with a foreign accent and in some cases when somebody is speaking from a crowded room with a lot of background noise and from mobile phones. Where we have had difficulty understanding words we have indicated this as [unclear] with the appropriate time stamp, or simply attempted to spell the word phonetically but followed it with [ph].

[Start of recording]

INT: So this is really just for us to catch up and for me to find out a bit more about how you're feeling at the moment, as opposed to how you were when you were having the radiotherapy and chemotherapy.

RES: Yes.

INT: Tell me how you're feeling, go for it?

RES: Erm, I think when I was having the combined radio and chemotherapy there were a number of things going on. First of all, it took up a lot of the day, err sitting in there waiting for the treatment, and secondly it seemed as though I was living in a bit of a dull sort of days ...

INT: Right.

RES: You know going to these appointments and I wasn't going to appointments, probably horizontal with my eyes shut and pretty dozy. Err, I did get to see people and stuff, I probably didn't, I tried to resist too much social stuff until the radiotherapy had finished and I had that little break ...

INT: Yeah.

RES: ... and then I started to sort of meet up with folk for coffee and so on.

INT: Okay.

RES: Erm, the biggest bugbear since the end of the radiation and over the last 2 or 3 months has been the being hard of hearing.

INT: Right.

RES: So for example, it sound [unclear: 0:01:32.8] have a coffee, it's amazing the noise of a cappuccino machine and it seems to catch and having to say pardon or what, you know it's just awful. Erm, so that's probably the worst bit, not being able to hear stuff very well and having to get the subtitles on the television.

INT: Yeah, absolutely.

RES: Erm, you know in terms of physical stuff, I can't remember if I talked to you about this, I have a static bicycle in the shed ...

INT: No, you didn't.

RES: I have a heart rate monitor ...

INT: Okay.

RES: This is from when I was training seriously, and so I did sort of graduated erm sessions, in terms of time, the intensity was very low. I sort of found a breaking point at which I was flattened. One session, it was only like up to 1 minute, the intensity was very low and I was flat. About 4 or 5 days.

INT: Oh wow.

RES: It was like this [unclear: 0:02:47.3] and this week for the first time I went for a swim which was great, just being in the water.

INT: Yes, and did you start the cycling after the radiotherapy had finished?

RES: Yes, yes.

INT: Okay. Are you still doing that?

RES: Yes, not that, the first occasion did some running, so running at, again it is, it was erm, on Monday I think it was 18 minutes, but the intensity was really low. I mean my heart rate was 139 which is fairly low and peaked at 147 and I, [unclear: 0:03:33.9] ...

INT: Yeah.

RES: Erm, wasn't very long, so kind of an indication of how things could change and I, you know tried to keep that, that progressing and I did have a thought that when all this finishes, which is around sometime September and I find a triathlon which is an indoor swim, a short one, and I might do it. I would do it for the brain tumour charity.

INT: Okay, great.

RES: I'd obviously have to let the organisers know but it's a long way to go before I get to that. I mean I know how far there is to go before I am ready to do that kind of thing. I thought it would be an objective, it would be for things that I believed in and I've never done it. I mean iron man stuff before but I've never ever done anything for sponsorship. I've always known I'm doing it for my own pleasure. Not for someone else to put their hand in their pocket. So it is a thought.

INT: Yes, yes.

RES: As I say, I'll probably do it ...

INT: That sounds lovely.

RES: Yes, so we'll see how I get on.

INT: Yeah.

RES: Sort of, it's about setting objectives.

INT: Absolutely.

RES: Moving towards something instead of this trickling all the time.

INT: Yeah, and how do you find that useful or helpful? It might sound obvious but do you think that's beneficial for you? To set the objective and for in particular for it to be something like this triathlon, why do you want to do that? What is it that's ...?

RES: Well I think principally because exercise has been such a big part of my life for probably all of my life, erm, is being virtually every day of the week ...

INT: Okay.

RES: Err, so 2012/2013 I did the iron man triathlon, the last couple of years my son has been competing with me and we both qualified for the Great Britain Age Group teams so we've been away with the Great Britain team.

INT: Great.

RES: So it's like it's just a part of my life, it's an easy thing to revert to you know. Erm and it's all the stuff, the endorphins from exercise, this is nice.

INT: Yeah, and it helps to kind of set yourself something to do, an objective to ...

RES: Yeah, yeah but I know I am not going, unfortunately I have a friend who had the exact same tumour as me, I worked with, he's also a triathlete and err he died 2 months ago.

