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“When the Spine Speaks First”: A Constructivist Grounded Theory of People’s Experiences of Discovering a Newly Diagnosed Advanced Cancer through Metastatic Spinal Cord Compression.

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This thesis is submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy. The candidate has already achieved 180 credits for assessment of taught modules within the blended learning PhD in Palliative care programme.

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere

Abstract

Background: Spinal cord compression can occur when cancer compresses the spinal cord, causing pain, limb weakness, or paralysis. For some, it is the first sign of a new advanced cancer. People facing this condition experience sudden physical decline alongside the emotional impact of a serious diagnosis. The need for timely, person-centred care increases, yet the experiences of this group remain under-researched.

Aims: To understand how people experience the sudden discovery of a newly diagnosed advanced cancer through spinal cord compression.

Methods: A constructivist grounded theory approach was used. Twelve participants were recruited through purposive and theoretical sampling. Semi-structured interviews were conducted. Data were analysed using initial, focused, and theoretical coding. Constant comparison, memo-writing, and theoretical sensitivity were central to the analytical process, allowing for iterative interpretation and conceptual development grounded in the participants lived realities. A delayed literature review was conducted in line with constructivist grounded theory methodology to refine the emerging theory.

Findings: Participants experienced spinal cord compression alongside a new diagnosis of cancer as a deeply disruptive and transitional event, triggering complex changes in physical function and emotional well-being. Three core categories were constructed: (1) “Making sense of bodily changes and disruption to normal life,” (2) “Focusing on living life for longer,” and (3) “Emotional consequences of a dual diagnosis.” An overarching concept of liminality, a transitional space between the loss of former health and an uncertain future, framed the experience. The synthesis identified four supporting constructs: (1) “Emotional impact of a dual diagnosis,” (2) “Competing priorities: immediate vs the future,” (3) “Adjusting to a new functional reality,” and (4) “The perception and processing of information about diagnosis and prognosis.” These findings informed the final theory titled “When the spine speaks first.”

Conclusion: Through this study, the resulting theory provides new insights to guide timely, compassionate, and person-centred clinical responses during this critical diagnostic moment.

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Chapter 1: Introduction

Throughout my nursing career, I have cared for and supported people with metastatic spinal cord compression, both as part of an existing cancer and as a new diagnosis. I have been involved at multiple stages of their journey, from recognising early symptoms and navigating the challenges of accessing timely assessment and investigations, to supporting initial management decisions and facilitating transitions to further cancer treatment or end-of-life care.

However, my involvement has always been through a clinical lens, often during moments of urgency. I have rarely had the opportunity to step back and consider, beyond the clinical perspective, the question: “What is this experience truly like for people, particularly when metastatic spinal cord compression is the first symptom of a previously undiagnosed advanced cancer?” This question lies at the heart of why I have chosen to undertake this research.

Through this PhD thesis, I aim to gain a deeper understanding of the experiences of people who present with metastatic spinal cord compression as their first symptom that subsequently leads to a new diagnosis of advanced cancer; what it is like; and what it means to face these sudden physical, functional, and emotional changes together with a cancer diagnosis, and how they cope with such an abrupt life transition. This study is therefore driven by my professional insight and a personal commitment to improving care. Understanding the experiences of people who present with metastatic spinal cord compression as their first symptom of a previously undiagnosed advanced cancer will help to ensure that future healthcare services, clinical pathways, and guidelines are not only evidence-based, but also responsive to the person’s needs. Through this work, I hope to identify ways in which care and outcomes can be improved and to inform a more compassionate, person-centred approach during this critical and life-changing time.

1.1 Aims and focus

The aim of this study is to understand how people experience the sudden discovery of a newly diagnosed advanced cancer through metastatic spinal cord compression. The study is focused on capturing the complexity of this critical initial period, which includes the development of the presenting symptoms, receipt of a diagnosis, and the initial stages of decision-making and treatment.

The intention is to provide insight into what unfolds physically, functionally and emotionally for people experiencing this situation during this period, and to understand what is important to them at this time. Focusing on each person's viewpoint, the study offers a deeper understanding of their experiences, concerns, and priorities. It is essential that these personal narratives are captured in order to develop meaningful, person-centred healthcare responses; to examine these experiences in a way that captures their complexity and honours the perspectives of those living through them. To do this, a research design was needed that could support depth, flexibility, and sensitivity to these emerging insights.

1.2 Research design – a constructivist grounded theory

This thesis, based on qualitative constructivist grounded theory research, aims to generate new insights that are grounded in the participants' experiences, voices, and own words. Given the limited amount of published research and pre-existing theories in this area, it was important to adopt a methodology that would support an emergence of new perspectives and understandings.

A constructivist grounded approach was chosen in order to facilitate an iterative, inductive process in which meaning would be co-constructed between the researcher and the participants. Use of this approach acknowledges the influence of both the researcher and participants in shaping the analysis (Charmaz, 2014). Its use is particularly valuable in under-theorised areas, such as this, in which the perspectives of people are often overlooked in favour of clinical or service level priorities (Birks & Mills, 2022; Tie et al., 2019).

1.3 Researcher positionality

I am a registered nurse and advanced practitioner with 25 years of experience across a range of specialist and generalist areas in neurosurgery, clinical oncology, radiotherapy, general practice, pain management, and palliative care. Throughout my career, I have supported people at all stages of their cancer journey from pre-diagnosis, through treatment, to end-of-life care.

In my role as an advanced practitioner, I played a key role in developing local radiotherapy assessment and treatment pathways, with the aim of improving the experiences of people who presented with metastatic spinal cord compression as an acute oncological emergency. Some people had no known primary cancer diagnosis. In my clinical experience, it became clear that people in this situation faced a complex and distressing set of challenges. They had to cope not only with the shock of a diagnosis of metastatic cancer with an unknown primary site, but also with the physical, functional and emotional consequences of acute neurological deterioration and spinal cord compression, sometimes the extreme result being paralysis.

In 2021-23, I served as a professional committee member and supported the development of the National Institute for Health and Care Excellence guideline update for spinal metastases and metastatic spinal cord compression (NICE, 2023). The guideline (NICE, 2023) further highlighted the lack of evidence around the experiences and needs of people with metastatic spinal cord compression as the first presentation of a previously undiagnosed advanced cancer. The lack of evidence highlights an urgent need for research that captures the human perspective of this group and their needs during this time. In many cases, their voices are absent from service designs and national policies.

1.4 Organisation of thesis

I have organised this thesis according to the outline described below. Each chapter builds on the last to support the choice of the constructivist grounded theory methodology and to demonstrate the study’s theoretical contribution.

Chapter 1: Introduction: I outline the rationale for undertaking this research and the study’s aims and focus. I briefly outline my reasons for choosing constructivist grounded theory. I also reflect on my professional background as a cancer nurse specialist acknowledging how these elements shape the research process. In Constructivist Grounded Theory, the researcher's context and standpoint are not only acknowledged but considered integral to the co-construction of meaning. This perspective informs both the interpretive lens applied and the way the thesis is organised to reflect a transparent and situated approach to knowledge generation.

Chapter 2: Background: I begin by providing an overview of the current landscape of cancer incidence and survival in the United Kingdom (UK). I highlight the UK's lower survival rates compared with those in other countries; this situation is often linked to late state diagnoses, many of which present through emergency routes. I draw attention to the urgent and complex challenges faced by people who present with metastatic spinal cord compression as their first symptom of a previously undiagnosed advanced cancer, including the significant physical, functional, and emotional impacts.

Chapter 3: Methodology and methods: I outline the philosophical and methodological foundations of the thesis, justifying the use of a constructivist grounded theory approach. I explain the rationale for delaying the literature review and the use of reflexivity throughout the research process. I describe the study protocol and constructivist grounded theory approaches that were used to analyse the data.

Chapter 4: The findings on people's experiences of discovering a newly diagnosed advanced cancer through metastatic spinal cord compression: I present the key findings and describe the emerging categories and subcategories that were constructed from the participant data through iterative coding and constant comparative analysis. These findings informed the development of the conceptual model "Navigating the consequences of a dual diagnosis: The physical, practical and emotional impacts of facing metastatic spinal cord compression and a newly diagnosed advanced cancer". I conclude the chapter with an introduction to the concept of liminality and an explanation of its relevance to understanding this evolving experience. At this stage of analysis, I also introduce the initial emerging theory, of "Navigating the liminal space of a dual diagnosis: experiencing metastatic spinal cord compression and the sudden discovery of a newly diagnosed advanced cancer".

Chapter 5: Critical interpretive synthesis of the literature: A comprehensive literature search was undertaken across four electronic databases. I synthesised publications, critically and interpretively, to compare the experience of receiving and adapting to a diagnosis of metastatic spinal cord compression with that of other life-limiting neurological cancer conditions. I also synthesised the experiences of coping with the sudden physical, functional and emotional changes brought about by such an experience and diagnosis, and how the published literature helped me to develop a further understanding of the three main categories identified from the primary study data. Completing this review after analysing the primary data enhanced my theoretical sensitivity, allowing the literature to act as a sensitising resource and helping refine the emerging theory.

Chapter 6: Discussion: In this chapter, I describe how the integration of the findings from the review and my primary study informed the final grounded theory, *"When the Spine Speaks First,"* and its connection to the concept of liminality. The increased theoretical sensitivity gained from the review enabled deeper reinterpretation of the primary data and strengthened the final theory. I explain how the thesis contributes to knowledge, and how my study positions the final grounded theory in relation to the existing literature.

Chapter 7: Conclusion: I summarise the thesis findings, discuss the study's strengths and limitations, and reflect on implications for practice, policy, education, and future research, and on what I have learnt from undertaking this thesis.

This study addresses a critical and timely gap in the understanding of the experiences of people for whom metastatic spinal cord compression presents as the first symptom of an advanced cancer. With the number of UK cancer diagnoses projected to rise significantly, early identification and management of metastatic spinal cord compression are increasingly important to prevent permanent neurological damage and to optimise care delivery. Despite this urgency, little is known about how people in this situation interpret their initial symptoms, navigate diagnostic delays, and cope with the sudden onset of functional loss, all of which are compounded if this is an unexpected life limiting cancer diagnosis . This population is underrepresented in research, and this situation hampers the development of responsive patient-centred care pathways and policy updates, such as the current National Institute for Health Excellence guideline update for spinal metastases and metastatic spinal cord compression (NICE, 2023). Through exploration of this group's experiences and needs, this study has aimed to generate novel insights that can directly inform policy, enhance clinical responsiveness, and guide service planning for this vulnerable and growing population.

Chapter 2: Background

2.1 Cancer trends in the UK

Cancer is one of the most pressing health challenges in the UK, as growing incidence and mortality rates place increasing demands on healthcare services. In 2019, approximately 384,339 new cancer cases were diagnosed in the UK; this means that during the year, one person was diagnosed with cancer every two minutes (Cancer Research UK, 2023). Over half (53%) of these new cases were diagnosed as primary breast, prostate, lung, and bowel cancers (Cancer Research UK, 2023). Cancer incidence is closely linked with age; more than a third (36%) of these new cancers were diagnosed in people aged 75 years and over, with the highest rates observed in those aged 85-89 years (Cancer Research, 2023).

It is projected that by 2038-40, the number of new diagnoses of cancer in the UK will have risen by approximately one-third from current figures to about 506,000 annually (Cancer Research UK, 2018). This rise is largely linked to an ageing population and a projected 3% rise in incidence rates (Cancer Research UK, 2023). This means that the burden of cancer on the people diagnosed, their families, and the healthcare system is set to grow substantially.

Despite improvements in cancer awareness and early diagnosis and treatment, cancer survival rates in England remain lower than continental European averages. This has been attributed to later-stage diagnosis and significant regional and demographic disparities in outcomes (Elliss-Brooks et al., 2012). In 2019, cancer accounted for 167,000 deaths in the UK, equating to 28% of all deaths that year, with over half (54%) occurring in those aged 75 years and over (Cancer Research UK, 2018). Comparative studies have shown that England has a higher cancer-related mortality rate than countries such as Norway and Sweden, especially within the first year of diagnosis, and the disparity is more apparent among older adults (Eva et al., 2011; Holmberg et al., 2010; Møller et al., 2010).

A significant contributing factor is the route to diagnosis. Many people in England are diagnosed after presenting with symptoms or as part of an incidental presentation, rather than through early detection or screening (Stares et al., 2021). Around one-fifth of cancers in England and Northern Ireland are diagnosed through emergency admission, which is a route associated with advanced disease, few treatment options, poor outcomes, and significantly worse care experiences than if diagnosis had been made earlier (Cancer Research UK, 2023; Smith, 2022). One emergency presentation is metastatic spinal cord compression a serious oncological complication that may be the first symptom of an undiagnosed advanced cancer.

2.2 Metastatic spinal cord compression

The spine is a common site of development of a secondary cancer, which may lead to metastatic spinal cord compression. This compression, or cauda equina syndrome, is caused by metastatic deposits in the vertebral column (Cancer Research UK, 2024; NICE, 2023; Patnaik et al., 2020). More rarely, it may result from direct tumour extension into the spinal canal (Robson, 2014). The pressure from the spinal cord stops the nerves from working normally, leading to symptoms such as severe back pain, limb weakness, sensory changes, and difficulty controlling the bladder and bowels (Cancer Research UK, 2024).

Metastatic spinal cord compression is a recognised acute oncology emergency that requires urgent diagnosis and intervention to prevent permanent neurological damage (Cowap et al., 2000; NICE, 2023). Prognosis varies depending on the type and stage of the primary cancer, functional status at presentation, and treatment options that are available to control the primary cancer. Survival rates are low; only about 10% of people survive for 18 months after diagnosis (Quraishi et al., 2011; Rades et al., 2022; Vassiliou et al., 2023).

In many cases, symptoms develop gradually and may be present in 95% of people with the condition for a few months before specific neurological symptoms develop (Al-Qurainy & Collis, 2016; Macdonald et al., 2019). Symptoms may be vague; a common one is back pain that may be constant, worse at night, and exacerbated by coughing, straining, or lying flat. In 79% of cases, the pain may radiate into the limbs, yet the clinical significance of this is frequently overlooked

(Lawton, 2019; Robson, 2014). Later symptoms may include lower-limb weakness, sensory changes and altered bowel and bladder function (Nagata et al., 2003; Skeoch et al., 2017). This is why prompt diagnosis and treatment are critical to prevent irreversible neurological damage, to manage pain and to preserve mobility, function, independence and quality of life (Patnaik et al., 2020).

Due to the urgency of metastatic spinal cord compression, it is often necessary to decide on treatment within days of symptom onset. The complexity of these decisions requires a multidisciplinary approach that involves oncologists, radiologists, neuro-spinal surgeons, nurses, therapists and social teams (Bouras et al., 2018; Nakata et al., 2020). Personalised care is essential, as each person presents with unique clinical, physical, functional, emotional and social needs (NICE, 2023).

Treatment goals vary depending on the primary cancer, neurological function, pain management, disease progression, expected prognosis, and further care requirements (Souchon et al., 2009). The aim of treatment is to control pain and preserve neurological function, thereby maintaining a person's functional status and quality of life (Barzilai et al., 2018). Treatment options include corticosteroids, surgery, radiotherapy, systemic anti-cancer therapies (depending on cancer type), or best supportive care (Skeoch et al., 2017).

The main surgical procedure that is considered in people with metastatic spinal cord compression is spinal decompression and stabilisation under general anaesthesia. Surgery can significantly reduce pain, preserve function, and contribute to extended survival in people for whom this treatment is appropriate (Harris, 2016; Lo & Yang, 2017; Patchell & Mohiuddin, 2005). For those who are not surgical candidates, external beam radiotherapy may be used to reduce neurological deterioration and improve pain control (NICE, 2023; The Royal College of Radiologists, 2024).

In cases in which metastatic spinal cord compression is due to a haematological malignancy, systemic anti-cancer treatment may be initiated prior to surgery and radiotherapy (NICE, 2023). For people with extensive disease, for whom intervention is not appropriate, the focus should move to the planning of end-of-life care (NICE, 2023). It is a particular challenge to decide how to manage metastatic spinal cord compression in cases in which a primary cancer has not been identified, as this lack of diagnostic information complicates treatment choices and prognostic discussions.

A brief scoping literature review conducted prior to this study revealed that most existing evidence on the treatment of metastatic spinal cord compression is predominantly quantitative, focusing on the efficacy of surgical intervention and, more recently, radiotherapy (Baker et al., 2016; Bouras et al., 2018; Ghori et al., 2015; Guzik, 2016; Hoskin et al., 2024; Lo & Yang, 2017; Nater et al., 2017; Younsi et al., 2020). While these studies provide critical insight into clinical outcomes, they overlook the broad experiences of people affected by metastatic spinal cord compression.

There is limited qualitative evidence that explores the experiences of people with metastatic spinal cord compression. Published studies primarily reflect retrospective accounts from those with a prior cancer diagnosis (Eva et al., 2008; Harris, 2016; Kardosod et al., 2023; Lee, 2013; Manson et al., 2017; Troke & Andrewes, 2019; Warnock & Tod, 2014). These studies highlight the emotional shock, loss of independence, and identity changes that this new diagnosis triggers. These studies reveal that people often feel isolated, anxious and helpless as they struggle with their new limitations compared with their former capabilities. People express a strong desire for a holistic understanding of their prognosis, including treatment side-effects, survival estimates and care options (Troke & Andrewes, 2019). Many of them stress certain priorities, such as remaining at home and being close to family, with long hospital stays having negative impacts on people's experiences (Manson et al., 2017).

Rehabilitation is identified as a key approach to improving functional outcomes and quality of life. Structured programmes have been shown to enhance independence and emotional well-being (Manson et al., 2017; Troke & Andrewes, 2019). For people with a previous cancer diagnosis who are transitioning from curative to palliative care, clinicians must understand and respect their wishes and preferences to deliver patient-centred care (Manson et al., 2017; Troke & Andrewes, 2019). While quantitative data informs clinical efficacy, qualitative evidence highlights the need to capture these emotional and functional complexities that affect decision-making and the quality of the lives of people with metastatic spinal cord compression (Eva et al., 2008; Harris, 2016; Kardosod et al., 2023; Lee, 2013; Manson et al., 2017; Troke & Andrewes, 2019; Warnock & Tod, 2014).

Metastatic spinal cord compression occurs in approximately 3-5% of people with advanced cancer; almost any type of cancer can spread to the spine (Al-Qurainy & Collis, 2016; Ellis-Brookes et al., 2012; Lawton et al., 2019). Within this group of people, most have a cancer diagnosis, but for a small number, the metastatic spinal cord compression is the first symptom of an undiagnosed cancer (Aizenberg et al., 2012; Quraishi et al., 2009; Wänman et al., 2017; Ho et al., 2023). From epidemiological studies, it is estimated that up to 20% of cases are of this type. This finding highlights its relevance in acute- and emergency care settings (Boussios et al., 2018; Lawton et al., 2019; Prasad & Schiff, 2005). For example, in a retrospective study of 1,225 people with malignancy of unknown origin, 55 (4.5%) presented as emergencies with metastatic spinal cord compression (Stares et al., 2021). Similarly, Savage et al. (2013) found that 21% of 191 people with metastatic spinal cord compression had no prior cancer diagnosis. They highlighted the need for vigilance in evaluating pain and neurological symptoms, even in people without a known malignancy.