INT: Oh, okay.

RES: He was a few months ahead of me in all of this erm but like we always used to joke about the crazy things we'd been doing. It's like part of the conversation that we had.

INT: Yeah.  
RES: You know this is when we were, before we were ill yeah.  
INT: Yeah.  
RES: He always had a story what happened to him at the weekend, and very sad, very sad.  
INT: Yeah, very sad.  
RES: So I don't have him to talk to [laughs].  
INT: Yeah, that must be a real shock.  
RES: Yeah, because he's, he was younger than me and he got it before me and erm then around December I found I had this and Mike was getting, well we got in touch and he was like trying to cheer me up and like a coach and it was a funny conversation, erm, it was, yes it was a good friendship, yes.  
INT: Yeah, okay.  
RES: It's an amazing coincidence.  
INT: Unbelievable yes, that you worked together and such similarities.  
RES: Yes, GP for and, the whole business, yes.  
INT: Yeah, okay, and you erm, so yeah that must be quite an effect then, something else that you want to do because you were thinking [unclear: 0:08:08.1]?  
RES: Erm ...  
INT: He would be supportive of you doing it?  
RES: It would be kind of err, a connection, yeah.  
INT: Yeah.  
RES: Yeah, connection with things in life.  
INT: Absolutely, yeah.  
RES: And of course it would be, you know nice to do something supportive of other people who have helped me in the last 5 months and I was, I never really did very much for other people.  
INT: Yeah, okay.  
RES: But that was only [unclear: 0:08:44.0]  
INT: Okay, that sounds like a good plan. So that's later in the year, early next year probably?  
RES: Yes, I don't know when it will be, I had thought maybe September, could be that's too soon. Erm, I just have to gauge it by progress. I'd prefer a pool swim because of the warmth and stuff because I've been, believe it or not I was competing in Spain with my son, it was the European Triathlon Championship last May and it was a, virtually rained the whole time through and I ended up with the medics all over me.  
INT: Oh.  
RES: And it wasn't nice so I, and then you're going to think we're really crazy, and in that last August, my son, my sister who is a couple of years younger me who is a good swimmer and my Scottish relatives, did a 5km swim in [unclear: 0:09:57.8] ...  
INT: Oohh ...  
RES: ... and it was bloody freezing.  
INT: Was it.  
RES: It wasn't meant to be that cold but the [unclear: 0:10:03.9] comes off the mountains in the summer. But it was cold. So I don't like the cold too much. So I try to find one that might be alright.  
INT: But you'd think August would, in effect, but it is Scotland isn't it.

RES: Yes, and I spoke to a couple of people when I was up there and they said yeah it's not just the time of the year, it's something to do with the particular where the water is coming from.

INT: Maybe in a different loch next time.

RES: Not as cold, yes.

INT: So you enjoy your swimming then as well as running?

RES: Not particularly, not as keen on swimming as I am at the running but I do like it. And because when I went for a swim this week, sorry if this is not what you want ...

INT: No, no it's useful.

RES: And I was on a real high, all I'd done was little 50m repetitions and stopped and you know for about 20 minutes or something and I was high as a kite afterwards and it's not just the endorphins, there's all this thing with women have children in the water and the new-born how they naturally swim. I just wondered if there's something innate in us which makes it, has some kind of connection with being in the water.

INT: Yes, feeling comfortable and ...

RES: I just love having [unclear: 0:11:49.2] yes.

INT: Yeah, that's good. So what about on a day-to-day basis, how are your days?

RES: Erm, okay a number of things to this. First is the brain, I seem to have problem in sorting dates and times. So if people say do this at time of day, before I had like a diary in my head and I knew I could, partly because the training stuff, I knew I was going to be doing it almost any time of the day, any day of the week for the next 7 days or more.

INT: Okay.

RES: Erm, and I've made a couple of foul ups and sort of, because I've got dates and times wrong.

INT: Okay.

RES: So I have to be careful I don't sort of mess up, more domestic arrangements than anything else. Or I am unaware of other things that have been arranged for me.

INT: Okay.

RES: First thing in the morning it is like I go through a bunch of emails which is stuff, work related ...

INT: Okay.

RES: ... and generally read the paper, if I am going to do any exercise I normally try and do it first thing in the morning.

INT: Yeah.

RES: Erm, and almost invariably sleep for about 45 minutes before or after lunch.