Despite its clinical significance, few studies have focused specifically on metastatic spinal cord compression as a first presentation of a previously undiagnosed cancer. Existing research has predominantly examined outcomes limiting the broader understanding of the experiences of this group.

People who present with metastatic spinal cord compression without established primary site are termed as having malignancies of unknown origin, or as having provisional or confirmed cancers of undefined primary (NICE, 2010; Stares et al., 2021). This group commonly presents for emergency care, faces complex diagnostic pathways, and may never receive definitive primary diagnosis (Jones et al., 2017; Stares et al., 2021).

2.3 Malignancy of unknown origin and cancer of unknown primary

In people who present with metastatic cancer, the primary cancer site is often identified through clinical and/or radiological investigations. However, in cases in which no obvious primary cancer site can be determined at the initial stage, the person is said to have a malignancy of unknown origin. Each person with an identifiable primary cancer typically follows an established diagnostic pathway, is referred to a tumour-site-specific multidisciplinary team and is monitored under cancer-waiting-time targets. In contrast, those with malignancy of unknown origin are often diagnosed during an emergency admission, face diagnostic delay, prolonged hospital stays, and involvement from multiple multidisciplinary teams across various specialities. This may lead to fragmented care and poor outcomes (Fizazi et al., 2015; NICE, 2010; Oien & Dennis, 2012).

For some, further investigations lead to the identification of defined primary cancers, but others never receive definitive diagnoses and are subsequently classified as having cancer of unknown primary (NICE, 2010). NICE (2010) sub-classified malignancies of unknown origin in order to guide healthcare professionals in ways to manage and investigate these cases. These classifications are shown in Table 2.1. People who are too unwell to undergo diagnostic procedures, such as biopsies, may retain the diagnosis of malignancy of unknown origin indefinitely. For others, further investigation may lead to one of three outcomes: i) identification of a non-cancer diagnosis; ii) confirmation of a primary cancer; or iii) classification as cancer of unknown primary (Fizazi et al., 2015; Hainsworth & Greco, 2018; NICE, 2010).

Cancer of unknown primary is diagnosed when a person has pathological evidence of a cancer but no confirmation of a primary site, despite undergoing a standardised, comprehensive diagnostic work-up. Cancer of unknown primary may be defined further as provisional cancer of unknown primary or confirmed cancer of unknown primary, depending on the extent of investigations. This terminology is well recognised by those who work in acute oncology and cancer of unknown primary teams, but it is less familiar to members of non-specialist teams, which may result in inconsistent use of terminology and confusion.

Table 2.1: *Taxonomy of definitions reflecting the phases of cancer of unknown primary* (NICE, 2010).

Malignancy of unknown origin	Metastatic malignancy identified on the basis of a limited number of tests, without an obvious primary site, before comprehensive investigation.
Provisional cancer of unknown primary origin	Metastatic epithelial or neuroendocrine malignancy identified on the basis of the histology or cytology, with no primary site detected despite a selected initial screen of investigations before specialist review and possible further specialised investigations.
Confirmed cancer of unknown primary origin	Metastatic epithelial or neuroendocrine malignancy identified on the basis of final histology, with no primary site detected despite a selected initial screen of investigations, specialist review and further specialised investigations as appropriate.

In many cases, prognosis depends on performance status, level of disease burden, and availability of further treatment options. The lack of clearly defined treatment pathways for this group, together with diagnostic uncertainty, further complicates the provision of timely and effective care (Greco & Pavlidis, 2009; Jones et al., 2017; Stares et al., 2021; Varadhachary & Raber, 2014).

There is little empirical research on the experiences and impact of being diagnosed with malignancy of unknown origin or cancer of unknown primary. However, the limited evidence that does exist highlights significant psychological and emotional burdens. Studies have found that people with these diagnoses report higher levels of uncertainty, distress, anxiety and depression, and overall poorer quality of life, compared with those who have known primary cancer diagnoses (Boyland & Davis, 2008; Hyphantis et al., 2013; Richardson et al., 2015; Wagland et al., 2017).

These findings underline the urgent need for early access to tumour-site-specific teams, timely and targeted diagnostic investigations, and tailored supportive care.

This is even more critical in cases in which metastatic spinal cord compression is the first presenting symptom.

Survival outcomes for people with malignancies of unknown origin or cancers of unknown primary are poor, especially if they are diagnosed via the emergency route, due to the absence of clear pathways and the uncertainty about prognosis, which add to the emotional and clinical burdens of this group (Jones et al., 2017; Varadhachary & Raber, 2014).

2.4 Cancer that presents as an emergency

The route by which someone is diagnosed with cancer has a major impact on their treatment options and experience of care. There are several recognised 'routes to diagnosis' for cancer; these routes are defined as the sequences of interactions between a person and the healthcare system that can lead to a confirmed diagnosis. These routes are categorised based on the setting of diagnosis, the referral pathway, and how the person enters secondary care (Elliss-Brookes et al., 2012).

In many cases, the diagnostic route begins with a consultation in primary care, which may lead to referral via the two-week-wait system, introduced in 2000. This system ensures that people are referred urgently for a suspected cancer by their general practitioner and seen by a specialist within two weeks. Other diagnostic pathways include referrals through national screening programmes (e.g. breast, cervical, and bowel screening) and via routine or non-urgent referrals for other symptoms. Elliss-Brookes et al. (2012) found that the most common diagnostic routes for cancer were: two-week-wait (26%), emergency presentation (24%) and general practitioner referral (21%), with other pathways including screening accounting for 29%.

However, a large cohort of studies has demonstrated that a significant proportion of cancer diagnoses still occur via emergency presentations. Zhou et al. (2017) reported an analysis of 739,667 cancers that had been diagnosed as emergencies, including bladder, central nervous system, breast, colorectal, kidney, lung, melanoma, multiple myeloma, non-Hodgkin lymphoma, ovary, pancreas, prostate, stomach and uterus. In England and Northern Ireland, approximately one-in-five cancers are diagnosed through emergency routes.

Regardless of the diagnostic route, receiving a cancer diagnosis is a life-changing and often a life-limiting event. People with cancer and their families are likely to experience significant psychological and emotional distress, including fear, anxiety, uncertainty, and concerns about the future (Boyland & Davis, 2008).

For those whose first awareness of cancer arises during an emergency attendance caused by metastatic spinal cord compression, the experience is especially traumatic. Those affected face a dual crisis: the sudden onset of acute neurological deterioration, which often results in pain, impaired mobility, function and quality of life, but is accompanied by the shock of an advanced cancer diagnosis of unknown origin and with an undefined prognosis (Boyland & Davis, 2008; Wänman et al., 2017). This complex presentation requires urgent, coordinated, and compassionate care to address both the immediate physical needs and the overwhelming emotional impact of such a diagnosis.

Consequently, metastatic spinal cord compression as the first symptom of advanced cancer is a deeply distressing and complex experience that has received limited attention beyond surgical or clinical outcomes. Existing research overlooks how people make sense of such a sudden diagnosis and its impact on identity, autonomy, and future outlook. A constructivist grounded theory approach is needed to explore these lived experiences and develop person-centred insights to inform compassionate, responsive care.

2.5 Summary

In this chapter, I have highlighted the increasing cancer burden in the United Kingdom and introduced metastatic spinal cord compression as a complex oncological emergency, which in some cases is the first symptom of a previously undiagnosed, advanced cancer. People who present in this way face sudden neurological decline, diagnostic uncertainty, and the emotional impact of a life-limiting diagnosis, all with little prior warning or preparation.

Despite the urgency of this situation, there is limited research that helps us to understand the experiences of people who present with metastatic spinal cord compression, particularly in cases in which no primary cancer has been identified. Most published literature is focused on clinical outcomes, leaving a critical gap in our understanding of how people experience and navigate this sudden life-altering event. While some people with cancer require minimal aftercare after diagnosis, others, such as those with metastatic spinal cord compression, need ongoing support to manage the physical and psychological consequences (Campling & Calman, 2018). This study addresses that gap by using a constructivist grounded theory approach to understand the experiences of this underrepresented group. By generating a final theory grounded in participants' own accounts, the aim of the study is to inform more person-centred care, influence future policy, and support improved service provision and research.

Chapter 3: Methodology and Methods

In Chapter 2, I introduced the background to this study. Building on that foundation, I now turn to the constructivist methodology that shaped how I approached the research, including the philosophical assumptions, design decisions, and analytical processes that guided the development of the study. In Chapter 3, I present the philosophical and methodological foundations for the primary study into understanding the experiences of people who present with metastatic spinal cord compression as their first symptom of a previously undiagnosed advanced cancer. I explain the choice of research design and justify the selection of constructivist grounded theory and the purpose and positioning of the delayed literature review. Finally, I describe the working methods, with attention to ethical considerations and researcher reflexivity throughout the study.

I address the primary research question, "What are the experiences of people who face the sudden discovery of a newly diagnosed advanced cancer through metastatic spinal cord compression?"

3.1 Philosophical positioning of this study

A strong research design begins with a research paradigm that is congruent with the researcher's beliefs about the nature of reality (Mills et al., 2006). Paradigms serve as essential frameworks that guide researchers' assumptions, decisions, and methodological choices (Guba, 1990). Two main components underpin any paradigm: ontology (the nature of reality, study of being) and epistemology (the nature and justification of knowledge) (Carter & Little, 2007). Establishment of the ontology and epistemology aids with identification of the methodological possibilities, the set of procedures to be followed, and the method of knowledge development (Cresswell & Poth, 2018; Lincoln et al., 2018).

The philosophical positioning of this study aligns with the constructivist paradigm, which emphasises that reality is socially constructed, and that knowledge is co-constructed through interaction between the researcher and the research participants. This perspective acknowledges the subjectivity in the research process and highlights the importance of understanding each person's unique experiences (Olmos-Vega et al., 2022).

3.1.1 Paradigm: constructivist

The choice of paradigm should align with the researcher's beliefs about reality and knowledge in order to ensure a robust research design (Mills et al., 2006). A paradigm is a system of ideas, a worldview that guides how knowledge is created and interpreted, shaped by its own ontological and epistemological assumptions (Fossey et al., 2002; Hussein et al., 2014). This study is grounded in a constructivist paradigm, which reflects my philosophical position as a researcher and embraces a relativist ontology and subjective epistemology.

With a constructivist paradigm, there is no single, true reality but instead, multiple, constructed realities, which are based on subjective experiences that can evolve and change (Levers, 2013). Operating within this paradigm means acknowledging that every perspective is unique, and that knowledge is co-constructed by the researcher and the participant, considering the values of both, as they are inseparable, with each bringing their beliefs, prejudices, and experiences to the research (Birks, 2015; Levers, 2013; Mann, 2015). This position is flexible and allows for in-depth exploration that appreciates that all humans are different and cannot be placed into scientific groups for analysis or be generalised (Carson et al., 2001). This paradigm embraces subjectivity and the subjective reality, encompassing the values of all involved in the research.

For these reasons, the constructivist paradigm was chosen for this research study. With its relativist, subjective and value-bound position, constructivism reflects the philosophical position of the research and aligns with the qualitative nature of the research, as opposed to the positivist and post-positivist paradigms that align with quantitative research. In the context of this study, which was intended to understand how people experience metastatic spinal cord compression as their first symptom of a previously undiagnosed, advanced cancer, a constructivist approach enabled the investigation of those deep personal, emotional, and complex experiences.

Other paradigms, such as positivism and post-positivism, were considered but were not regarded as congruent with the research question for this study. Positivism assumes a realist ontology and objectivist epistemology, in which a single, objective reality exists independent of the human mind. This reality can be measured through systematic, objective observation in a controlled environment, with a clear separation between the values of the researcher and participant (Bunnis & Kelly, 2010; Carson et al., 2001; Park et al., 2020; Ritchie et al., 2013). This paradigm is suited to controlled, quantitative research but is incompatible with a study focused on subjective, emotional, and contextual human experiences. Use of this paradigm would make it difficult for the researcher and each participant to work as one: a positivist needs to be detached from the participant during data collection and analysis. Post-positivism acknowledges that absolute truth may be difficult to obtain, but it retains a realist ontology and favours quantitative methods. Although it allows for the possibility of theoretical interpretations beyond observable data, it prioritises objectivity and generalisability (Annell, 1996; Birks, 2015). It was considered that adherence to these paradigms would not adequately support the relational and interpretive nature of this study, which was centred on co-constructed meaning and the experiences of people in acute health crises and diagnoses.

3.1.2 Ontology: relativism

Ontology refers to the nature of reality: what is there that can be known (Guba & Lincoln, 1994). There is a continuum of types of ontology, which begins with realism and moves through to relativism. In realism, it is considered that a single reality exists; a realist ontology holds that there is one, single reality that can be studied and is experienced as 'truth', and the reality is relative to each person who experiences it at any given time or place (Moon & Blackman, 2014). At the other end of the continuum is relativism, which holds that there are multiple realities, that realities exist in the mind, and that everyone creates their own reality (Levers, 2013; Moon & Blackman, 2014).

In this study, the research question involved understanding the experiences of a life-changing event: the discovery of metastatic spinal cord compression with neurological deterioration, reduced function, and diagnosis of a previously undiagnosed, advanced cancer for which the primary is uncertain, prognosis is unknown, and the quality of life is likely to deteriorate. This research sought to understand the processes of participants' experiences and feelings, which naturally sat within a relativist ontological view: reality is constructed within the human mind, there is no single truth, but reality is relative according to how people experience it at any given time and place (Levers, 2013). This is why the exploration of this question was not possible through, for example, the use of a positivist approach, as this would focus on objectively controlled and measured variables of this group that were outside the human mind. This was the opposite of what was sought here.

3.1.3 Epistemology: subjectivism

Epistemology is how knowledge is acquired, what is required for an idea to be accepted as knowledge, and the nature of the relationship between the knower and what is known (Bryman, 2008; Crotty, 1998). The epistemological stance influences the role of the researcher, modes of data collection and analysis, and how the data were presented as knowledge. There is a continuum of epistemology from objectivism through to subjectivism. Crotty (1998) defines objectivism as the belief that truth and meaning are within an object and are independent of human subjectivity. An objectivist uses knowledge to explain, predict, and control (Grant & Giddings, 2002). This means that human influences are removed, so that what is observed is not changed by the observer, nor is the observer influenced by what is observed (Denzin & Lincoln, 2005). The contrasting epistemological stance that the researcher can take is subjectivism, which refers to a person's own experience, perception, and interpretations of the world, and holds that the subject is constructed in relation to others (Levers, 2013). Observations are influenced by the observer, and the observer is influenced by what they observe (Denzin & Lincoln, 2005).

In this research study, as the research question was concerned with the understanding of experiences, a subjective stance was required for knowledge development. New knowledge can only be discovered through the experiences of each of the participants and their interpretations; the image perceived is dependent on the person who perceives it (Levers, 2013). The subjective stance, as discussed above, distinguishes the role of the researcher. In this study, the researcher needed to take an active role by engaging with and interpreting the participants' interpretations to create meaning (Bryman, 2008). There was no place in this study for a researcher who was distant from the data that was collected. For these reasons, the researcher's epistemological stance for this study was that of subjectivism.

3.2 Choice of research design: grounded theory

Given the research question, aim, and philosophical positioning, a qualitative research design was considered most appropriate. This study adopted a constructivist paradigm to understand the participants' experiences over a defined period, particularly their experiences of presenting with both acute neurological deterioration and a diagnosis of an advanced cancer. Given the subjective and personal nature of these experiences, an aim to test a hypothesis or to define variables in line with a positivist and objectivist research design would not be appropriate (Annells, 1996; Birks, 2015).

Grounded theory was chosen because this methodology goes beyond thematic description to include the development of categories and theoretical explanations, which are essential when investigating a complex, emotionally and clinically significant phenomenon such as this study (Charmaz & Thornberg, 2020; Makri & Neely, 2021).

Unlike other qualitative methods, grounded theory facilitates the development of theoretical explanations through inductive reasoning so that theories emerge from participants' narratives rather than through application of pre-existing frameworks (Mills et al., 2006; Morse, 2001). This feature made it well suited to this study, in which people were dealing with the previously explained dual crisis; the use of grounded theory enabled an exploration of how participants understood, adapted to, and acted within this dual crisis.

The grounded theory process includes several defining features: theoretical sampling, constant comparative analysis, coding (initial, focused, and theoretical), memo-writing, and a delayed literature review. Use of these tools supports an iterative process of simultaneous data collection and analysis, encouraging the development of a theory that is ‘grounded’ in the experiences of participants (Charmaz, 2020; Lauridsen & Higginbottom, 2014). This means that the researcher does not impose preconceived ideas to be proved or disproved; instead, the issues of importance to the participants emerge from their stories that they share about an area of interest (Mills et al., 2006). After the initial data are coded and categorised, new data are added through theoretical sampling, which involves the seeking of additional data that is based on concepts developed from initial data analysis. This process continues until saturation occurs (Hood, 2007). Following a process of collecting and analysing data simultaneously as the research progresses, theory is generated (Howell, 2012; Mills et al., 2006). The provision of an explanation of these social processes and behaviours is particularly valuable in guiding future practice and informing policy in a clinical area that lacks person-focused evidence.

3.2.1 Rationale for use of constructivist grounded theory

Grounded theory has evolved into three main approaches: traditional (Glaser & Strauss, 1967), Straussian (Strauss & Corbin, 1994), and constructivist (Charmaz, 2014). The selection of an appropriate approach depends on the researcher’s ontological and epistemological stance (Mills et al., 2006).

Traditional grounded theory is rooted in a realist ontology and objectivist epistemology, aligned with a positivist paradigm. It assumes that reality exists independently of the researcher, who must remain detached to avoid influencing the data (Birks & Mills, 2022; Sebastian, 2019). Given my clinical experience, such a level of detachment was neither feasible nor appropriate for this study.

Straussian grounded theory occupies a middle ground between post-positivism and constructivism. It recognises multiple realities (relativist ontology) and co-construction of meaning (subjectivist epistemology), while still encouraging a degree of researcher objectivity and reflexivity (Sebastian, 2019; Strauss & Corbin, 1990; Urica, 2012). However, its emphasis on the maintenance of distance was incompatible with my role and the aims of this research.

Constructivist grounded theory, as developed by Charmaz (2014), most closely aligns with the philosophical underpinnings of this study. It adopts a relativist ontology and a subjectivist epistemology, recognising that both the researcher and the participants bring their own perspectives to the construction of knowledge (Annell, 1996; Mills et al., 2006). Constructivist grounded theory values reflexivity and acknowledges the interpretive role of the researcher throughout the research process. This approach is particularly suited to the gaining of an understanding of emotionally intense and complex healthcare experiences, such as those discussed in this study.