INT: Okay.

RES: Erm, funny I struggle to find good literature to read.

INT: Okay.

RES: Which really bothers me. I, just stop me if this is off the piste or whatever, but erm, before this all kicked off I had been a bit down and this happened a few times and I had read some philosophy books and stuff and then I was sort of, began to get interested in the Greek philosophers and I found them, provided a useful way to manage things. I mean I sort of paraphrase things a little bit which is you can't stop whatever happens happen. You can't control what happens to you but you can control how you

react to it so you can decide to go in a panic or be cool or whatever, you've got some control over those things. And so I happen to err mention this to one of my friends, a French guy and I've forgotten his brain box. He had gone back to Paris some years back and studied a whole load of Greek and Latin so I mentioned the philosophers and he said oh yeah, he said, and then he told me about Seneca and his letters he wrote. I went and got the book and have been reading it. It would be quite nice that other people that read them ...

INT: You can discuss it.

RES: I'd be kind of understood, some of them are very interesting but maybe that is a bit heavy. But I, the letters because I can read like a letter before I go to bed.

INT: Yes, okay.

RES: It's mostly you know it is listening to ways of people that have to deal with life if you would.

INT: Yeah, yeah.

RES: But I think I am, I am, I keep going into bookshops, you know the times I go into a bookshop and come out with an armful and I don't find so much interesting.

INT: Yeah, why do you think that is? Are you looking for something different or you think there just isn't ?

RES: No, I don't really know why it is. I was in Dundee seeing my daughter few weeks ago, picked up a sports biography which is great you know, [unclear: 0:16:17.6] ...

INT: Yeah.

RES: And, I don't know.

INT: Okay. But it's something you enjoy doing and would like to do more of?

RES: Yeah.

INT: Okay.

RES: Yeah, it'll probably [unclear: 0:16:32.2] I can't remember, I was talking to someone recently said well maybe you should go back and read some of the things that you've read in the past that you like, erm, so for example, I do like Dickens and I do like erm Scott, you know Scottish writer erm so maybe I'll go back to some for pleasure and which I enjoyed and I know that I'll read.

INT: Yeah, okay, sounds like a good plan.

RES: Pardon?

INT: That sounds like a good plan, if you enjoy them you might as well ...

RES: Ah I am looking for something. Partly escapism but it's partly erm just engaging.

INT: Yes, of course yeah, but then some of the purpose is kind of finding out about something new isn't it I suppose, that's why we read something again.

RES: Don't worry, I forget stuff awfully quick so I probably would, be like reading a new book.

INT: [laughter] so when you, you said you had some work emails, are you still doing some work?

RES: Right, erm, I don't know if I explained before but I worked for an investment fund, they call me a consultant but basically I was working there all the time, advising on things they'd bought and the things that they sold and so I used to meet lots of companies and managements and stuff. And they

kept in touch so I get emails on what's going on erm and err, they wanted to throw some work at me and I kind of noticed that I was backing off a bit.

INT: Okay.

RES: And erm, but, actually it was last Friday afternoon, some [unclear: 0:18:30.7] analysis of a fund and the fund's performance and trying to identify their characteristics of whether we'd made good investment decisions and bad investment decisions.

INT: Right.

RES: And it was interesting, there were three of us talking about it and I started to think well actually maybe I should go into the office for an hour or two and just start getting into it again, and I think I'd like that, like the conversations, engagement erm so I am much keener now to have a shot at that. Whereas before I was, I can't remember [unclear: 0:19:12.9] explained to the, is it xxx, the oncologist?

INT: Yeah.

RES: Erm how most of investment, certainly me, we've got this insatiable appetite for information, the latest newspapers, journals, err stock exchange announcement, company account comments, you know kind of insatiable appetite and I was quite lukewarm.

INT: Okay, and when was that?

RES: Well that's only been since err, since I started the radio and chemo thing.

INT: Okay.

RES: You know it's not this [unclear: 0:19:51.7] thing, it's sort of, a bit cool and I think probably [unclear: 0:19:59.7] a bit.

INT: Okay.

RES: Feel more able to do it.

INT: Okay, can you think of any reason why you feel more able to do that then?

RES: Yeah, erm, yes. I can. The one thing is the chemo brain, my daughter is a doctor, she's working in neurology hospital in Dundee and has told me something, they call it chemo brain. She said, actually the longer it is away the treatment the clearer I find I am thinking, so partly it is I am thinking oh a bit clearer, or things feel a bit clearer.

INT: Do you notice it, because you are still having the temozolomide chemotherapy, do you notice it changes depending on where you are in the month or ...?

RES: Yeah, yeah, so as time progresses since it stopped, so 3 or 4 weeks since it stopped and I am probably at my best before I start getting ...

INT: Okay, yeah.

RES: So it is probably that and also a little bit more energy.

INT: Yeah, okay, good.

RES: Yeah, I think that's why, and, and a desire ... the other thing is a funny thing, I have figured I am quite solitary individual, I am happy in my own company and for the first time in the last few months I've rather, well I get a lift from company, from [unclear: 0:21:43.3] and I get a bit of a lift from that. And less happy in my own company for too long which is new for me. I suppose [unclear: 0:21:55.5] ...

INT: [laughter] something to do.

RES: It is new and erm, secondary I think.

INT: Okay. Because it feels like a change?

RES: Pardon?  
INT: Because it feels like a change?  
RES: Yeah.  
INT: Okay.  
RES: And not a change that I would wish because I do start to think looking at the clock thinking well any time you can do that.  
INT: Okay, yes.  
RES: Like that you know, don't really want to be in that position. You know 1) because you know she's been hauling me along for all these months, she's got to have her own life and I want her to have her own life, to do our own things. I don't want to limit that. She'll be happier if she's able to do stuff.  
INT: Mmm. And do you think that's because you're spending more time on your own than you're used to? Do you think because you are, do you find you're at home on your own more often?  
RES: Yes, I am at home on my own more often.  
INT: Yeah.  
RES: Yeah, so it'll sort it out as I sort of start to ...  
INT: Get busier.  
RES: Yeah, yeah.  
INT: Okay.  
RES: Sure.  
INT: So it's mainly on a day-to-day basis there's some work, some exercise, some reading, some sleeping ...  
RES: Yeah, yeah, pretty good summary actually.  
INT: Yeah [laughter]  
RES: Very dull.  
INT: Well you are having treatment still.  
RES: Sounds very dull.  
INT: No, it's, they are important things for your wellbeing which is ...  
RES: Yes, the biggest bugbear is financial things. [Unclear: 0:23:42.7] and it is just, I don't know why there was a big pile of stuff to get sorted, it sort of, I've probably got two thirds of the way through now.  
INT: Okay.  
RES: You know. All the bloody papers and stuff, yeah.  
INT: And stats, it can be stressful, as you said it doesn't stop things needing to be paid does it?  
RES: It's a bit of a bugger, yes. Erm yes.  
INT: Okay, and do you manage to keep on top of that?  
RES: Not particularly well no, I am behind on that.  
INT: Yes, okay.  
RES: Just needs a bit more perseverance I think.  
INT: Okay, erm and what, do you know any kind of, we talked about the triathlon plans, but any other plans or goals that you are kind of thinking about setting for yourself and your life after the treatment finishes? Are you not at that point yet?  
RES: Erm, no. I, somebody asked me something similar a while back and I don't really know quite how to answer it. I have thought that come this September I might have retired ...  
INT: Mmm.  
RES: I don't think like that at the moment. Erm, I don't really know, I suppose because, I don't really know the objectives I have. I think because as



a copying strategy I have taken the view that we are not going to think too far ahead. We know we are in, it's a big boys' game and we know the consequences can be and we don't think too far ahead, we think about what the milestone is. We know the next milestone sometime in September, with the scans and so on. It's these things with the monthly. But I haven't really thought very far ahead.

INT: Yes.

RES: And I am not really sure how much I should think ahead.

INT: No, well if the way that you find best to manage it is to only think short-term then that is, seems like the best thing to do.

RES: Yes, I am puzzled by it. Sort of with my son and my daughter, had little conversations where we'd just been creeping round the subject a little bit.

Err, I suppose mention of mortality and, I think crikey, I don't mean to use them, I don't even know what the score is. erm, I think, I just said how much I'd enjoyed competing with him, I'd never have even tried to enter the Great Britain team if he hadn't said to me let's have a go at this. You know and then all over the place together and cracking good times, some real funny times. And then the conversation was a little bit difficult, a little bit different and I think what it got to, what it started from was I said to her, xxx I've never asked you this but I've had lots of time to think about it over the last few months, why don't you become a doctor.

INT: Okay.