For this study, constructivist grounded theory provided the methodological approach that enabled the development of a mid-range substantive theory, grounded in the empirical data yet transferable across similar contexts (Charmaz, 2016; Merton, 1968). This theory was intended to explain how people navigate, make sense of, and respond to the simultaneous experience of neurological deterioration and the diagnosis of a previously undiagnosed advanced cancer. Such a theory can offer practical and conceptual insights to inform clinical practice, service design and national guidance.

Therefore, constructivist grounded theory was chosen for its alignment with the study’s interpretivist stance and for its capacity to capture the complexity, emotional nuance, and dynamic meaning-making processes of participants who were experiencing a life-changing event. It was expected to provide the relational and methodological flexibility required to co-construct meaning and to develop theoretical insights in cases in which there is little existing literature (Charmaz, 2014; Mills et al., 2006).

In summary, grounded theory was selected to develop theoretical insight in cases in which none currently exists. Specifically, constructivist grounded theory was selected for its alignment with the relativist ontology and subjectivist epistemology that underpinned this study (Charmaz 2014; Mills et al., 2006). It was considered to offer the interpretive depth, methodological flexibility, and relational sensitivity needed to understand the complex, multifaceted experiences of people undergoing life-altering transitions.

3.3 Managing preconceptions

3.3.1 Relationship between myself and study data

An important component of constructivist grounded theory is the active management of my preconceptions. In this theory, researchers are not positioned as neutral observers; instead, their perspectives, assumptions, and professional experiences are acknowledged as part of the research process. This includes their influence on the interpretation of both the primary study data and the critical interpretive synthesis review (Olmos-Vega et al., 2022; Tie et al., 2019). Rather than attempting to eliminate subjectivity, constructivist grounded theory actively encourages ongoing reflexivity to enhance the transparency, credibility, and authenticity of the findings.

Rather than viewing my personal and professional background as a source of bias, constructivist grounded theory sees these as tools for interpretation. Researchers are encouraged to engage with their participants' accounts through listening, memo-writing, and iterative coding to generate rich, contextually grounded meanings (Charmaz et al., 1995; Mills et al., 2006).

3.3.2 The timing of the literature review in constructivist grounded theory

In grounded theory, the full literature review may be undertaken either before or after the data collection and analysis, although this has long been debated (Dunne, 2010). In Glaser and Strauss's (1967) traditional grounded theory, it is recommended that engagement with the literature should be avoided until the theory has been generated from the primary study data, for the following reasons:

1. To avoid introducing bias into the outcomes by bringing preconceived knowledge into the final theoretical findings.

2. To avoid the researcher subconsciously merging published findings with new findings.
3. To allow the cross-comparison of other, similar studies in order to understand similar concepts and how they relate, or do not, to the newly developed categories and concepts.

In this study, the delay in reviewing the literature was not intended to avoid introducing bias, which would be methodologically incongruent with a constructivist grounded theory approach, but rather to enable a focused, theory-informed review that allowed meaningful comparison between existing research and the study's emerging categories and concepts. In line with the Glaser & Strauss (1967) approach and given my role as a clinical specialist in the area of metastatic spinal cord compression, it would have been very difficult to avoid engagement with the literature prior to undertaking this research, particularly as it required ethical approval (Dunne & Üstűndağ, 2020). In cases such as this, Charmaz (2014) recommends that the current published evidence be reviewed briefly but not in-depth until after the data collection. Such a review was explained in Chapter 2. The literature should then be reintroduced in a timely way that reflects the emerging theoretical categories during the data analysis. This reintroduction involves a delicate balance of the integration of empirical data with the synthesis of the literature.

However, as Giles et al. (2013) point out, Charmaz (2014) does not specify what an in-depth review should entail. Instead, Charmaz emphasises the importance of initially setting aside the identified literature and gradually reintroducing it during data collection and initial analysis, particularly as categories begin to emerge. As a constructivist researcher, I considered myself open to the idea that both my professional experience with metastatic spinal cord compression and the data would inform and co-construct meaning together. Had I remained neutral or completely detached from the literature and theories during the early phases of this research, I would not have been able to support the co-construction of knowledge, which is fundamental to constructivist research. In light of this, I followed the recommendations of Thornberg and Dunne (2019) and proportionally introduced the literature in this study using the following staged approach. This approach allowed me to remain open to the participants' meanings during early analysis while still drawing on the literature later to support theoretical development. Across all stages, theoretical sensitivity developed through ongoing reflexive engagement with the data, memo-writing, supervision discussion, and the later critical interpretive synthesis.

Stage 1: Locate and justify the research. During the development my research proposal and the ethical approval process, I briefly engaged with existing published studies, both quantitative and qualitative, on the outcomes and experiences of people diagnosed with metastatic spinal cord compression. This preliminary work is presented in Chapter 2, aimed to establish whether the areas I intended to investigate had already been studied, how, by whom, and for what purpose. This early, broad review supported justification of the study focus and ensured that the research addressed a genuine gap. At this point, my theoretical sensitivity began to develop through reflexive consideration of how my clinical knowledge might influence what I might find.

Stage 2: Maintain ongoing awareness of the literature. During the data collection and analysis phase, which employed the constant comparative method, I maintained only a light and non-directive awareness of the relevant literature. This ensured that I was not constrained by pre-existing theories while still allowing me to recognise where emerging ideas front the data might later align with established concepts (Thornberg & Dunne, 2019). My engagement at this stage was deliberately minimal, so that initial coding remained grounded in participants' accounts rather than influenced by existing theories. Throughout, theoretical sensitivity was strengthened through memo writing, comparing incidences within and across interviews, and examining how my assumptions might shape the analytic process. These practices supported the inductive development of categories and movement toward saturation.

Stage 3: Contextualise, compare and contrast. The final literature review is used to position the grounded theory emerging from the study data in relation to existing theories and empirical findings. This process helps refine the study's contribution and integrate it into current knowledge and theoretical concepts (Dunne & Üstűndağ, 2020). After light background engagement in Stage 1 and 2, I engaged more substantively with the literature in Stage 3 by analysing the study data while identifying relationships between emerging categories and existing theoretical perspectives. Following Thornberg & Dunne's (2019) staged approach I increased my theoretical sensitivity by carefully exploring existing theories linked to my emerging categories, using memoing to capture reflections and ensure that developing ideas remained grounded in the data.

Although the formal literature review was delayed, I maintained awareness of initial assumptions through reflexive supervision discussions and ongoing memoing about my positions and perceptions that might have influenced the study. Reflexivity is widely recognised as a valuable tool in qualitative research to enhance ethics, quality, and interpretive depth (Probst & Berenson, 2014).

Consistent with Charmaz (2014), I applied reflexivity not only to my data but also to my engagement with the literature. The systematic critical interpretive synthesis review conducted after data analysis added conceptual depth and rigour, acting as a sensitising resource that enabled me to revisit and refine the emerging theory. In this study, the systematic review was carried out after data analysis and conceptual development in order to enhance rigour (Birks & Mills, 2022; Charmaz, 2014; Dunne, 2010; Giles et al., 2013). Comparing memos over time helped me to assess whether my interpretations were truly grounded in participants' experiences or unduly influenced by my own assumptions about the phenomenon. This supported a transparent and rigorous development of the final grounded theory.

3.3.3 Reflexivity

Reflexivity is a continuous, active process in which the researcher critically examines how their experiences, values, and assumptions influence the research process and outcomes. This ensures the quality of the work (Birks & Mills, 2022; Dodgson, 2019; Fox, 2015). In constructivist grounded theory, reflexivity is essential, as the researcher's interpretations shape the co-construction of the theory (Charmaz, 2014).

As a clinical practitioner with 25 years of experience supporting people with metastatic spinal cord compression, I brought knowledge and emotional investment into this study. Recognising this, I engaged in reflexive practices throughout, using a journal and analytical memos to document my thoughts, feelings, and assumptions, especially after the interviews, analysis, critical synthesis review, and formation of categories, to prevent my thoughts and assumptions from influencing the data. This procedure is recommended by Charmaz (2014). Both of my supervisors are experienced nurses, which provided a shared professional lens and deep clinical understanding. This common ground enhanced reflexivity by allowing critical dialogue about assumptions, values, and interpretations, helping to maintain analytical rigour and challenge taken-for-granted perspectives throughout the research process.

While my professional background provided valuable insights, it was essential to remain open to participants' experiences that differed from mine. I had no prior clinical relationships with any of the participants and was not involved in their current clinical episodes. When I introduced the study to each of them, I clearly positioned myself first as a researcher and second as a clinician to establish trust and encourage openness. I reassured participants that their contributions would be confidential, emphasised non-judgement, and made no comments on their clinical care before, during, or after the interviews. If a need for support was identified, I directed the involved participant toward the most appropriate healthcare professional involved in their care. This transparent and reflective approach helped to ensure the authenticity of participants' voices and the integrity of the emerging theory.

3.3.4 Patient and lay-member involvement

A person with lived experience of metastatic spinal cord compression was consulted during the early development of the study to help ensure its relevance and sensitivity to participants' needs. Lay representatives were present at the regional Metastatic Spinal Cord Compression Service Steering Group meetings when the study proposal was presented. Additionally, a person who had lived experience of presentation with metastatic spinal cord compression as their first symptom of cancer took part in a practice interview, which was used to inform and refine the semi-structured interview approach. This involvement enhanced the clarity, accessibility, and emotional sensitivity of the interview process. One participant later reviewed the conceptual model and provided feedback that confirmed the authenticity and resonance of the findings. These contributions strengthened the study's credibility, methodological rigour, and real-world applicability.

3.4 Methods

The purpose of the methods section is to describe the steps taken throughout the research part of this study and to justify the approach taken to answer the chosen research question.

3.5 Research question

The research question for this study was:

What are the experiences of people who face the sudden discovery of a newly diagnosed advanced cancer through metastatic spinal cord compression?

3.6 Setting

The study was conducted across the Northwest of England. It involved participants who had presented to their local hospital and met the eligibility criteria shown in Table 3.1. Participants were referred to the regional Greater Manchester Metastatic Spinal Cord Compression Coordination Service, which is based at the specialty cancer hospital, where participants' care was coordinated and managed, and where some received external beam radiotherapy. For some participants, if surgery was clinically indicated, care involved onward referral to the regional spinal surgery centre.

3.7 Participant selection

3.7.1 Population

The population of interest for this study was people who had experienced a diagnosis of metastatic spinal cord compression as their first presentation of a newly diagnosed advanced cancer. This population is unusual, as its members are experiencing the trauma of acute neurological deterioration, which has implications for their quality of life and ability to function, while simultaneously receiving diagnoses of metastatic cancers, of which the primary cause is, at least initially, unknown. This latter situation brings uncertainty about prognosis and about the treatment options that may be available for either the metastatic spinal cord compression or the cancer, which will be life-limiting.

3.7.2 Inclusion and exclusion criteria

The eligibility criteria that were used to identify people from this population of interest who were deemed appropriate for the study are shown in Table 3.1.

Table 3.1 *Participant eligibility criteria to take part in the study*

Inclusion	**Exclusion**
1. People with metastatic spinal cord compression or impending compression with neurology of epidural spinal cord compression scale (ESCC) grade 1C-3 2. People for whom the primary cancer had not been confirmed 3. Those who had received a previous cancer diagnosis but had been discharged from cancer follow-up services 4. Aged 18 years or older	1. Spinal cord compression of non-malignant origin 2. People who had a known primary malignancy prior to the development of metastatic spinal cord compression

The degree of spinal cord involvement was assessed using the Epidural Spinal Cord Compression Scale, an MRI-based system that standardises the description of tumour extension into the spinal canal. The scale ranges from Grade 0 to Grade 3, with intermediate grades (1a–1c) indicating increasing epidural involvement. Grade 1C, where the tumour abuts the spinal cord without compressing it, is clinically important because it carries a high risk of progression to true compression. People may already have early neurological symptoms or be at risk of developing them, and Grade 1C is therefore often used as a threshold for urgent intervention and as an inclusion criterion in metastatic spinal compression research (Bilsky, et al., 2010).

3.8 Sampling

3.8.1 Initial purposive sampling

The study began with the application of broad purposive sampling, which meant that participants were selected based on the eligibility criteria outlined in Table 3.1 and who were experiencing the phenomenon being studied. This approach aligns with the constructivist grounded theory sampling approach (Charmaz, 2014).

3.8.2 Theoretical sampling

Following initial data collection, theoretical sampling was employed between interviews 9 and 12. This met the requirements of an essential element of grounded theory, which involves gathering data based on the emerging categories, rather than predefined characteristics (Birks & Mills, 2022; Glaser & Strauss, 1967). Unlike other methodologies, grounded theory allows the data to guide further sampling decisions (Birks & Mills, 2022; Charmaz, 2014; Foley et al., 2021).

Theoretical sampling was used to refine, compare, and develop categories until theoretical saturation was reached. Theoretical saturation was defined as the point at which no new insights were generated, and the categories became fully developed. This development included defining categories, exploring variation, and identifying relationships between categories. There was not always time for complete transcription of one interview before the next took place, but sufficient analysis was performed to enable the emerging data to be used to inform and shape subsequent interviews. There were distinctions observed between older compared with younger participants, and single participants compared with those in partnerships. These findings led to targeted theoretical sampling to compare and refine the categories relating to physical, functional, and emotional adjustment and perceptions about the future.

The goal of theoretical sampling in this study was not to achieve a representative sample, but to construct a theory grounded in the experiences of people who faced the sudden discovery a newly diagnosed cancer through with metastatic spinal cord compression (Conlon et al., 2020).

3.8.3 Sample size

The number of participants that was expected to be required was between 12 and 18, with the primary focus on the quality of data in order to thoroughly describe the phenomenon and to achieve saturation within the emerging categories through theoretical sampling, as outlined. This approach aligns with the principles of constructivist grounded theory (Birks & Mills, 2022; Charmaz, 2014).

3.8.4 Recruitment

Participants were recruited from across the Northwest of England through collaboration with the relevant regional Metastatic Spinal Cord Compression Coordination Service, local acute oncology teams, and the regional spinal team. These groups were engaged through the Metastatic Spinal Cord Compression Service Steering Group and acute oncology pathway board meetings and were provided with recruitment support materials (Appendix A).

Due to the emergency situation of metastatic spinal cord compression, and the likelihood that potential participants would be transferred to other hospital sites within days, each participating hospital was set up as a research site to enable recruitment and interviews regardless of location.

Following the receipt of approval for the study from the National Health Service (NHS) Research Ethics Committee, local acute oncology and spinal specialist nurses identified and initially approached eligible people who had been referred to the Metastatic Spinal Cord Compression Service. Each potential participant was given a participant information sheet (Appendix B) and a brief overview of the study and was asked if the researcher could contact them to discuss further. If they agreed to this, an expression of interest form (Appendix C) was completed and sent to the researcher electronically.

As the researcher, I contacted the potential participants by telephone, introduced myself, explained the study purpose, and that this research was part of my PhD, and outlined how I would use in-depth interviews to explore their experiences of presenting with metastatic spinal cord compression as their first symptom of cancer. Verbal consent was obtained initially, followed by written confirmation at least 24 hours after that and before the interview. There was an opportunity for the participant to ask questions before I took consent. Once consent was confirmed, a consent form (Appendix D) was signed prior to the interview. I retained one copy, and another was offered to the participant. I explained clearly to the participants their right to withdraw without explanation before, during, or for two weeks after the interview, and that such withdrawal would have no impact on their ongoing medical management or care. It was explained to the participants that withdrawal after the interview was only possible if their data had not been analysed.

3.9 Data collection

3.9.1 Participant demographic data

Charmaz (2014) is not opposed to the collection of demographic data but cautions against allowing this data to drive theory development. She suggests that it should be used sparingly to provide contextual understanding. In this study, demographic information was collected to illustrate the diversity of the sample and to support theoretical sampling during the later stages of recruitment, when the recruitment of participants with certain characteristics became analytically relevant. Demographic information collected included each participant’s gender, age, marital status, and any previous cancer diagnosis. The Eastern Cooperative Oncology Performance Status (ECOG/PS) was recorded to understand their ambulatory status and the extent of disruption to daily life. This tool is commonly used in oncology and specifically in metastatic spinal cord compression cases to support treatment decision-making. Definitions of (ECOG/PS) are provided in Table 3.2.

Table 3.2: *Eastern Clinical Oncology Group Performance Status (Eastern Cooperative Oncology Group-American College of Radiology Imaging Network Cancer Research Group, 2024)*.

Grade	Description of person
0	Fully active, able to carry out all pre-disease tasks without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light housework, office work
2	Ambulatory and capable of all self-care but unable to carry out any work activities; up and about for more than 50% of waking hours
3	Capable of only limited self-care; confined to bed or chair for more than 50% of waking hours
4	Completely disabled; cannot perform any self-care; confined to bed or chair
5	Dead

3.9.2 Interviews

Following receipt of consent, semi-structured, in person interviews were conducted in line with constructivist grounded theory, which emphasises intensive interviewing to explore participant experiences in depth. Interviews are considered one of the main methods of data generation (Birks & Mills, 2022; Charmaz, 2014; Foley et al., 2021).

Interviews were arranged at times convenient for the participants, depending on their stages of management of their condition. Some interviews took place while participants were in hospital (before or after treatment); others were conducted at the participants' homes after discharge. Every effort was made to ensure privacy and comfort, especially in inpatient settings.

Interviews were audio-recorded and ranged from 40-120 minutes. At the start of each interview, participants were asked the demographic questions (Appendix E). An interview topic guide (Appendix F) with open-ended questions was used in the early interviews to maintain focus while allowing flexibility.

As the study progressed into theoretical sampling, the interview questions evolved to enable exploration and refinement of the emerging categories. In line with grounded theory, the structure was kept minimal to allow the participants to guide the conversations naturally and to uncover deep insights rather than force the direction of the emerging theory (Birks & Mills, 2022; Makri & Neely, 2021).

3.9.3 Data management

Interviews were digitally audio-recorded and securely uploaded to a secure online system. To maintain anonymity, any identifiable participant information was removed from audio files and anonymised in transcripts. Transcripts were cross-checked against audio recordings to ensure accuracy.

3.10 Analysis tools

Initially, I used the Atlas-Ti qualitative analysis tool, but later I switched to Microsoft Excel for initial coding. Initial codes from each interview were entered into Excel, colour-coded and grouped into focused codes. These were further organised into subcategories and categories, contributing to the emerging theory.

3.11 Definitions of Key Analytic Terms

To clarify the analytic language used throughout this thesis, I define here what is meant by 'conceptual model,' 'emerging theory,' and 'final grounded theory'.
In this thesis, I use key analytic terms in line with Charmaz's constructivist grounded theory approach. The conceptual model was an early analytic representation constructed from the primary data following initial and focused coding and sustained memo-writing. Through constant comparison, I developed

subcategories and integrated these into main categories. The conceptual model captured my early analytic interpretations and tentative relationships, supporting initial sense-making rather than serving as a final analytic outcome.