RES: And you know I know how she is about being a doctor, she loves it, she loves it. Every new rotation she gets up to here, she's so absorbed by it, it's like t's what she was meant to be. And I know, I just talked a little bit about that and conversation and again it sounds terribly morbid but you know sometimes I wonder should I write them a letter.

INT: Yeah.

RES: You know how good it's been.

INT: Yeah, yeah. Okay.

RES: Don't know if it would help them or not.

INT: Yes, it's very difficult to know. Do you feel like you get much support from erm people here or from, where do you get your support from?

Obviously they are big issues to have in your head and to be thinking about.

RES: Well, I did briefly go upstairs at one point, a couple of months ago, April because there is a temptation to take matters into my own hands. And just knock it on the head, but you know and I've had this before, probably see my notes I've got HIV positive, it was my own fault. There's an enormous sense of guilt, there's an enormous sense of having broken all of the things which I believed really important in life like loyalty and integrity and honesty and the most intimate way breaking and throwing them out the window. Err, had it, just dealing with that.

INT: Yeah.

RES: And it's only because [unclear: 0:29:32.1] been so good, erm, but it's always there.

INT: Yeah.

RES: Erm, so I did have a brief conversation with them upstairs, and I am also [unclear: 0:29:48.8] a hospice locally and I had a talk with a chap there, didn't really provide much help, you know people virtually saying you know if you feel that way phone the Samaritans or whatever. Whereas I think what

drew me towards the philosophy of things was it's a [unclear: 0:30:13.6] for dealing with things that you don't really want to feel. So that's ...

INT: It's like coping strategies that you can, coping strategies that you can read about so that you can feel useful.

RES: Yes, things, yes erm you know it's something which comes to me, I described, it's like a toy, you know play with this little toy in my head which is sort of, sort it out for myself. And it is frightening. And actually the reason I've never done it apart from being a coward is that erm, the damage it leaves in its aftermath for like xxx and xxx, never mind xxx, erm, and you know that's probably the biggest single reason that what it means for them to feel, it's not very nice.

INT: No okay.

RES: Can do without that.

INT: Yeah [laughs] yeah that's the thing that kind of stops you from taking it any further, so the impact it has on the people that love you?

RES: Yes, yes.

INT: Yeah. But you didn't particularly find the interactions you had ...?

RES: No, I said I had these feelings and that I hadn't done anything, and why, and every sort of, I don't know what I was looking for.

INT: No, I was going to say what were you hoping to get out of it?

RES: I suppose in a way I was looking for, is it coping strategies, you know just little [unclear: 0:32:16.4] just help straight me out or whatever. Erm ...

INT: Yes, I mean I think they are doing, there's more awareness of psychological coping mechanisms for helping people to manage themselves by teaching people things like that which ...?

RES: Yes, that's why, reading on this philosophy was so interesting.

INT: Yeah, erm and I think they are kind of starting to run more courses on, well kind of helping to overcome problems in your, in your head and that kind of thing and dealing with what's happening on a day-to-day basis.

RES: Yeah.

INT: So maybe more things like that, so things that you might find more useful ...

RES: I am interested in, yeah.

INT: Okay.

RES: Interested in that.

INT: Yeah, okay.

RES: Yeah.

INT: And many other symptoms that you are experiencing day-to-day now that you are ...

RES: Symptoms?

INT: Anything from the treatment or anything from ...

RES: From the tumour.

INT: ... the tumour or just, I mean they kind of wrap up into one really don't they, it is the whole package of what is going on with you that ...

RES: Yes, I think a couple of things which I can identify, one is I think there's part of the brain affected, affects my sense of direction and space. I have a hopeless sense of direction at the moment. That, a couple of things before this all kicked off where I had been coming back, travelling home, I used to have a motorbike but had to get rid of that and I came home a couple of notes and I said to, I said I've just taken a couple of wrong turns, this is a

route I really know. I said I must be going doollally. Erm so that sense of direction is there.

INT: Yeah.

RES: Erm, not there really as it used to be. Erm, although it's never been particularly good. The other thing is I think I mentioned to you, this, the way the memory is implanting dates and times and arrangements, yes. You know I have to write stuff down and be very careful I've got it right.

INT: Yeah.

RES: Err, not seeming to take it on without making a note. So that's a change.

INT: Okay.

RES: And ...

INT: How about problems with sleeping, [unclear: 0:35:08.8] or anything like that?