I then developed the conceptual model into an emerging theory. The categories and subcategories were carried forward, with development occurring through deeper interpretive engagement with their relationships, meanings, and theoretical possibilities. I increasingly situated my developing interpretations in relation to existing concepts and literature as sensitising resources. Although not examined in depth at this stage, these informed my analytic sense making and shaped a provisional, evolving interpretive account grounded in participants' experiences.

With continued analysis and refinement of category relationships, alongside insights from the critical interpretive synthesis review, I further developed the emerging theory into the final grounded theory. The final grounded theory provides a coherent, integrated conceptual account of participants' experiences and represents the highest level of abstraction generated in this study (Charmaz, 2014; Birks & Mills, 2015).

3.12 Data analysis

I transcribed the interviews and reviewed them multiple times alongside the audio recordings to ensure accuracy and familiarity with the data. In line with grounded theory methodology, I collected and analysed the data simultaneously as much as possible through the constant comparative method, which is a core component of grounded theory (Charmaz & Thornberg, 2020; Lillemor & Hallberg, 2009). Although I found it challenging sometimes to maintain this iterative process alongside ongoing recruitment, it allowed for the continuous comparison of new and existing data. This enabled me to develop subcategories inductively, these captured specific elements or variations in participants' experiences. I then grouped these into broad categories that represented key parts of the underlying process. Through further refinement, I developed a conceptual model to illustrate how these categories related to each other and to the central phenomenon. This process led to the emerging theory, which was a grounded explanation of how and why participants navigated their experiences.

Following Charmaz's (2014) constructivist grounded theory approach, I undertook three main stages of coding: initial, focusing, and theoretical. Each level built upon the one before, so that a progression was facilitated from the detailed descriptions of each participant to a conceptual understanding and further theoretical development that was grounded in the data. An example of this data analysis process is illustrated in Figure 3.1.

3.12.1 Initial coding

The first stage, initial coding, involved the coding of all 12 interviews line-by-line to generate a wide range of initial codes (a total of 1,216). I used gerunds, as recommended by Charmaz (2014), to support a process-focused analysis. In grounded theory, gerunds-verb forms ending in *–ing*, help direct analytic attention toward actions and processes rather than static descriptions, enabling the researcher to stay close to the data while identifying how participants navigate and interpret their situations (Birks & Mills, 2022; Charmaz, 2014). Using gerunds therefore strengthened my ability to attend to what was happening in the data and to begin conceptualising emerging processes. Initial coding is intended to break up the data analytically to expose potential meanings and areas of interest without imposing an early structure (Charmaz, 2014). Even within this large volume of codes, relationships and recurring ideas began to emerge after the first few interviews. These early insights laid the foundation for subsequent focused coding.

3.12.2 Focused coding

In the second, focused-coding phase, I grouped the most significant and recurring initial codes into focused codes for interviews 1-8 to produce more analytical, meaningful codes (total 167). This process reduced the data volume while capturing shared experiences across participants. Focused coding enabled me to develop early subcategories through constant comparison, helping to refine and elevate the analysis. This is a key step in grounded theory that allows the researcher to identify the most relevant data for theory construction (Charmaz, 2014).

3.12.3 Theoretical coding

The final phase, theoretical coding, involved refining and integrating the relationships between subcategories and categories through constant comparative analysis. In this stage, I focused on how the categories were conceptually related, how they emerged from the data, and the consequences that surrounded them.

Through ongoing constant comparative analysis, I examined how categories interacted and supported each other. This led to the construction of a conceptual model that was grounded in the participants' experiences. This iterative process contributed to the development of the emerging theory and increased the explanatory power of the findings. Theoretical saturation was considered to have been reached when no new insights emerged, and categories were thoroughly developed, coherent, and well-integrated (Charmaz, 2014).

3.12.4 Theoretical sampling

For interviews 9 to 12, theoretical sampling was employed to explore and validate the emerging categories. This process enabled deeper clarification and refinement of co-constructed categories in response to ongoing analysis. I paid particular attention to age differences and participants' living situations, whether single, partnered, or living with dependents, in order to capture important details related to these factors.

3.12.5 Memoing

I used memoing throughout to record thoughts, questions, reflections, and analytical decisions. These helped to track the development of ideas to support the explanatory process of grounded theory through the maintenance of an audit trail and were particularly useful when refining categories and building the evolving conceptual model (Birks & Mills, 2022; Foley et al., 2021; Tie et al., 2019).

3.12.6 Theoretical Sensitivity

Theoretical sensitivity developed throughout the study as I engaged reflexively with the data, compared incidents, and wrote analytic memos (Charmaz, 2006, 2014; Birks & Mills, 2015; Glaser, 1978). This sensitivity was also supported by a staged approach to the literature, in which early engagement was intentionally limited, later engagement was reflexive and analytical, and the critical interpretive synthesis served as a sensitising resource offering conceptual lenses to support interpretation without prescribing categories, through which broader theoretical concepts were introduced to inform interpretation rather than generate categories (Charmaz, 2014; Dixon-Woods et al., 2006, 2007). Delaying the full literature review helped ensure that early coding remained grounded in participants' accounts, while the later synthesis deepened conceptual understanding and enabled refinement of the emerging theory (Charmaz, 2006, 2014).

The interaction of reflexivity, memo-writing, constant comparison, and staged literature engagement fostered theoretical sensitivity and supported the development of an analytically robust grounded theory grounded in the data (Charmaz, 2014; Birks & Mills, 2015). These practices helped me recognise patterns, question assumptions, and remain open to multiple interpretations during coding and category development (Charmaz, 2017; Clarke, 2005), supporting the progressive abstraction and integration of categories into the final theory.

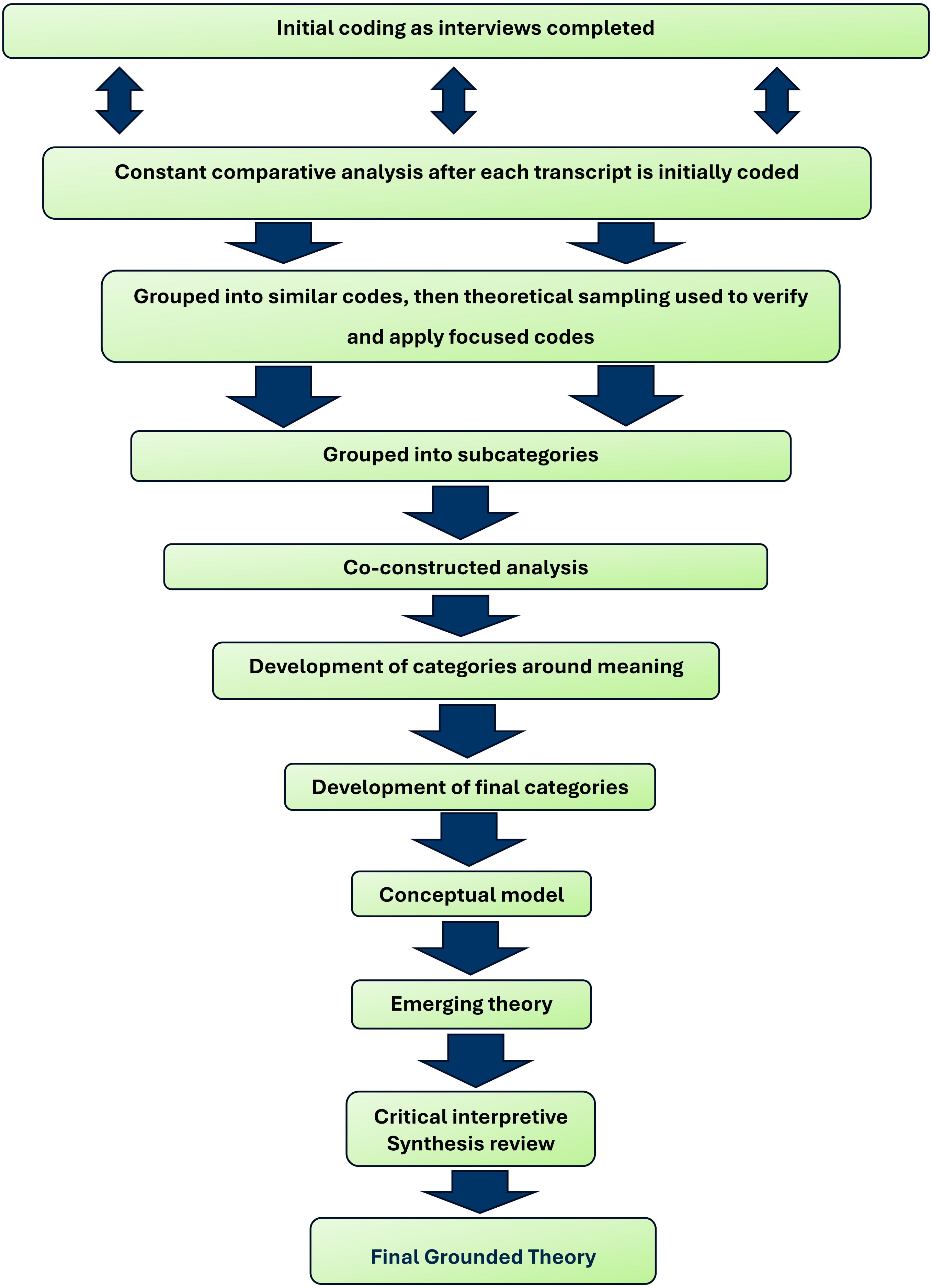

Figure 3.1: *The analytical process of constructivist grounded theory*

3.13 Ethics considerations

3.13.1 Ethical approval

The research protocol related to this study was approved by Lancaster University for sponsorship in August 2022 (Ref: YO16458QBE0122A/080) (Appendix G). The submission was made through the Integrated Research Application System to Northwest Greater Manchester Research Ethics Committee on the 2nd of December 2022 (Appendix H). On the 23rd of January 2023, approval was received from the Committee, the Health Research Authority, and Health Care Research Wales (REC reference: 22/NW/0372) (Appendix I).

3.13.2 Ethical concerns in qualitative research

The study received appropriate sponsorship and ethical approval and followed research procedures throughout. Key ethical principles were upheld, including informed consent, avoidance of harm, confidentiality, anonymity, and participants' right to withdraw.

To avoid coercion, potential participants were initially approached by the clinical team at the research sites. They were provided with a participant information sheet and asked if they would be open to the researcher making contact. If they said they would, I followed this up by phone, gave a full explanation of the study, and obtained their verbal consent at least 24 hours before the interview. Written consent was confirmed prior to the interview, and participants retained the right to withdraw at any time before analysis or within two weeks of the interview without explanation or impact on their care.

I had no clinical involvement in the participants' care so that conflicts of interest would be avoided. Given the sensitive nature of the topic, three distress protocols (participant/researcher/transcriber) were developed (Appendix J) and would have been activated if significant emotional distress had been identified. My background in supporting people in emotionally challenging circumstances informed this preparation. When participants were interviewed in their homes, the Lancaster University Lone Worker Policy was followed.

My duty of care to the participants was addressed by informing them that their involvement (or non-involvement) would not affect their care. I also explained during the consent process that if concerns regarding their safety or care were noted during the study, I would have a duty of care to report those concerns.

The study complied with the General Data Protection Regulation and the UK Data Protection Act (2018) regarding the secure handling of personal information throughout and after the study. All data were anonymised; however, participants were informed that due to the small sample size, complete anonymity could not be guaranteed. Participants were assigned codes (P1-P12), and direct quotes were identified by these codes only. Paper and audio records were kept securely in locked storage until they were uploaded to a password-protected device and Lancaster OneDrive servers. Only my supervisors and I had access to the data, and all materials will be destroyed post-examination, in line with Lancaster University policy.

3.14 Summary

This chapter has outlined how constructivist grounded theory informed the methodological approach and how its use justified the research design in relation to the study aims. In Chapter 4, the initial findings that were developed from participant interviews are presented, including the codes, subcategories, and categories that led to the proposed conceptual model.

Chapter 4: Findings on people's experiences of discovering a newly diagnosed advanced cancer through metastatic spinal cord compression

In Chapter 3, I outlined my philosophical position as a constructivist, and I detailed the chosen constructivist grounded theory methodology and methods that would be used in this study. In this chapter, I present the participant demographics and findings on people's experiences of discovering a newly diagnosed advanced cancer through metastatic spinal cord compression and describe the emerging categories and subcategories that were co-constructed through iterative coding and constant comparative analysis (Charmaz & Thornberg, 2020; Birks & Mills, 2022). These findings have contributed to the development of the conceptual model entitled: "Navigating the consequences of a dual diagnosis: The physical, practical and emotional impacts of facing metastatic spinal cord compression and a newly diagnosed advanced cancer".

The chapter concludes with an introduction to the concept of liminality and highlights its relevance to understanding this experience (Van Gennep, 1960; Turner, 1969). From this, the initial emerging theory that I named "Navigating the liminal space of a dual diagnosis: experiencing metastatic spinal cord compression and the sudden discovery of a newly diagnosed advanced cancer" is introduced. As outlined in Chapter 3, the use of constant comparison during data collection and analysis facilitated the development and refinement of codes and categories (Charmaz, 2014). In constructivist grounded theory, an emerging theory develops inductively and iteratively from the data, remaining flexible and open to refinement as new insights emerge (Makri & Neely, 2021). Throughout this process, I maintained a light link with the literature, and this contributed to the development of the emerging theory through sensitising concepts (Blumer, 1969). The data analysis process, and examples of initial coding, focused coding, and tentative subcategories and categories, can be seen in Appendices K, L, M, and N.

4.1 Participant demographics

Twelve people (seven males and five females) participated in the study. The participants' ages ranged from 53 to 86 years old. Three participants were single, one had a long-term partner, five were married, and three were widowed at the time of the study.

Prior to developing symptoms of metastatic spinal cord compression, six of the participants were categorised as ECOG/PS 0 (fully active), three participants were categorised as PS 1 (had physical restrictions but could carry out light work), and three as ECOG/PS 2 (ambulatory and could maintain self-care). After the onset of metastatic spinal cord compression symptoms and at the time of their interviews, there was clear deterioration in their performance status. Four were ECOG/PS 2, four were ECOG/PS 3, and four were ECOG/PS 4 (one participant was on bed rest awaiting a surgical decision, so had the potential to improve after treatment). Only one participant had a previous cancer diagnosis, which was of sarcoma and had been made 10 years before. A summary of the participant demographic details can be seen in Table 4.1.

Table 4.1: *Summary of participant demographics (n=12)*

Characteristic	No. of participants
Gender	
Male	7
Female	5
Age	
50-59 years	4
60-69 years	1
70-79 years	3
80-89 years	4
Previous cancer diagnosis	
Yes (10 years+ since last diagnosis and end of treatment)	1*
No	11
Marital status	

Single	3	
Married	5	
Partnered	1	
Widowed	3	
Performance status (Metastatic Spinal Cord Compression Service referral form data)	Before diagnosis of compression	After diagnosis
ECOG/PS 0	6	0
ECOG/PS 1	3	0
ECOG/PS 2	3	4
ECOG/PS 3	0	4
ECOG/PS 4	0	4
Employment status		
Employed	4	
Unemployed	1	
Retired	7	

*Sarcoma

4.1.1 The situation of the participants at the time of the interview

Here, I present a summary of the situations of the participants at the time of the interviews. This is important as it provides an in-context background to the study and gives a better understanding of their positions in regard to their diagnosis and clinical management, and to the research. When the interviews were undertaken, 11 participants had not received a primary cancer diagnosis and were undergoing oncology investigations. Potential primary cancer sites had been discussed in some cases, but most were waiting for results of completed tissue or bone biopsies. However, one participant had received news of their primary diagnosis on the day of the interview.

Participants were at different points in their initial management of the metastatic spinal cord compression. Four participants had received urgent external beam radiotherapy, another four had undergone urgent spinal surgery (spinal decompression and stabilisation), and two were awaiting treatment decisions for their spinal compression. The participant who had received a diagnosis had received a treatment plan for their primary cancer; the rest had no ongoing management plans, so did not know whether that would be best supportive care or whether there were further options for treatment to control their cancers. They were awaiting further discussions from the teams in charge of their care. Multiple teams were involved; these included medical, surgical, and oncology teams, which were in charge at different points during this period, depending on the stage at which the patient was within the metastatic spinal cord compression pathway.

4.2 Construction of the conceptual model

The conceptual model was developed through the analytical process described in Chapter 3, using Charmaz's (2014) initial, focused, and theoretical coding. Through constant comparison across interviews, key patterns and relationships were identified and refined to produce a conceptual model grounded in participants' accounts. This early conceptual model illustrates how people navigate the physical and functional consequences of metastatic spinal cord compression while simultaneously coming to terms with a newly diagnosed advanced cancer. It was constructed from three conceptual categories:

1. Making sense of bodily changes and disruption to normal life
2. Focusing on living life for longer
3. Emotional consequences of a dual diagnosis

The development of these categories is shown in Appendix O. Figure 4.1 presents a visual representation of the conceptual model. This period represented a time of significant upheaval, characterised by shifts in physical ability, disruption to routine life, and emotional turbulence. Rather than a linear progression, participants described, across interviews, a fluctuating and often cyclical experience in which they start attempting to understand bodily disruption, adapt functionally, and manage the emotional impact of their diagnosis, frequently reflecting through the cycle trying to revisit the earlier stages to understand what is happening to them.

Although each person's response varied, many described drawing on support from healthcare professionals, family, and personal resilience as they navigated this period. The aim was not a return to a previous sense of ‘normality’ but an effort to move forward with the resources available, to live as fully as possible in the present while facing a profoundly uncertain future.

The circular structure reflects the cyclical and shifting nature of this experience. Rather than representing fixed stages, the arrows indicate fluid transitions shaped by changes in symptoms, information, treatment decisions, and emotional responses.

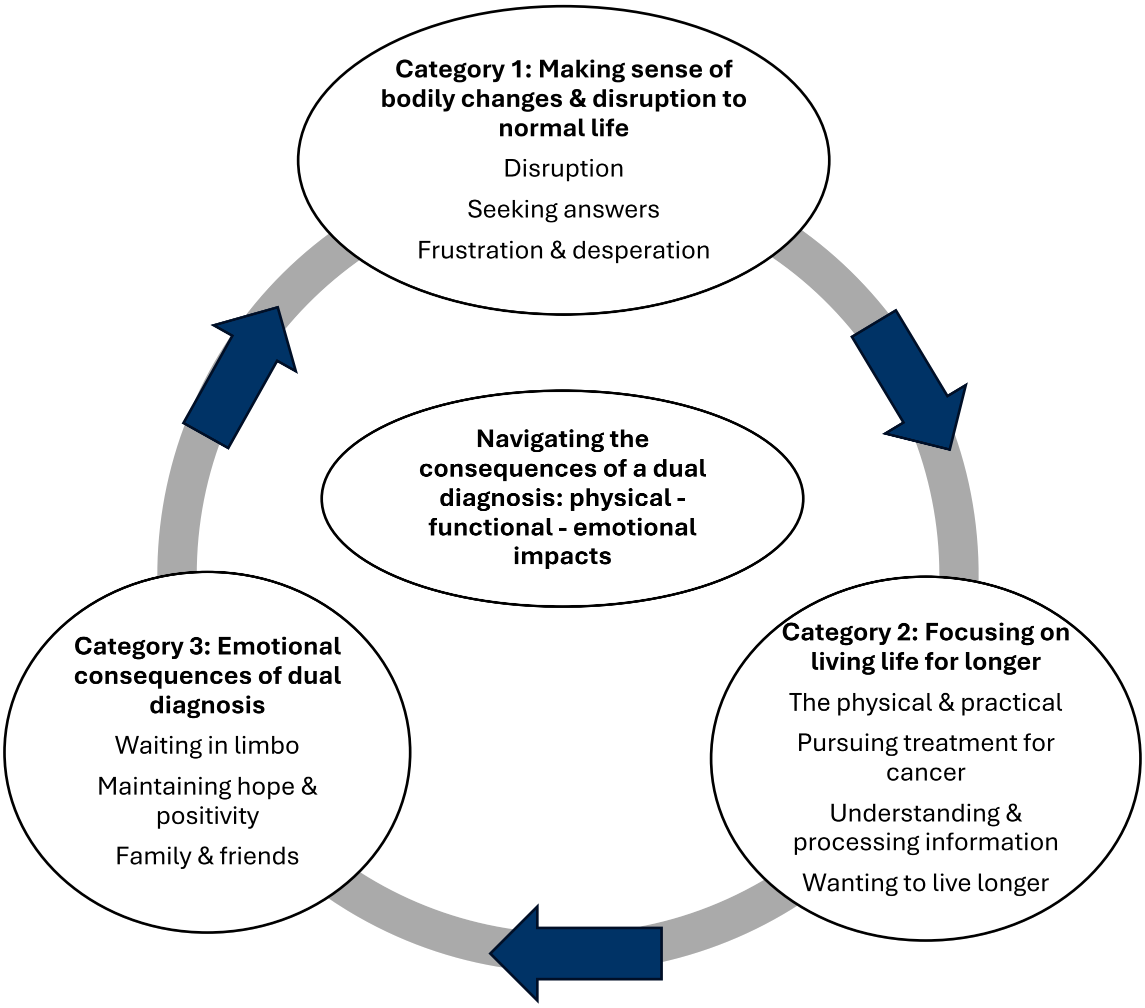

Figure 4.1: Conceptual Model: Visual Representation of “Navigating the Consequences of a Dual Diagnosis: The Physical, Practical and Emotional Impacts of Facing Metastatic Spinal Cord Compression and a Newly Diagnosed Advanced Cancer”

Category 1 covers participants "making sense of the bodily changes and disruption to normal life" during their initial symptoms, subsequent diagnosis and immediate management of their metastatic spinal cord compression diagnosis of advanced cancer while waiting for a primary cancer diagnosis. The category comprises of three subcategories: (1) "disruption", (2) "seeking answers", and (3) "frustration and desperation". Category 2 involves "focusing on living life for longer", as participants prioritise their wish to extend their lives as much as possible and work out how they can do that. It comprises of four subcategories: (1) "coping with the physical and practical changes"; (2) "pursuing treatment"; (3) "understanding and processing information"; and (4) "wanting to live longer". Category 3, "the emotional consequences of a dual diagnosis", involves dealing with the emotional impact on themselves and others of this dual diagnosis. It is formed from three subcategories: (1) "waiting in limbo", (2) "maintaining hope and positivity", and (3) "family and friends". All these categories are interlinked by the physical, functional, and emotional changes that occur for each person, as illustrated in Figure 4.1.

I now report the findings of the interpretation of the data and present how each category and subcategories were created to develop the evolving conceptual model, in line with the use of a constructivist grounded theory approach. Examples that illustrate the development of the three categories are shown in Appendix O.

4.2.1 Category 1: "Making sense of bodily changes and life disruption"

The first category represents participants' first experiences of new body changes and disruption to their normal lives during their initial symptoms, subsequent diagnosis and immediate management of their metastatic spinal cord compression and new advanced cancer diagnosis, while they wait for a confirmed primary cancer diagnosis. During this time, they have entered a period of trying to understand what is happening to them physically, functionally and emotionally. Participants are "making sense" of what is happening, and this is the first step they take as they try to navigate all these changes and to move out of the cycle they have entered. They undergo disruption, frustration and desperation, and they seek knowledge; hence the three subcategories that were created. An example illustrating the development of this category is provided in Appendix P.

4.2.2 Disruption

The subcategory of “disruption” to normal life was created from participants’ first reflections at the beginning of their interviews about how their pre-diagnosis lives, which they described as being active, routine, and fulfilled to a disrupted life. For most participants, this disruption had occurred over a period of time. Only one participant had developed neurological deterioration within hours of diagnosis; the other 11 participants described progressive changes over weeks or months that ranged from severe pain, sensory changes, and limb weakness to paralysis for some. Participants had initially tried to dismiss and minimise these symptoms before they became progressively worse. This is illustrated in the following quote, in which the participant describes their dismissal of their back pain.

> *‘Backache. I’ve had backache before, and I just dismissed this. I thought, “Oh, it’s a sore back. It’ll get better.” And it didn’t. It got progressively worse.’ (P8 L4)*

Participants initially associated and dismissed their symptoms as being due to common causes such as generalised musculoskeletal pains, but over time, the pain became persistent, unremitting, and increasingly severe, and caused disruption to their daily existence. For some, this was accompanied by unexplained and unfamiliar neurological symptoms.

This quote demonstrates how initially participants noticed subtle sensory and coordination changes, which progressively worsened.

> *‘The build up to it, I noticed, [I] was out with my friend, and I noticed I was going straight, and I was going sideways…I was tripping on things that weren’t there, and it just got gradually worse.’ (P3 L41)*

The escalating pain that participants experienced became impossible to dismiss, as they recognised that these changes were now affecting their ‘normal’ routines, not only during the day but also at night; some participants were unable to sleep or lie flat due to the severity of their pain.

The following quote demonstrates the persistent, unremitting nature of this pain and the distress it was causing by disrupting participants' usual routines.

> *'I was awake all night, couldn't sleep, because I couldn't sleep on that side...I'd not stayed at my partner's for a whole month because I was struggling with a horrible back.' (P7 L62)*

The following quote illustrates how the severity of the pain forced participant 11 to sleep downstairs in a chair, as it was the only position that offered any relief and allowed them to rest.

> *'It (the pain) came back with an absolute vengeance. It was shocking, and basically, I haven't been able to sleep in bed for over six weeks. I've been on that chair; that chair has been my little friend, bless it.' (P11 L36)*

The disruption to participants' everyday routines led to growing feelings of disappointment, as persistent symptoms failed to resolve and pushed participants even further from their normal lives. The following quote highlights how ongoing pain began to disrupt activities that participants had previously enjoyed. Participants described conflicting feelings: although they recognised that the symptoms were significant and warranted attention, in another way, what they were complaining about seemed insignificant, as they otherwise felt well, and they were unsure how to communicate this to healthcare professionals. The next quote illustrates how the symptoms were minimised in the hope that they would resolve without intervention, but they did not.

> *'I noticed pain. It's probably around this time of year [the previous December, 12 months before the interview]. Yeah, a little niggle. Yeah. I didn't really think much of it, really. I thought it was perhaps related to golf. I thought I'd just pulled something.' (P10 L22)*

These persistent ‘little niggles’ gradually led to a growing realisation that something was ‘not right’. This marked the beginning of a journey, from initial dismissal of the symptoms, to experiencing increasing disruption to daily life, and ultimately to participants facing a life-threatening diagnosis with life-changing disability.

4.2.3 Seeking answers

It was the ongoing disruption to their usual routines, the disappointment that their persistent symptoms were not resolving, and that they were gradually shifting away from their ‘normal, routine lives’ that prompted participants to begin seeking answers, which was the next subcategory. They turned to healthcare professionals to find out why these bodily changes were causing this disruption in their lives. Recognition of the connection between the increasing, persistent body changes that they had initially dismissed and the escalating disruption to their everyday functioning was a critical step in realising that something was wrong and that they needed to find out why this was happening to them.

A significant challenge that participants found when seeking answers was that they did not consider themselves clinically unwell. As a result, they struggled to communicate these progressive bodily changes, the disruption they were causing, and how different they felt now compared with their previous ‘normal’ functional states. The disconnection between how they felt and how they considered themselves made it difficult for them to communicate the seriousness of their experiences, because their symptoms, though disruptive, did not conform to their understanding of illness. The next quote illustrates this difficulty.

> *‘Because it’s hard to like explain and I’d gone from being able to get out of here and run around the corner to I can’t walk in a couple of weeks.’ (P12 L150)*

Participants then became increasingly confused by the responses they received from the healthcare professionals they approached for advice. Clinicians were unable at this stage to explain clearly what was happening, which added to participants’ frustration. The following quote illustrates how participants experienced this confusion. They frequently encountered mixed messages about the root cause of their symptoms, while at the same time they began to recognise that their condition was not improving, and their hope was diminishing of returning to their previous physical and functional state.

> *‘I’ve got someone saying I’ve got piriformis [deep gluteal muscle]; I’ve got another one saying I’ve got a herniated disc. So, I got another appointment with my doctor, because I thought, “I’m not doing those exercises, nobody’s got X-ray vision, they don’t know what’s going on.” So, I had a face-to-face appointment with my GP. (P7 L58)*

Some participants, as shown in the following quote, were advised that they had to cope with the pain and that there should be some signs of improvement, but this did not occur.

> *‘He just said, “Yeah, it’s sciatica, I’m really sorry, but you just have to go through it...”’ (P11 L328)*

The following quote demonstrates that although participants clearly communicated the severity of their physical and functional changes, such as being unable to walk or experiencing loss of power in their lower limbs, the healthcare professionals made no effort to investigate the underlying cause. Instead, they focused on managing symptoms and offered solutions to address the functional problems without exploring what was driving them.

> *‘Then I start to tell them, “I can't walk; I can't put any power on this leg”, and then everybody started to come in now. The doctors, the pharmacist, everybody came to see what was happening. And then they keep putting me on all different kinds of heavy painkillers. The crisis team came when, about Thursday night, about 8:00 and they brought me a commode and a Zimmer frame and showed me how to stand up to use it, but I couldn't. I must have used it for about twice, the commode, and that was it.’ (P9 L27)*

Older participants (such as participant 9, who gave the previous quote) were initially managed by rehabilitation teams under the assumption that their symptoms were age-related. Only later did healthcare professionals begin to consider that the increasing symptoms and disruption might be connected to something more serious that warranted further investigation. This delay left participants feeling disappointed and confused. They sensed that something was seriously wrong, so far removed from their normal lives that they recognised urgency. However, this urgency was not reflected in the responses they received from healthcare professionals, and this situation contributed to their frustration when they sought answers.

4.2.4 Frustration and desperation

The subcategory of frustration and desperation sits within the category of "making sense of bodily changes and life disruption," as participants made multiple attempts to seek answers from healthcare professionals about the increasing and persistent changes in their bodies that were disrupting their daily lives. The following quote illustrates participants' awareness that something was wrong and their frustration that healthcare professionals were unable to connect their physical changes with the disruption they were experiencing. The participants believed these changes should be investigated.

> *'I knew, I just said to my wife, "It's not right. Something is not right here. I just know myself." Because the pain was like I've never, ever experienced it before' (P11 L420)*

Participants who had previously experienced benign musculoskeletal pain recognised that these symptoms were different, unremitting, and severe, and unlike any issues that had required them to take time off work previously. This is illustrated in the following quote.

> *'Totally different, totally different, and it's just, like, in my head, thinking…because, I knew as well with that degenerative disc disease, I thought of, like I had years of pain, but I was never off sick.' (P7 L225)*

Participants' frustration was heightened by the difficulty they faced in accessing appointments as they recognised that they needed answers. Many made repeated visits to emergency departments and local primary care services and became increasingly annoyed and worried about the ongoing challenge of communicating the changes they were experiencing and seeking meaningful responses from healthcare professionals. The following participant illustrated their dilemma: in order to secure an appointment, they felt they had to appear visibly unwell or 'make a fuss', yet the participants did not feel acutely unwell and did not feel the need to make a fuss.

> *'Of course, the trouble is you can't see doctors anymore. Well, you can see a doctor, you can get an appointment in about two weeks' time or something like that, three weeks' time. And if you are ill and you can make enough fuss about it, the triage nurse gets you to see a doctor.' (P1 L70)*

The following quotes demonstrate both the frustration that participants felt after attending multiple assessments and the challenges they faced in communicating their symptoms. Despite their efforts, healthcare professionals failed to connect the urgency of the situation and the need to escalate for further investigation.

> *'So, I presented myself three times to the doctors, I also went to A&E – I think then somebody has got to be looking at this and saying, "this is more than sciatica". That would be my only concern; I think it got brushed off too easily.' (P11 L870)*

Participants in these situations felt that healthcare professionals were not taking their bodily changes seriously and that access to investigations was delayed, which added to their frustration.

> *'I don't think they were taking it serious like how I was.' (P9 L43)*

As most participants did not present with typical 'red flag' symptoms of a primary cancer or a neurological emergency, such as numbness or bladder and bowel incontinence, they did not meet the criteria for urgent assessment or investigations. In metastatic spinal cord compression, symptoms such as these often appear late in the progression. The constant inaction compounded participants' frustration and, in many cases, escalated it into desperation.

The following quote illustrates the level of desperation that one participant reached while seeking help. Still, they did not see themselves as unwell, yet they were acutely aware that their symptoms of pain and lower-limb weakness were increasing, and their bladder control was deteriorating.

> *'I phoned 111. I went, you know "I need somebody to see me I can't move." I couldn't even get out of bed to have a wee. I've got to buy a new bed because it'll be stinking of wee by the time I get home. But I mean that's how bad it was.' Just pick me up and throw me on that ambulance.' (P5 L233)*

This highlights the challenge that participants faced in trying to communicate these serious bodily and life changes to healthcare professionals, because they lacked symptoms that are typically recognised as requiring urgent attention.

The category of "making sense of bodily changes and disruption to normal life" summarises the initial phase of the participants' journeys as they began to experience unfamiliar and progressively worsening physical symptoms, leading to significant disruption in their everyday lives. Through the subcategory of disruption, participants reflected on the contrast between their previously active, routine lives and the gradual, or in one case, sudden onset of pain, neurological changes, and loss of function. As these symptoms increased, participants moved into the subcategory of seeking answers, making repeated attempts to engage with healthcare professionals to understand what was happening to them. However, a lack of clear or consistent medical explanations left many feeling unheard and confused. This led to the subcategory of "frustration and desperation" as participants not only sought appropriate care but also to communicate effectively the seriousness of their symptoms, especially as they did not present with classic 'red flag' signs. The emotional toll of not being believed or prioritised increased their distress. Together, these subcategories illustrate the complex, often isolating process of trying to make sense of a life-altering situation while navigating a healthcare system that failed to recognise the urgency of their condition.

4.2.5 Category 2: “Focusing on living life for longer”

Category 2 captures the stage at which participants have shifted their focus toward adapting to life following a diagnosis of metastatic spinal cord compression and a newly identified, life-limiting, advanced cancer. In the midst of significant physical and functional changes, participants concentrated on whatever actions they could take to support their goal of continuing to live for as long as possible. This included efforts to improve their physical functioning, find practical ways to adjust to a new ‘normal’, and make it known to healthcare professionals that they wanted to pursue cancer treatment.

As participants began to process the physical and emotional disruption caused by their symptoms and sought understanding, they reached a pivotal shift, from trying to making sense of what was happening to actively attempting to live with their new reality. This transition underscores the importance of timely, person-centred care that recognises when a person is ready to shift from crisis to adaptation. It also highlights the need for early supportive intervention and future planning to guide the next phase of their journey.

Despite the uncertainty of their prognosis, participants demonstrated a strong will to regain control and purpose in their lives. The category was composed of four subcategories: (1) “focusing on the physical and the practical”, (2) “pursuing cancer treatment”, (3) “understanding and processing of information”, and (4) “wanting to live longer”. Each of these is discussed in more detail in the next sections. An example of how this category was developed is provided in Appendix P.

4.2.6 Focusing on physical and practical changes

At the time of the interviews, participants were primarily focused on their physical experiences. Before diagnosis, they were becoming increasingly aware that the changes in their bodies were affecting their function and disrupting their usual routines. For most, these symptoms progressed gradually; however, for one participant, the change was almost immediate. When these physical changes were finally acknowledged and a diagnosis of metastatic spinal cord compression was confirmed, participants described an initial sense of shock, but also a sense of relief that finally, there was an explanation for the physical deterioration and disruption they had been experiencing.

The following quote illustrates this mix of feelings. This shift to relief that they had an explanation for their symptoms allowed participants to become more solution-focused; it also offered a renewed sense of hope for resuming their 'normal' lives.

> *'So, there was a shock, yeah. But then again, once I knew, but also relief, wasn't there, that actually I knew?' (P12 L217)*

At this stage of their experiences, participants were in the acute phase of their illness, as the urgency of their metastatic spinal cord compression required immediate attention. From their perspectives, there was a clear focus on the management and treatment, whether that involved surgery, radiotherapy, biopsy, or immediate progression to systemic anti-cancer therapy. These interventions were understood to be necessary to preserve neurological function and maintain the participants' physical and functional abilities as much as possible. All participants received some form of treatment for their metastatic spinal cord compression; none were considered immediately to be reaching the end of their lives.

Participants described this period as one in which both they and their healthcare teams were highly focused on managing the metastatic spinal cord compression, making urgent decisions about treatment pathways, and working towards physical recovery. From the participants' viewpoints, this shared urgency aligned with their strong desire to return to their pre-diagnosis 'normal'. Many noted that, at this stage, their primary cancer was not causing them to feel unwell, and this reinforced their hope and motivation to improve their physical status.

The following quotes illustrate participants' determination to continue to live and their focus on returning to life as it had been before diagnosis. This was an important goal for them as they navigated the physical and practical challenges that followed their diagnosis.

> *'When I get home, everything's just going back to…I will make it go back to normal.' (P5 L184)*

> *'The most important thing to me now is for me to get well again and to be me again; get back to normality, which is work; enjoy my weekends; just sort of be as I was before – that's the most important thing to me now. That's what I'm focusing on.' (P11 L649)*

Participants focused on living by working hard to regain their independence and improve their physical function, with the aim of returning to their pre-diagnosis sense of 'normal'. While this goal remained central, there was also a growing acceptance that they might have to live with some level of disability. Participants began to reflect on how they could negotiate, adapt to, and accept support in order to live as fully as possible and as closely as they could to their pre-diagnosis 'normal life'.