RES: I go to sleep really easily, straight away, can't wait to get in bed. I wake up quite early and ... it's not, I am not exercising the way I was so the change that might be, you know what's really the cause and what's not.

INT: Yeah.

RES: Erm, it's not as good as it was, it's okay.

INT: No, okay.

RES: The number of hours, I am getting a kip.

INT: Okay.

RES: What was the other thing you said, you said something else?

INT: Feeling tired during the day?

RES: Yes, I mean I don't like feeling tired during the day, it actually, funnily enough we live at the bottom of a hill, anywhere we go I've got to go up the hill. I know now that does have an effect and at some point later in the day I need some recovery time from that.

INT: Okay, yeah.

RES: Erm, but I can sit around the house and I wouldn't think oh I'd better have a sleep. You know only if 've done something and it has ...

INT: Brought it on, okay, okay.

RES: Yeah.

INT: Erm and just finally want to ask you about the support that you get for the hospital and things, can feel, it seems from what people tell me it can be quite different. Obviously with radiotherapy you are coming daily, and seeing people quite a lot.

INT: Yeah. Erm and then you move to this and you're only seeing people once a month. How do you feel the support is and is there anything you think we could be doing differently or more of that you would find helpful?

RES: I'm reluctant to say too much because I think that xx has been so fantastic.

INT: Yeah, it's not a criticism, it is just us wanting to think about how we can keep improving.

RES: Yes, which is another thing which I think is admirable in the things I've encountered at xxx, is the desire for improvement and desire to be the best you can be. I think it is, it is, I am really impressed and as an investment and an analyst of corporations and how they behave, I've actually written a calcular piece of what they might learn from the NHS.

INT: Really?

RES: Yes.

INT: [Laughter] Okay.

RES: A little unit of specialist nurses erm which has been a great support to me and to the family, erm, and I wrote in one of the pieces I said you know can we still learn from this, that instead of you know when you send me a complex product like a financial service product or a car something, you know it may not be cost effective but it might be better than having somebody in India you can't understand on the telephone. Erm, and dedicated to yourself, to the service. So I am very loathe to ...

INT: Yes, it's a personal relationship.

RES: I think it is marvellous, in awe of all the people that we've encountered and dealt with, from the radiology department to surgeons and consultants and nurses and doctors. What would I say differently? Erm, might do better ... you touched on something and xxx had warned us about it before we finished the radiotherapy. She said you are here all the time and you are going to feel you've been cut loose and it was an element of that and it was slightly, I am adrift here and I am just drifting. And it had taken a little while and I guess if there was a suggestion sometimes, I am conscious of resources, is why not a phone call and say how are you doing, or you know is anything going on. Just it's difficult because you can't hold someone's hand 24 hours a day but you know maybe that, you know we've learnt things that's been going on which are normal which we were wondering about, you know. What else would I think?

INT: So a phone call while you are having chemotherapy?

RES: It's just a suggestion, it is not ...

INT: Yes, I know, that's useful.

RES: I am not saying you must.

INT: No, of course not no.

RES: It seems like for example I am aware there might be this sense of adrift, if you are aware of it and you want to address it, then perhaps that's the way to do it is to say okay see if I can catch up with someone, might be an irritant to people I don't know but it might be a comfort at some point. I'll ask them about that and see if that's normal.

INT: Yes, that sounds good.

RES: It's not ... can't really think of anything else

INT: Okay, do you find we ask you about how you are doing in terms of your wellbeing and very often do not.

RES: I was going to compliment you actually, you are the first person that has asked about some of those things which I'd rather not talk about for obvious reasons.

INT: Yes, yes.

RES: And you are the first person, and yet I know how important it is for lots of reasons, obviously in case I go and do myself harm but just you know it must have an effect on one's physical wellbeing.

INT: Absolutely, yes.

RES: Erm, I don't want to wallow in it or anything erm but you are the first person who has asked.

INT: Okay, yeah.

RES: And of course if folk say something, ask them, I have asked and got a little bit of help. Just talked through some stuff.

INT: Yeah.

RES: But I can't be taking up everybody's time with all this stuff.

INT: No, but those issues must be huge for you in your, kind of what you are thinking about ay-to-day and then ...

RES: Yes, some of it is wrapped up in the HIV stuff you know.

INT: Yeah, yeah. You don't necessarily want to talk about that very often.

RES: I find it's erm, just awful thing err for, I've never told xxx and xxx and I don't want them to know.