The following quote illustrates participants' motivation to recover physically. They were determined to achieve the best possible with their levels of function, with the overarching goal of continuing meaningful and fulfilling lives that acknowledged their new diagnosis but did not define their futures.

> *'I want to try and say, "What's the best I can get to?" I want to be spurred on by others to tell me what's the best I can get to. I don't know what my best is, but what is the best I can get? I want as fulfilling a life as I can, whatever that may be.' (P6 L367)*

None of the participants wanted to remain bedbound, and they did not consider this level of disability acceptable or consistent with the life they wanted to lead.

> *'Yeah, I don't want at all to be bedbound.' (P1 L95)*

Participants did not view their limitations as a complete barrier to restoring a sense of normality. In particular, participants who were inpatients expressed a strong desire to return home, and they recognised that doing so would require adjustment to a new physical functional baseline. They understood the need to adapt in order to reconnect with family life and continue to live as fully as they could.

> *'No matter what happens from here on in, this is now a new me in some way, and I've got to reflect on that and how I can take that new me forward. But with strength and determination and, even in a wheelchair.' (P6 L396)*

> *'It's no big deal. If I've got to go in a wheelchair, I'll still get up to the pub and play bingo and have my pints of lager.' (P5 L168)*

The quotes above demonstrate that participants were focused on how they could adapt and continue to enjoy social activities and maintain their normal life routines, even with a level of disability. At this stage of their experience, participants did not perceive their advanced cancer diagnosis as an immediate barrier to physical recovery. Many were determined to keep pushing forward with their rehabilitation and functional improvement, while awaiting clarity on how their primary cancer would be managed.

The physical and functional impacts of the metastatic spinal cord compression had brought huge changes to their lives, reducing their independence and forcing rapid adjustment and a change in identity. For many, this period was emotionally overwhelming and marked a sense of lost control.

> *'It's difficult to explain, because I've always been an active person, and with my friends of 40 years. So, things like that, I won't say I'm beginning to miss, but it's been pushed to one side' (P2 L42)*

Some participants found their transitions from active, independent, and routine-driven lives to their new, completely contrasting situations difficult to accept. Some found themselves confined to bed, heavily dependent on others, and subject to the structured routines of inpatient care.

> *‘As I say, I've always done everything I wanted, when I wanted. To have to rely on other people, it's mission impossible sometimes.’ (P2 L192)*

Despite these challenges, participants expressed strong, solutions-focused mindsets as a means of regaining a sense of control. This involved negotiating a new level of disability, working to improve their physical function, and making practical adaptations to their homes to facilitate their return there.

> *‘Yes. I could have a stairlift. Like I say, it’s not that be-all or end-all.’ (P5 L188)*

Healthcare professionals were perceived as playing crucial roles in helping participants to navigate the loss of independence brought on by their physical decline. How this support was delivered, particularly the extent to which it preserved participants’ dignity and autonomy, had a profound impact on their ability to adapt emotionally and to begin regaining a sense of control. For many, the sudden need to rely on others for intimate care was one of the most challenging and disempowering aspects of their experience. However, if healthcare professionals approached these situations with sensitivity, respect, and understanding, participants were more able to accept help and to adjust to their new circumstances.

> *‘The physicality of it. Being washed by total strangers. It’s not so bad if it’s these young women, but yesterday it was a man, and I rejected him. I said you can go to your meeting. I can’t be doing with that. But in the end, I had to give in. And it was alright. Well, it was a total loss of dignity and it’s, but come on, I’m not in a position to argue. I had to. It has to be done. The most demeaning task you can do for a person was done for me, and I found I accepted it. So, adaptations have been necessary. And I had to adapt to the nurses who are not so tender.’ (P8 L182).*

> *‘It boosts me on, as well. It boosts me to get well. They talked to me with dignity. They talked to me with respect and [that] boosts me to move on.’ (P6 L342)*

These quotes demonstrate that these life-changing physical changes caused by metastatic spinal cord compression have had a significant impact on participants’ levels of independence, in both mobility and personal care, and that this has led to a loss of control. It was clear that it was important for participants to start to regain this control in order to regain some normality in their lives. Participants emphasised the importance of healthcare professionals understanding the profound impact of their diagnosis. They expressed a need for support in working towards their pre-diagnosis routines, as a way to restore a sense of normality, regain control, and move forward with living.

The following quotes illustrate that, at this stage in their experience, physical progress was perceived as a sign of recovery and gave participants hope that they might return to their ‘normal’ lives. Physiotherapists were seen as a key to facilitating this progress, and participants expressed a strong sense of dependence on them for support. This focus on physical improvement was present regardless of disease stage, and it posed particular challenges for those with more advanced disease, for whom time might be short. The final two quotes reflect the perspectives of participants in this situation.

> *‘But here it was a question of healing. There, well, I suppose it's healing as well, but it's a different kind of, its physical progress, I want to make progress.’ (P8 L204)*

> *‘They have actually said about the community physio, which I’ve said I’m happy to take. I said anything I can be taught, any exercises I need to do.’ (P12 L398)*

> *‘But I knew I had to work with the physiotherapist and think about what other treatment I could have.’ (P4 L113)*

> *‘I can’t sit in a wheelchair, although hopefully the physios are going to work on that.’ (P1 L113)*

It was important to participants that they made progress with even little things that they had taken for granted pre-diagnosis.

> *'So, it's all right there. I got my hair cut yesterday, which is...I know it's a bit irrelevant – but I cut my hair religiously virtually every single Sunday, a number three, and it was that long and I'm like just looking at myself going...even as soon as my hair was done, a better wash because I did myself in the hospital, sat on the chair and stood by the shower, I could wash all my bottom half the first time because I'd got the catheter out after a few days. So, I just felt, you know, even getting my hair cut and things like that felt much better and more like me.' (P12 L446)*

This quote demonstrates that starting to return to parts of their usual routines led participants to feel that they were improving physically and returning to some normality while they were waiting for their results and news of what was to happen next.

4.2.7 Pursuing treatment for cancer

The subcategory of "pursuing treatment for cancer" emerged from participants' responses after their diagnosis of metastatic spinal cord compression. From the outset, it was clear that participants were focused on living and understood that treatment would be necessary to control the cancer. They expressed a strong willingness to accept whatever treatment was available to extend their lives. The following quote illustrates the desperation that participants felt to pursue treatment in any form in order to live as long as they could.

> *'If I can live, and they can zap me and blast me, and put a load of shit in me, to just keep me waking up every day, I'll do it.' (P7 L86)*

Initial treatment discussions were focused on active management of the study participants' metastatic spinal cord compression. Naturally, these discussions gave participants a sense of hope. Some interpreted these conversations as an indication that additional treatment options would be available once their primary cancer was identified, even in cases in which the disease was advanced and further treatment was unlikely. For many, the confirmation of primary histology represented a turning point, with the expectation that this would open the door to treatment that was aimed at controlling the disease and enabling them to move forward. The following quote illustrates how strongly participants were focusing on receiving further treatment. At this stage in their experiences, their primary focus was to continue to live life.

> *'Until we get the biopsy report and can plan a way ahead with chemotherapy, we're not going anywhere immediately.'* (P2 L50)

Even participants with extensive disease had hope and were keen to know what would come next, particularly regarding treatment options. As illustrated by participant 4 in the next quote, there was an expectation that further treatment would be available following the initial management of their metastatic spinal cord compression.

> *'I will try whatever treatment next to get my mobility and try to carry on.'* (P4 L125)

4.2.8 Understanding and processing information

The subcategory of "understanding and processing information" captures the period just after their diagnosis, during which participants described themselves and the healthcare professionals involved in their care as being engaged in a complex process of managing their metastatic spinal cord compression. This involved ongoing discussions with multiple teams, all focused on delivering the most appropriate treatment. Participants described this phase as overwhelming. For weeks, many had been seeking answers, and many had been reassured that their symptoms were not serious. The following quote illustrates the extent to which participants felt unprepared for and disconnected from the reality of what was happening when they finally received their advanced cancer diagnosis. For most, cancer was not on their radar.

> *'I had three scenarios in this. So, in my head, I knew I wasn't well. I knew I had problems. I knew there was something wrong. And I had three scenarios. The scenario I thought of was I've probably*

> *got a trapped nerve or a slipped disc or something, and I need to get that sorted.' (P6 L153)*

Many participants found it difficult to distinguish the roles of the various healthcare professionals and teams involved in their care. They encountered a wide range of professionals, including physicians, acute oncology nurses, spinal surgeons, oncologists, palliative care specialists, physiotherapists and occupational therapists, across multiple sites in primary, community and acute hospitals. For many, the involvement of multiple teams led to information overload, making it difficult for participants to process and make sense of the constant flow of information. Some of the professionals involved had direct contact, whereas key information from others was transferred via other healthcare professionals. This was overwhelming for participants, who had gone from thinking they had a non-serious condition to a diagnosis of metastatic cancer and felt unprepared for this information. As demonstrated in the following quote, contact with multiple teams caused information overload and participants found it difficult to process and make sense of all the information being given at once and constantly.

> *'There's a team for everything. The special skin team, there's oncology, there's palliative care, there's...you name it. There's a special team for every single aspect of care and they are trailing through, giving you information all the time. And I don't know if it was Tuesday. I just had it up to here and I thought, "Please, please don't give me anymore of this, I can't take it. I cannot deal with this anymore."' (P8 L126)*

Participant 10 suggested the need for a central communications point:

> *'It can be a bit confusing sometimes, with all the people involved, and it'd be a lot easier if all the information was central.' (P10 L416)*

Participants reported that professionals often explained things at a level they did not understand, or different people used different terms. The following quote illustrates that information should be given at a level that a lay person can understand so that they can process the information.

> *'These people think…they're that far up their own arse half the time that they don't…they've forgot what it's like to talk to people like me. You know, and often, I'll go like that, "I don't know what you're talking about. Go back (to something said previously)". (P5 L85)*

The following quote demonstrates the level of distress that can be caused when different terms are used by healthcare professionals without them taking time to introduce the idea of cancer.

> *'This guy came to see me on the Saturday morning, and he didn't say "lump", he said "tumour" for the first time. It scared me. When the lump…obviously, it was a lump, and I didn't know what it was, and at that moment, I don't know why, but I didn't even think "tumour".' (P11L195)*

The conditions of people in these situations should be appreciated. Participants were sleep-deprived and on new pain medication, both of which, alongside the shock of their diagnosis, impacted their ability to process and retain large volumes of information that they were receiving from multiple sources and often verbally. This caused confusion and distress, particularly for those with extensive disease.

> *'But it was very, very difficult, wasn't it? You had about seven or eight nights of indescribable, that level, no sleep. And of course, that's kind of affecting your mental state.' (P8 L75)*

Participants who did not understand the extent of their primary cancer demonstrated limited comprehension of treatment decisions related to metastatic spinal cord compression and the implications of their diagnosis. In order to move forward, they needed to be able to understand the information that they were being given.

> *‘I'm still confused. I'm still not clear what it is they found.’ (P8 L117)*

> *‘I’m assured that they’re doing everything they can to try and find out what’s going on. I feel very assured that they will find out what’s going on, and I trusted fully that that’s what was happening. But did I really know what was going on or what they were trying to look for or find? I had no idea because I’ve still got no idea what was wrong with me.’ (P6 L191)*

Participants described receiving information from a range of sources, including Macmillan booklets and verbal explanations from healthcare professionals. However, they expressed a need for a personalised, written summary of what was happening. This would help them to better understand their situation; it would support clearer communication with family members and give them time to absorb the complexity of their situation. Having this written summary would also enable them to process and prepare questions so that they felt more informed and in control of the care journey.

> *‘My younger daughter was taking notes on her phone, bullet-pointing everything, because I wanted to document my…not the word “journey”, my “what was happening”. I had everybody’s names, and what they were doing, and why they were doing it. Fully aware, fully able to communicate and ask a million questions, and never at one point felt that I was being rushed.’ (P7 L98)*

> *‘This young woman came. She was, I think she was called (name of doctor). And she was a young doctor. And she was peace. She was peace on legs. She came in and I just exploded and said, “Look, this is too much. There's too much information and I can't take it in. My head's all screwed up with the drugs. I'm not in a good place. Don't tell me anything else.” I said, “I'm trying to process all of this, ready to tell my daughter.”’ (P8 L127)*

> *‘I said I was trying to process all this to give my daughter information because she always asked me, “Who's been to see you and what did they say? Where can I get the information?” And she has been looking at the notes, and she has been talking, as you can see, she's talking to people. So, she said, “Would you like me to make you some notes?” “Oh, yes, please.” So, she went away, and she wrote a whole page of notes in her own handwriting. And it was all legible.’ (P8 L132/33)*

The participant quotes above highlights how overwhelming this period was, as they were faced with a large volume of complex information, not only about metastatic spinal cord compression but also the implications of a new metastatic cancer diagnosis. Participants described feeling confused about what this meant for their physical abilities and the future. They needed healthcare professionals to recognise that it was difficult to process verbal information from multiple people and teams, especially when they were alone. Participants expressed a need for information to be delivered in a way that helped them to understand the broader meaning, not just the clinical facts about the metastatic spinal cord compression, but also what to expect next in terms of their metastatic cancer, including realistic outcomes in terms of neurological recovery and life expectancy.

4.2.9 Wanting to live longer

The subcategory of “Wanting to live longer” captures the strong desire that the participants had to continue living, despite being faced with a new life-limiting diagnosis of metastatic cancer. This diagnosis brought death into sharp focus; they knew it would come eventually, but now it seemed more immediate and real. Participants openly acknowledged that death was a natural part of life but stated that they were not ready to give up living. All participants expressed the view that as long as they were able to enjoy a full, active life as they had before the diagnosis, they wanted to continue to live.

> *‘I knew one day - I'm going to die one day; like everybody else, you can't live forever.’ (P4 L69)*

> *See if I can get myself into a wheelchair so I can get about, the roads, go up to the shops and various things like that. Live a normal life as I can from a chair. (P1L42)*

Despite the seriousness of their diagnosis, only one participant said they had asked a direct question about their prognosis, while others preferred to process this information gradually, step-by-step, as it was delivered.

> *'(I asked) "How long have I got? Am I going to live?"' (P5 L67)*

Taking this approach suggests that participants wanted to focus on living in the present and maintaining hope, rather than dwelling on the uncertainty of how much time they had left. Participants who were receiving input from palliative care teams valued the support primarily for pain and symptom management, rather than for the broader, holistic conversations about the future. Many found the term "palliative care" difficult to accept, as they associated it more with dying than with support to live well alongside serious illness. The next quote is an example of this.

> *'You know, it's not something I think you ever want to hear. I'm not going to die today or tomorrow, but you're under palliative care. "Palliative care" is a horrible word, isn't it?' (P6 L375)*

In summary, the category "Focusing on living life for longer" illustrates how participants face life-changing diagnoses, focusing actively on redefining and preserving their quality of life. Even with uncertainty, physical, functional limitations, and emotional turmoil, their efforts are focused on living meaningfully, wanting recovery, pursuing treatment, making sense of complex information and refusing to give up in the face of this new diagnosis. This stage marks a turning point, between the balance of hope and realism where support from healthcare professionals can either hinder or empower the person's path forward.

While participants focused on living life and pursuing treatment, their determination was accompanied by a growing emotional burden, not only from the diagnosis itself, but from the relational and existential impacts of their rapidly changing reality. The next category explores the emotional consequences of this dual diagnosis, reinforcing the need for integrated support that responds not only to physical decline but to the emotional and relational disruptions that shape the person's, families, and friends' experiences.

4.2.10 Category 3: "Emotional consequences of a dual diagnosis"

The category captures the emotional impact on the diagnosed person and those around them of dealing with this dual diagnosis of metastatic spinal cord compression and the presence of a previously undiagnosed advanced cancer. Participants described a complex emotional time while they took in life-changing information. The category reflects the ways in which participants were trying to grapple with not only their own emotional responses but also how the situation would affect those close to them. The emotional burden was heavy due to the suddenness and severity of their diagnosis, and the rapid shift from being previously well to becoming seriously ill and dependent on others. Participants had been transported into a new reality that required immediate physical adaptation and emotional processing, but without being given the time and space to achieve this.

The emotional consequences of this experience of a dual diagnosis are described by three subcategories: (1) "waiting in limbo", the emotional toll of uncertainty and disrupted expectations; (2), "maintaining hope and positivity", trying to preserve optimism as a way of coping; and (3) "family and friends", the emotional weight of sharing the impact of the diagnosis and the participants' dependence on others. Together, these subcategories reflect the internal and external emotional negotiations that participants undertook as they tried to make sense of their diagnosis, to maintain a sense of control, and to support their loved ones while coping with their own fears. An example illustrating the development of category 3 can be seen in Appendix Q.

4.2.11 Waiting in limbo

"Waiting in limbo" was a recurrent emotional experience for participants. Participants described their initial sense of being in a place of uncertainty while healthcare professionals worked to assess and connect the physical changes to a diagnosis. During this phase, they waited for clarity and for further investigations to produce answers. By the time of the interviews, participants had transitioned out of that initial period of waiting and uncertainty, as they now had an explanation for their symptoms. However, they had entered a new space of waiting and uncertainty as they awaited news of their primary cancer diagnosis and decisions about treatment, if any, that might follow. This period of waiting took different forms: some participants had completed treatment for their metastatic spinal cord compression and were working on improving their physical function; others were waiting for histology results to decide whether their primary cancer could be controlled; and a few, having undergone treatment for their spinal cord compression but with no further treatment options due to extensive disease or frailty, were waiting to discuss the next steps in care and planning.

Regardless of their clinical status, whether inpatient or outpatient, all participants described themselves as being in limbo; emotionally, as being in a place of "not knowing" what the future would hold, as described in the next quote.

> *'You've got to wait, and nothing you can do about it. Just carry on, but no, I'm just in a sort of limbo.' (P2 L132)*

This quote captures the essence of this phase, the emotional weight of waiting and participants' lack of control and entire dependence on healthcare systems and professionals to decide the next steps. Importantly, for those with advanced disease, time was short, and they did not have time to wait, yet they had no choice.

Participants adopted a step-by-step mindset as a coping mechanism to deal with this 'limbo'. They focused on one day at a time. As illustrated in the following quote, this strategy helped them to accept and acknowledge the wait.

> *'It's all compartmentalised, but no, it's just we are where we are, and we've got to wait another day.' (P2 L196)*

Although none of the participants expressed fear or anxiety during the interviews, they became tearful and emotional when thinking about what would be next and particularly when talking about their families.

4.2.12 Maintaining hope and positivity

The emotional consequences of receiving a dual diagnosis of metastatic spinal cord compression and a new advanced cancer diagnosis were profound. Within this context, the subcategory of “maintaining hope and positivity” emerged as a key emotional coping strategy. Participants described the importance of maintaining optimism, especially during the early phase when healthcare professionals were actively managing their spinal cord compression. This active medical management, urgent treatment and focus on physiotherapy created a sense that progress was being made and a sense of purpose and helped to maintain hope.

Even while describing themselves as in limbo, uncertain about their primary cancer diagnosis and what the future would hold, participants said that this waiting period allowed space for hope. It became a time in which the possibility of recovery, or at least improvement, could be imagined. Although participants acknowledged that staying positive was often difficult, they also viewed it as essential to look forward, plan and aim to get better again.

> *‘Try to be as positive as possible, which is not easy.’ (P1 L136)*

> *‘It’s not been too bad because I’m waiting to get better. Do you know what I mean? I’m not...yeah, to me...I’m telling you, I’m getting better. So...’ (P5 L228)*

> *‘I’m trying to stay as positive and looking forward as I can. I want to make the most recovery that I can possibly make.’ (P6 L320)*

These quotes illustrate that hope was emotionally important, as it helped participants to remain future-focused even when their clinical circumstances were unclear. After the shock of diagnosis, but with the relief of having answers for their changes, participants shifted to a mindset of action and proactivity. Working with physiotherapists, planning for discharge or even just recovering some of their routine gave hope of normality. The next quote illustrates the importance of returning to routine to maintain hope and positivity.

> *‘I said to (wife’s name) in the morning, “I want to go out”. We like going out for breakfast on a Saturday morning. I just like it; it’s the weekend, and it starts my weekend off. So, I said to (wife’s name) on Saturday, “I just want some normality, please; let’s just go out for breakfast…” (P11 501)*

Small acts, as described in this quote, fostered hope and a sense of progress, enhancing positivity.

4.2.13 Family and friends

The roles of family and friends emerged as powerful emotional links for the study participants as they navigated the challenge of this dual diagnosis. This subcategory, within the broader category of emotional consequences captures the deep emotional impact caused by the presence or absence of loved ones during this time of significant physical, functional, and emotional changes.

For many participants, being in the hospital or suddenly losing their independence led to increased dependence on family and friends for both practical and emotional support. This dependency generated conflicting feelings of gratitude for the care they received, alongside guilt and concern about becoming a burden, as demonstrated in the following quote.

> *‘I think my mobility has to be better, well, I know it does, I’d be a burden (wife’s name), do you know what I mean? It would drain her; she would probably become ill with doing everything’. (P4 L153)*

Separation from family, particularly for inpatients, was described as a painful aspect of their experience. This was a lonely time, and the effect of being away from loved ones was very hard.

> *‘I just remember one part where I was thinking I was on my own.’ P3 L135)*

> *‘It’s just hard being separated when things like this are going on.’ (P4 L345)*

These quotes illustrate that contact with family and friends during this time brought vital emotional support. Participants described regular phone calls, messages and visits, which provided reassurance and comfort during this time of significant disruption.

Participants without immediate family support recognised the vital role that friends played while they were inpatients, as there was a need to maintain their lives outside the hospital setting. This took the form not only of practical support but also of a sudden transfer of trust to friends who had never been placed in this role. The following quote illustrates this unexpected dependence and the need to place a high level of trust in someone quickly.

> *'Now, he has got the keys to the house, so he has been moving the car to the house from the airfield, putting the shopping in, cleaning up. He even managed to pay a bill on my magic box here. No, he has done a good job, but the other ones, like (friend's name) here, they all want to be helpful in their own way, but, using a pair of blinkers, I'd really only want to talk to (friend's name), because I know he'll get things done, never want anything. I can close my eyes and say, "Go to the wooden desk, middle drawer. You'll find my razor in there", and he'd do it. It's simple things like that, but he knows his way around now.' (P2 L63)*

For participants with families, it was important that family members were involved in conversations with healthcare professionals for the reasons discussed above, as moving forward depended heavily on their support.

> *'Oh, we have, like, the family, and I've had discussions about this. I realise that in my present condition, I cannot go home. I'm going to need help and support.' (P8 L169)*

Participants who were parents said that this status gave them a reason to fight in order to stay alive for their children, to be there for even their adult children.

> *'I'm not fighting for me. I'm fighting for me to stay here with them.' (P5 L97)*

> *'I, kind of, went into a joke mode. What happened at the same time, because I'm sat with my two beautiful girls, it sounds really weird, but I wasn't concerned about me.' (P7 L82/83)*

Participants often described how this experience had brought their loved ones more closely together, and that this had helped them as they knew their family was there to support them. The following quote demonstrates how important it was for participants to have regular contact with family and how this diagnosis had made them reflect on the importance of having family and friends.

> *'Yeah, bringing the family back together. But they're ringing me. They'll WhatsApp me, and they're ringing me. You know, I'm not short of calls or texts or messages.' (P6 L473)*

As some participants' roles within their families had changed due to their condition, they considered it a priority to maintain close connections and make shared decisions about the future. Their motivation to keep living was from a desire to continue supporting their loved ones, even if in a new or adapted role. For inpatients, especially, separation from family was emotionally difficult and increased feelings of loneliness during this significant life change. Study participants who had families had a strong emotional need to be with them, while those who were single had a strong desire to be with friends to bring a sense of purpose and normality. Participants wanted healthcare professionals to recognise the importance of involving families and friends in holistic care planning, and this was essential to support participants' emotional well-being.

In summary, the emotional consequences of this dual diagnosis were profound, as participants navigated a period of waiting in limbo that brought uncertainty, while trying to maintain hope and positivity and relying on the support of family and friends. These emotional responses were shaped by these sudden life changes, loss of independence, and an urgent need to adapt. The category highlights the importance of connection and clear communication and of addressing a person's holistic needs in order to support them in finding meaning and emotional reassurance and regaining control in the face of this rapidly changing situation.

The evolving experiences of people who are diagnosed with metastatic spinal cord compression alongside a previously unsuspected advanced cancer form a complex process that encompasses physical, functional, and emotional experience. Their experience develops through three interconnected categories: “Making sense of the bodily changes and disruption to normal life”, “Focusing on living life for longer”, and “Emotional consequences of a dual diagnosis”.

In the initial phase, which is named “making sense of the bodily changes and disruption to normal life” (category 1), people begin to grapple with unexpected bodily changes and disruptions to their daily lives. As symptoms emerge and increase, they are moved into a period of uncertainty, in which they try to seek answers and navigate health systems, and they face frustration and desperation due to delays, challenges with communication, and being heard.

Next, “focusing on living for longer” (category 2) represents the point at which participants shift their focus towards adapting and actively pursuing ways to live meaningfully with this new, life-limiting, dual diagnosis. This involves managing physical limitations, seeking cancer treatment, understanding complex information, and holding on to the wish to live as long as possible. This phase highlights the resilience and determination of people in this position to maintain control and purpose in the face of uncertainty.

Woven through these phases are the issues in category 3 “emotional consequences of a dual diagnosis”, in which participants describe the emotional toll on not only themselves but also those around them. Their sudden shift from health to serious illness forces immediate physical, functional, and emotional adjustments, often without time to process. During this turbulent time, participants try to maintain hope and positivity and rely on family and friends to support them while they wait in limbo.

Together, these categories form an interconnected model of the experience that illustrates how participants navigate adaptation and emotional negotiation. This period is about recognising that a return to their former life is no longer possible. Instead, their focus shifts towards making sense of what has happened and connecting the meaning, significance, implications, and prognosis of both the advanced cancer diagnosis and their metastatic spinal cord compression. At this point in the analysis, these three categories formed the conceptual model representing participants experiences. While the model captured the cyclical and shifting nature of this process, deeper theoretical development required examination of how these categories related to broader conceptual ideas. Through continued constant comparison and light, reflexive engagement with the literature, a more abstract interpretive understanding began to take shape. In particular, across interviews, participants, descriptions of uncertainty, disruption, and feeling ‘in-between’ during this period of upheaval resonated strongly with the broader theoretical notion of liminality. This recognition arose from the data and did not drive earlier coding but later served as a sensitising concept that supported conceptualisation of the emerging theory at a higher analytical level.

4.3 Theory development: introducing the concept of liminality

As outlined in Chapter 3, the use of constant comparison during the data collection and analysis facilitated the development and refinement of codes and categories. In constructivist grounded theory, an emerging theory is one that develops inductively and iteratively from the data, remaining flexible and open to refinement as new insights emerge (Makri & Neely, 2021). It captures participants' experiences and meanings as they are constructed through interaction and continues to develop until theoretical saturation is reached. Throughout this process, I maintained a light link with the literature, and through this, an emerging theory began to take shape: “Navigating the liminal space of a dual diagnosis: experiencing metastatic spinal cord compression and the sudden discovery of a newly diagnosed advanced cancer”. The concept of liminality did not emerge as a category from the data but was introduced at this stage as a sensitising concept inductively recognised through participants' accounts that helped to deepen the interpretation of the transitional, uncertain, and in-between experiences described by participants.

To support the development of this emerging theory, I drew diagrams throughout the analytical process, as recommended by Charmaz (2014). Use of this visual technique, illustrated in Appendix R, helped me to map and clarify the evolving relationships between categories and subcategories and offered a blueprint of the findings. Figure 4.2 illustrates this emerging theory and visually positions liminality as an overarching interpretive space within which participants navigated the physical, functional, and emotional complexities of their dual diagnosis. This emerging theory was provisional at this stage and was further shaped after completion of the delayed literature review, using critical interpretive synthesis to increase the conceptual understanding.

Liminality is a key concept that supports the interpretation of these findings. It was originally developed by Van Gennep (1960) to describe the transitional phases through which people pass during significant life events. He termed these phases “rites of passage”. These rites involve three stages: a person cuts all ties with their previous situation; they pass through the rites of transition, in which they are “in-between” social statuses; and they go through the rites of reincorporation, in which they are reincorporated into a new social status with a new identity. In this way, people move from one state of being to another and doing so, acquire a new identity, status, and rank (Dauphin et al., 2019; McKechnie et al., 2010).

The concept of liminality captures the ambiguity and disorientation that may occur if people do not transition through these components and may be considered as being on the threshold of both old and new in an interim state of ambiguity, where they are in both the old and new spaces, linked with associated identities, social norms and practices (Dauphin et al., 2019; McKechnie et al., 2010).

The concept of liminality has been explored in the literature on cancer and other life-limiting conditions, particularly in the context of curative or palliative pathways. However, there is a gap in understanding regarding people diagnosed with metastatic spinal cord compression or other neurological life-limiting conditions (Dauphin et al., 2019; McKechnie et al., 2010).

For many who present with metastatic spinal cord compression as the first symptom of an undiagnosed advanced cancer, they face not only an uncertain prognosis but, in many cases, neurological impairment, which can bring significant and acute life changes. For some people, this transition from being an active, normal member of their community to a new identity as someone living with an uncertain future and disability can be difficult to navigate. Conceptualising this life episode in terms of liminality offers a structure from which to understand the experiences faced by people with metastatic spinal cord compression and a new advanced cancer diagnosis as they navigate this extreme life change, in which their focus is on living.

The lack of research in this area highlights the need for a deepened understanding of the particular liminal space that those affected occupy as they navigate their new physical, functional, and emotional states, their diagnosis and treatment, and the uncertainties that surround their prognosis and neurological recovery.

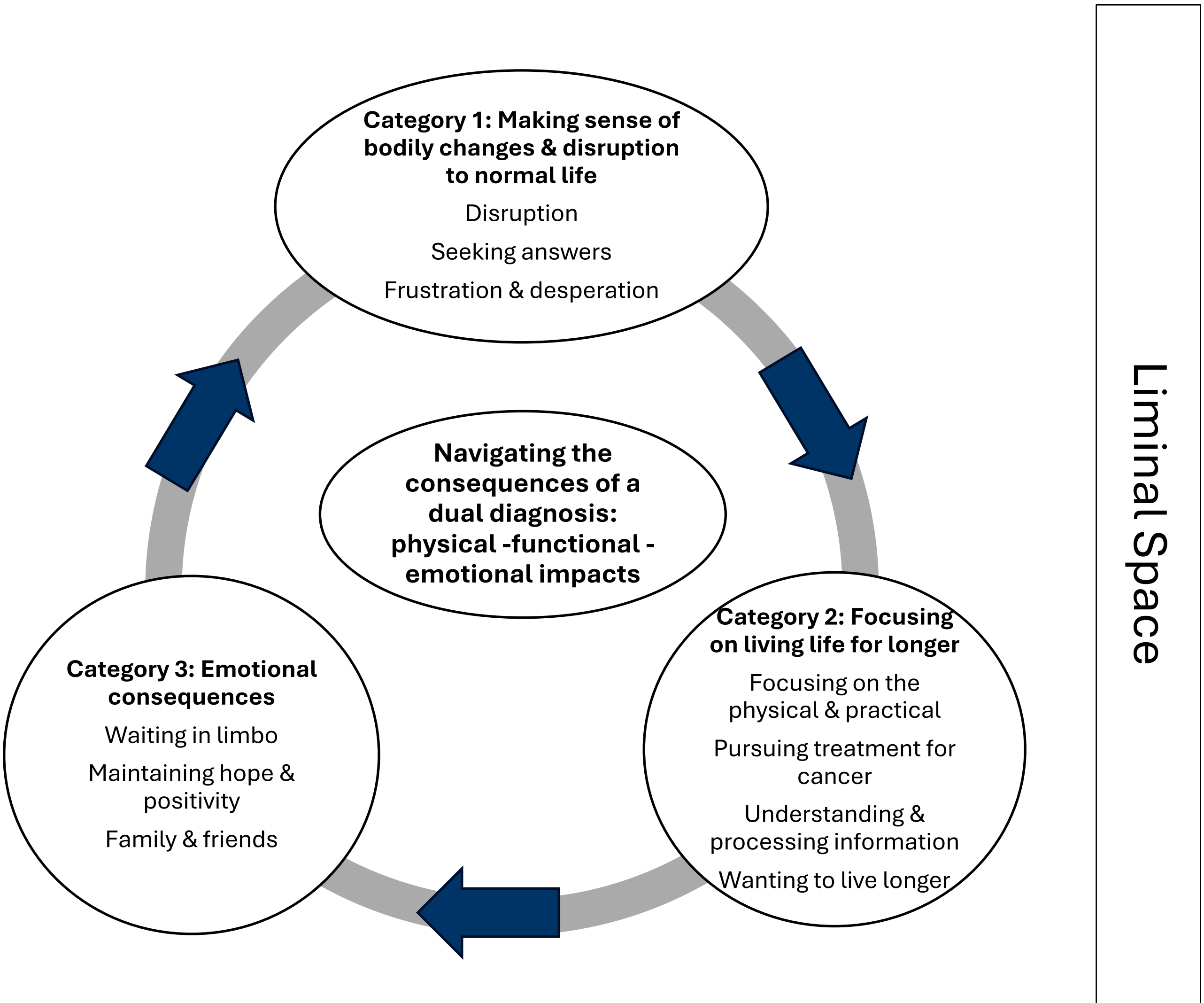

Figure 4.2: *Emerging theory:* "Navigating the Liminal Space of a Dual Diagnosis: Experiencing Metastatic Spinal Cord Compression and the Sudden Discovery of a Newly Diagnosed Advanced Cancer".

Chapter 5: Critical interpretive synthesis of the literature

In Chapter 4, I presented the initial findings of people who present with metastatic spinal cord compression as their first symptom of a previously undiagnosed advanced cancer. These findings have informed the emerging theory of "navigating the liminal space of a dual diagnosis: experiencing metastatic spinal cord compression and the sudden discovery of a newly diagnosed advanced cancer".

This emerging theory captures the transitional (liminal) space that people occupy as they confront both the immediate physical disruption of metastatic spinal cord compression and the existential impact of that and a new advanced cancer diagnosis. It highlights the interaction between clinical realities, shifting identity, and the search for meaning in the face of uncertainty.

In chapter 5, I present the delayed systematic literature review, as outlined in Chapter 3, which was performed using a critical interpretive synthesis approach. This method was chosen to align with the constructivist grounded theory methodology (Charmaz, 2014) to evaluate critically how existing literature contributes to, strengthens, or challenges the emerging theory and the three core categories described in Chapter 4.

By synthesising the relevant literature, I have positioned the study within the most relevant published research and theoretical insights and highlight how this study contributes to the wider understanding of people who present with metastatic spinal cord compression as the first symptom of a previously undiagnosed advanced cancer.

5.1 Focus of systematic literature review

Several areas for potential exploration emerged from the primary data. However, in line with the principles of constructivist grounded theory, I avoided narrowing the focus of this literature review too early, for instance by concentrating solely on how people understand and process information when they receive a diagnosis of metastatic spinal cord compression. Instead, I kept the aims broad to prevent any forcing or limiting of the emerging theory and to remain grounded in the participants' experiences.

The decision to focus the review on how people experience the transition into a new physical, functional, and emotional state when diagnosed with a life-limiting neurological cancer, particularly in relation to metastatic spinal cord compression, was directly shaped by the findings of the primary study. These findings highlighted that participants' experiences were not limited to receiving their diagnosis; rather, they involved a profound sense of disruption, a need to reorient their sense of self, and efforts to adapt rapidly, often to irreversible bodily and life changes.

Examination of how these areas are represented in the literature has provided further insight into how the dual diagnosis of metastatic spinal cord compression and a new advanced cancer creates a liminal experience. This analysis enhances understanding of the conceptual categories in the primary study, particularly those concerned with the navigation of physical, functional, and emotional consequences, and with re-evaluation of personal priorities, during this time of clinical urgency and existential uncertainty.

5.1.1 Aim of the literature review

- To identify and understand how the experiences of people with metastatic spinal cord compression compare with those who face other life-limiting neurological cancer conditions, particularly in relation to receiving a new diagnosis and transitioning to a new physical, functional, and emotional state. Through this comparison, the aim was to develop or refute the emerging theory of "Navigating the liminal space of a dual diagnosis: experiencing metastatic spinal cord compression and the sudden discovery of a newly diagnosed advanced cancer".

5.1.2 Review methods

5.1.2.1 Review question

What are the experiences of a person transitioning to a new physical, functional, and emotional status when diagnosed with a life-limiting neurological cancer?

5.1.2.2 Review design

This review of qualitative evidence employed critical interpretive synthesis, as outlined by Dixon-Woods et al. (2006), to analyse systematically and integrate the findings from qualitative studies that had explored patient experiences of life-limiting neurological cancer diagnoses only. The critical interpretive synthesis approach was chosen as it is based on constructivist epistemology, which supports multiple and context-specific interpretations of complex phenomena such as health, illness, and diagnosis. Use of this methodology also enabled the use of theoretical sampling of the literature and therefore allowed for the iterative refinement of data and the development of conceptual categories grounded in the literature (Barnett-Page & Thomas, 2009).

This chapter presents the findings of the literature review alone. In Chapter 6, I compare and integrate these findings with the primary study data, and I present and refine the emerging theory that was developed from participants' experiences.