INT: No. But you are only human, you know.

RES: It's all the things which I have encouraged them to be and to do and I've let myself down, let them down and err, and xxx most of all and I can't undo it.

INT: No, I know.

RES: Err ...

INT: But it sets the bar very high doesn't it you know for all these, for the person that you try to be and everybody ...

RES: Yes, I still fell pretty badly and you know I've often tried to analyse and think about why and I can't think, explain it except for arrogance and all sorts of things.

INT: Yeah.

RES: What lead me down that path?

INT: Yeah.

RES: And I can't even explain it, you know I say what an idiot.

INT: And yes, you are human and things happen, things happen in people's lives that no one else knows goes on.

RES: Yeah, that's right, that's right.

INT: You can hold other people as examples and you never know what ...

RES: Yeah.

INT: ... what else is going on but you know.

RES: You see it's things like it is wrong for that to be loaded on a counsellor department, you know some [unclear: 0:43:56.4] all these other things, you know you can't ...

INT: You can't really separate them out can you because it is ...

RES: No, I know.

INT: ... you know it all ends up in your head, you can't segregate them like that. Not that straightforward is it?

RES: No.

INT: But ... I mean there might be, I know they run a HOPE cause up there which is called Helping Overcome Problems Effectively which is about erm kind of management strategies, err, dealing with anxiety and internal things that might be useful.

RES: And I suppose for a lot of people I imagine that the, one of the things they try and tell you is the impending mortality. And I don't know, like sometimes I like to think I've come to terms with that, I don't really know if I have or not. Erm, I seem to have had a lot of time to have thought about it.

INT: Yeah, yeah.

RES: I could hope to come to terms with it.

INT: What does coming to terms with mean anyway?

RES: The fact that err, you can't change what's going to happen and you've got to sort of find a way to relax to enjoy what's good, think about the good things and the rest will take care of itself.

INT: Yeah, yeah. Focus on the triathlon ambitions. [Laughs]

RES: Yeah, yeah. Maybe that's right.

INT: Okay.

RES: Thank you.

INT: Is there anything else you think might be useful for us to know in terms of how your, how you feel your wellbeing is at the moment or ...?

RES: Not ...

INT: It's physical but also actually very, the psychological side is extremely difficult [0:46:00.3]

RES: I would say that's the bit I've found most, actually it is the mental side of the last couple of months, since about April I remember it really kicking in and really sort of struggling to get around this.

INT: Yeah.

RES: Erm, yeah.

INT: Yeah, and then what's out there to deal with it, you know how do you manage it and how do you, who do you talk to?

RES: Yes.

INT: What are the answers?

RES: Listen, we know, we've talked at home, you know. And I think probably since, well maybe I am probably more aware of it than the other, we've always made this pact, we are not going to look stuff up on the internet because we probably wouldn't understand it and not going to burden xxx by asking her about stuff. But I think we've always known you know what the possible consequences of this is. We've never asked anybody because no one can give us a probability, sort of time tables of this stuff, I know roughly what they are and that is probably all I need to know. And I will take each step as it comes and the next step is some point in September I guess.

INT: Yes, yes.

RES: See what that is.

INT: Okay.

RES: Yeah.

INT: So it would be good if it's okay with you if after September if you are coming to clinic, if we could have a quick chat again and you could just tell me how it feels once you've got to that September point?

RES: I'd be very happy, I mean for lots of reasons. Erm, one because I think it's quite useful and two if I could help other people that come after me then that's great, and might get your PhD.

INT: I will, one way or another I will.

RES: That's be good.

INT: It would, I will get there.

RES: So it is absolutely no problem.

INT: Okay, great, yes, just ...

RES: Even if I was grumpy when we started a few months ago.

INT: Well, it's reasonable to be grumpy, we can cope with grumpy. Err, but I think yes at that point as well, what happens at the point where the treatment stops and you are, you know what do you do, you are being monitored and it's a very different time and it would just be good to know how that feels and ...

RES: Sure.

INT: Because there's obviously a big difference in what you are doing day-to-day now compared to what you were doing a few months ago, you are doing a lot more things that you know are good and positive for your wellbeing.

RES: Yeah.

INT: So it's useful to see that change, I think.

RES: Yes, and welcome to call, although there's a problem with the phone number.

INT: Yes, it happens all the time.

[End of Recording]

## Appendix 12: Hermeneutic circle process example-‘Importance of Normality’ theme development