Critical interpretive synthesis can be used to synthesise qualitative literature in order to explore the meaning and interpretations behind a person's experiences (Barnett-Page & Thomas, 2009). Although there is no hierarchy of review design or a universally accepted method for qualitative research, there is a risk that the use of traditional review methodologies may lead to the exclusion of rich data due to small mistakes made during the review, because these methodologies are limited to using a hierarchy of evidence that focuses on the weaknesses in papers (Dixon-Woods et al., 2006). The critical interpretive method, in contrast, recommends use in the early research stages of a broad purposive sampling approach to ensure the prioritisation of papers that are connected to the review area.

Dixon-Woods et al. (2006) recommend the use of a quality appraisal tool in the review to identify fatally flawed papers, thereby ensuring the overall review quality. Dixon et al. (2006) propose their own criteria, adapted from the National Health Service Electronic Library for Health's evaluation criteria for qualitative research, to provide a structured approach for assessing the methodological rigour of included studies.

Eakin and Mykhalovskiy (2003) describe the method of critical interpretive synthesis like using a compass rather than an anchor, as the needle will not settle until the review reaches the final stages. This is because the use of critical interpretive synthesis allows for modification of the review question in response to the research findings, hence allowing for flexibility with the emerging and explanatory nature of the iterative approach. Flexibility is important in constructivist research, in which knowledge is co-constructed between the researcher, participant, and the literature (Dixon-Woods et al., 2006; Mills et al., 2006). This encourages critical engagement with the literature to assist in identifying gaps or areas of bias in it and to investigate how existing theories may support, reshape, or conflict with current study findings. Employment of critical interpretive synthesis offers strong explanatory power beyond just description, enhancing the impact of the findings with their potential to inform meaningful change (Flemming, 2009). The outcome of this iterative, emerging process is the development of a new theory that offers a focused, in-depth understanding, thereby strengthening the research argument and enhancing credibility (Charmaz, 2014).

This aligns with the aim of my review, which was to develop the emerging categories that had been constructed during the initial data analysis (Tong et al., 2012). Given these strengths, it was decided that the use of critical interpretive synthesis would lead to a rich, nuanced, and theory-generating synthesis that would not only inform the findings of this study but also offer actionable recommendations for clinical practice and policy.

Other literature review methodologies, such as narrative synthesis, were considered but were rejected as unsuitable as they lacked the interpretive depth required to support the aim of this review (Tong et al., 2012). Critical interpretive synthesis was deemed better suited to constructing a new final theory to explain how people navigate the liminal space that metastatic spinal cord compression creates while trying to process a new advanced cancer diagnosis. A review that employed critical interpretive synthesis was the natural choice as it aligns with the philosophical underpinnings, accommodates qualitative literature and uses a sampling process that is designed to achieve the desired outcomes of this review (Drisko, 2019).

5.1.2.3 Literature search and selection

Few studies have focused on people who present with metastatic spinal cord compression as their first presentation of cancer. Therefore, the scope of this review was broadened to explore the experiences of people as they were diagnosed with other life-limiting neurological cancers. Identifying the appropriate focus of the review presented a challenge; consideration of various neurological conditions was considered, but it was decided to broaden the focus to people diagnosed with high-grade malignant brain tumours. This decision was made due to the similarities in how this condition presents (acutely, with neurological deficits and a life-limiting prognosis). This review, therefore, was focused on the theoretical interpretation of qualitative evidence to understand the experience of being diagnosed with a new life-limiting neurological cancer.

5.1.2.4 Search strategies

A comprehensive search was conducted across four electronic databases. MEDLINE, the Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsycINFO and Academic Search Ultimate were searched in November 2024. This combination of databases was considered optimal to enable a focused and efficient search that would ensure sufficient coverage to produce a qualitative review of this area rather than a fully comprehensive and exhaustive search intended to find every possible relevant source (Bramer et al., 2017).

A targeted search strategy was developed to identify studies on the experiences of a person transitioning to a new physical, functional, and emotional status following a diagnosis of a life-limiting neurological cancer. No date/year restrictions were applied, as I would not consider this experience as being confined to a specific time frame. Inclusion of literature from various periods allowed for a comprehensive understanding of this evolving experience over time.

In addition, citation tracking and reference-list searches were conducted on included studies and relevant systematic review papers to identify any additional studies that may not have been captured in the initial database search.

5.1.2.5 Database searches

The searches were adapted to each database. An example of the MEDLINE search strategy is illustrated in Table 5.1. Subject headings and Boolean operators were used to connect terms such as ‘metastatic spinal cord compression OR malignant spinal cord compression’, and the searches were checked and refined with a Lancaster University librarian.

Table 5.1: *Example of search terms used in the MEDLINE database*

Search terms	No. of papers retrieved from all searches
TI ((MH "brain neoplasms+") OR (MH "spinal neoplasms+" OR “Brain cancer*” OR “brain tumo*” OR “brain neoplasm*” OR “brain metastases” OR glioblastoma OR Glioma OR “intracranial tumo*” OR meningioma OR “cerebral tumo*” OR Medulloblastoma OR "primary brain neoplasm*" OR "central nervous tumour*" OR "malignant brain tumo*" OR “Spinal tumo*” OR “spinal cancer*” OR “spinal neoplasm*” OR "spinal Cord Compression" OR “metastatic spinal cord compression’ or “malignant spinal cord compression” OR “non-traumatic spinal cord injur*”) OR "Spinal Cord Compression" OR ((Terminal OR inoperable OR untreatable OR advanced OR Progressive OR "end-stage" OR "life-limiting" OR Palliative)) N5 OR AB ((MH "brain neoplasms+") OR (MH "spinal neoplasms+" OR “Brain cancer*” OR “brain tumo*” OR brain neoplasm*” OR “brain metastases” OR glioblastoma OR Glioma OR “intracranial tumo*” OR meningioma OR “cerebral tumo*” OR Medulloblastoma OR "primary brain neoplasm*" OR "central nervous system neoplasm*" OR "malignant brain tumo*" OR "central nervous tumo*" OR “Spinal tumo*” OR “spinal cancer*” OR “spinal neoplasm*” OR "spinal Cord Compression" OR “metastatic spinal	MEDLINE: 235,568 CINAHL: 26,978 PsycINFO: 4,598 Academic Search Ultimate: 42,604

cord compression' or "malignant spinal cord compression" OR "Spinal Cord Compression" OR ((Terminal OR inoperable OR untreatable OR advanced OR Progressive OR "end-stage" OR "life-limiting" OR Palliative)) N5	
TI ((MH "Life Change Events") OR (MH "Change Management") OR (MH "Adaptation, Psychological+") OR (MH "Social Adjustment") OR (MH "Emotional Adjustment+")) OR "recent* diagnos*" OR diagnos* OR (((transition* OR chang* OR adjust OR impairment OR limitation OR adapt* OR Symptom*) N5 (physical* OR mobility OR body OR function* OR disability)) OR "sense-making" OR "Making Sense" OR "coping" OR "well-being" OR "Quality of Life" OR "inbetween" OR in-between" OR betwixt OR "embodied experience*" OR Liminality OR "Liminal space"* OR "rites of passage")) OR AB ((MH "Life Change Events") OR (MH "Change Management") OR (MH "Adaptation, Psychological+") OR (MH "Social Adjustment") OR (MH "Emotional Adjustment+")) OR "recent* diagnos* OR diagnos* OR (((transition* OR chang* OR adjust OR impairment OR limitation OR adapt* OR Symptom*) N5 (physical* OR mobility OR body OR function* OR disability)) OR "sense-making" OR "Making Sense" OR "coping" OR "well-being" OR "Quality of Life" OR "inbetween" OR in-between" OR betwixt OR "embodied experience*" OR Liminality OR "Liminal space"* OR "rites of passage"))	MEDLINE: 7,506,258 CINAHL: 1,691,509 PsycINFO: 863,973 Academic Search Ultimate: 3,047,855
(MH "Qualitative Research+") OR (qualitative OR interview* OR "focus group*" OR ((experience* OR View* OR Perception*) N5 (patient OR user OR inpatient OR outpatient)) Or construction*) OR (qualitative OR interview* OR "focus group*" OR ((experience* OR View* OR Perception*) N5 (patient OR user OR inpatient OR outpatient OR Primary Care OR Community Care)) Or construction*	MEDLINE: 1,298,330 CINAHL: 642,613 PsycINFO: 834,574 Academic Search Ultimate: 2,552,033
1 AND 2 AND 3. This encompasses all three concepts on the experiences of a person transitioning to a new physical, functional and emotional status when diagnosed with a life-limiting neurological cancer	MEDLINE: 3896 CINAHL: 785 PsycINFO:260

	Academic Search Ultimate: 941 Total: 5882 Duplicates removed: 4432

5.1.2.6 Selection criteria

5.1.2.7 Literature inclusion and exclusion criteria

The criteria for inclusion or exclusion of studies in this review are outlined in Table 5.2.

Table 5.2: *Literature inclusion and exclusion criteria*

Inclusion criteria	Exclusion criteria
○ Qualitative studies ○ Focused on the experience of being diagnosed with a neurological cancer that includes spinal tumours (primary or metastatic) and brain tumours (primary or metastatic) ○ Focused on people’s experiences of transitioning to a new physical, functional and emotional state while coping with an advanced neurological cancer diagnosis ○ Studies of adults aged 18 years and older ○ Any healthcare setting (community, primary or hospital care) ○ Full text available in English ○ Any date/year of publication	○ Not empirical research ○ Newspaper, online, editorial or non-peer-reviewed articles ○ Studies focused on non-life-threatening illness ○ All paediatric or young adult populations (under the age of 25 years) ○ Studies related to families, caregivers or health professionals’ experiences

5.2 Data extraction and analysis

5.2.1 Identification and selection of studies

Titles and abstracts were scanned to see whether they potentially met the inclusion and exclusion criteria (Table 5.2). Any discrepancies were discussed, and then we decided whether or not to include the paper in the full-text review. I screened all papers, and 28% were blind screened by two other reviewers (reviewer 1 = 21% and reviewer 2 = 7%, same papers) in order to enhance rigour by minimising bias, increasing transparency, enhancing reliability, ensuring comprehensive coverage and improving validity of the review.

5.2.2 Data collection and analysis

Once papers were confirmed as meeting the inclusion criteria, each full-text paper was read multiple times to ensure a thorough understanding.

Data analysis followed the approach recommended by Dixon-Woods et al. (2006), intending to produce a synthesised argument, similar to the analysis of the primary study data. As noted by Dixon et al. (2006), full transparency in qualitative synthesis is limited due to the interpretive and creative nature of the process.

I coded the findings and discussion sections of all papers, using the evolving conceptual model to guide the analysis. Only data related to patients' experiences were extracted, as the focus of both the primary study and this qualitative synthesis review was not on the perspectives of carers or healthcare professionals. The relevant data was compiled into a table to support cross-study comparison. This table included key study details: author, year of publication, country in which the study was performed, research question or aim, participant details, methods of data collection and analysis, relevant categories and key findings relevant to the aim of the qualitative systematic review.

The coding process was iterative; each paper was coded individually before I moved to the next. This was consistent with the constant comparative method, allowing for continuous refinement of categories and theoretical insight. The coding outcomes were regularly reviewed and discussed with my research supervisors to ensure rigour and reflexivity. A range of tools was used during data extraction, including memoing, tables to assist with code sorting, and diagramming to assist with my thought processes when constructing categories. The iterative and reflexive process of critical interpretive synthesis used can be seen in Figure 5.1.

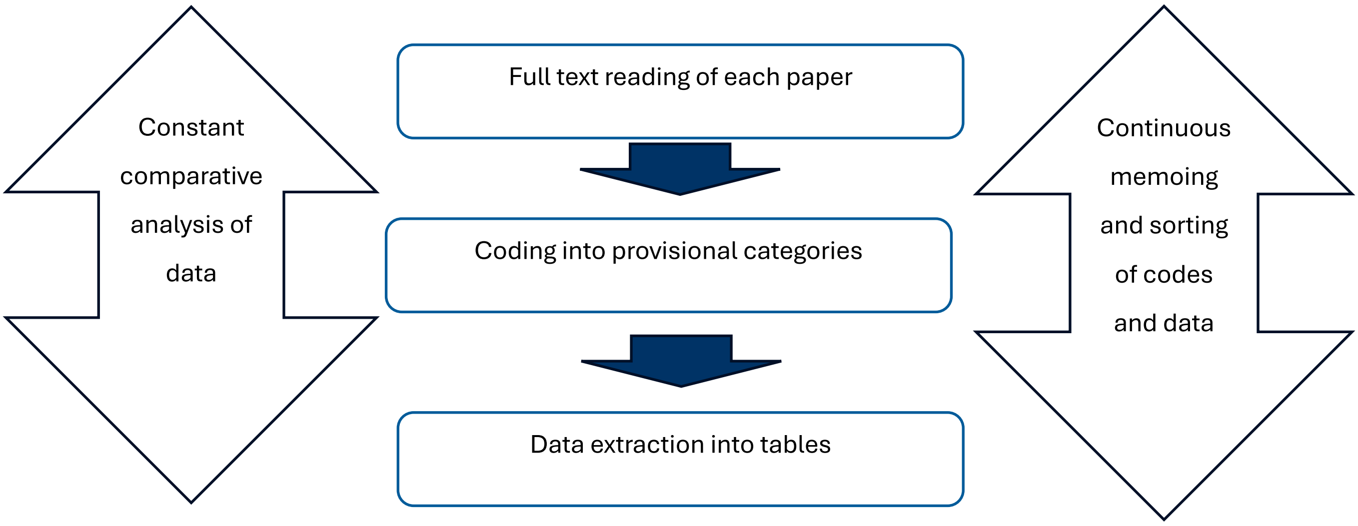

Figure 5.1: *The iterative and reflexive process of critical interpretive synthesis.*

5.2.3 Results of the review

The preferred reporting items for systematic reviews and meta-analyses (PRISMA) flow diagram of study selection is shown in Figure 5.2 (Page et al., 2021). It illustrates the selection process. Database searches returned 5882 papers, and these were uploaded to the Rayyan systematic literature review software tool, where 1450 duplicate papers were removed, so 4432 papers were screened. A total of 4,418 papers were excluded for not meeting the inclusion and exclusion criteria leaving 16 papers for final review.

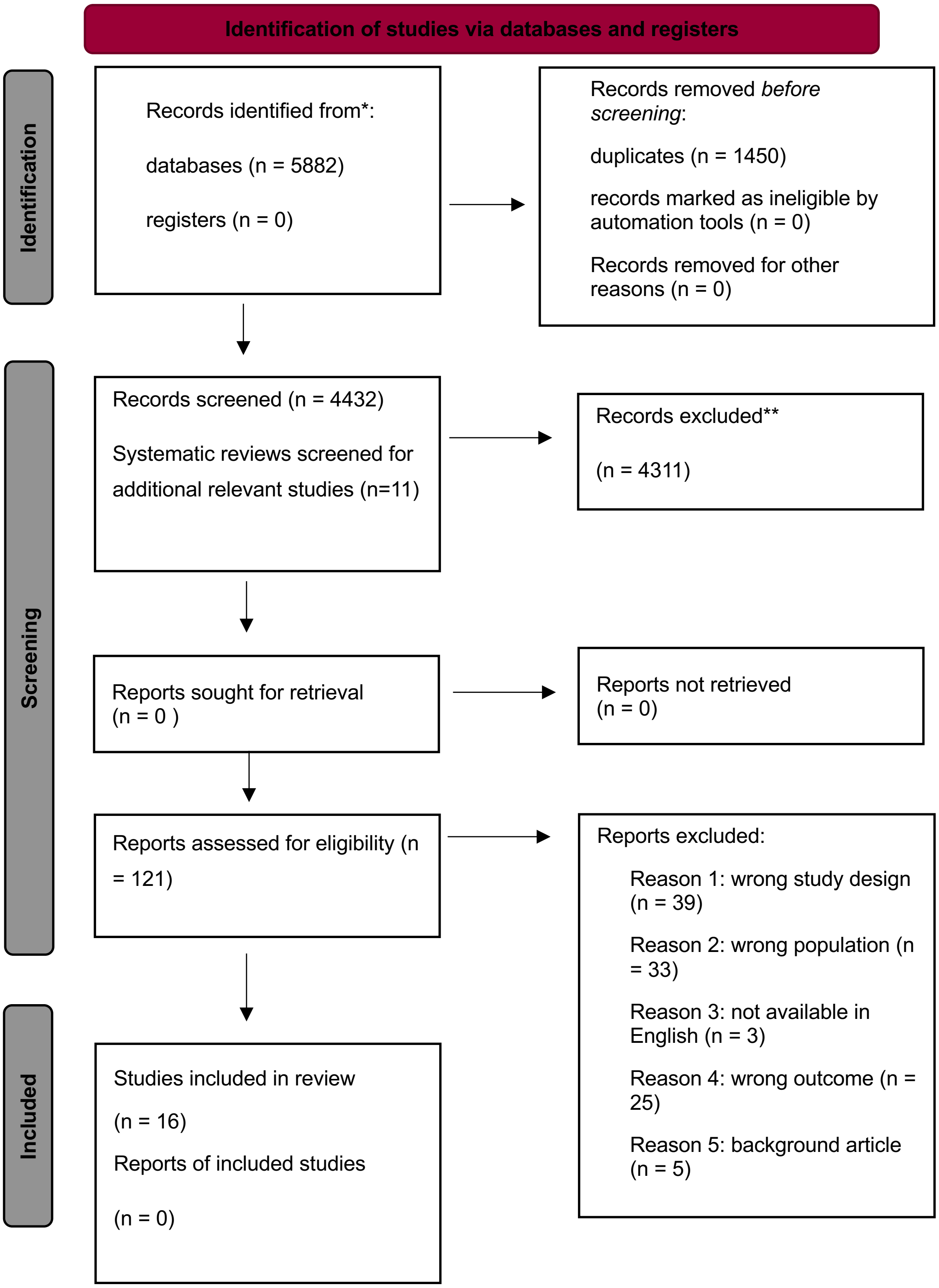

Figure 5.2: *PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only (Page et al., 2021).*

5.2.4 Assessment of quality

The 16 included papers were assessed for quality using the critical quality appraisal criteria proposed by Dixon et al. (2006), which can be seen in Table 5.3. The aim was to eliminate papers with “fatal flaws” and to identify whether they had conceptual relevance. As discussed earlier, Dixon-Woods et al. (2006) proposed this flexible appraisal approach for qualitative research and emphasise that the reviewer should consider how well the study contributes to the research question and the methodological robustness of the study rather than using rigid checklists. They recommend an assessment that uses a “yes” or “no” judgement rather than a rigid quality scoring system.

Table 5.3: *Quality appraisal criteria recommended by Dixon-Woods et al. (2006) for use in critical interpretive synthesis.*

Quality appraisal criteria: appraisal prompts for informing judgements about the quality of papers
○ Are the aims and objectives of the research clearly stated? (Yes or No) ○ Is the research design clearly specified and appropriate for the aims and objectives of the research? (Yes or No) ○ Do the researchers provide a clear account of the process by which their findings were reproduced? (Yes or No) ○ Do the researchers display enough data to support their interpretations and conclusions? (Yes or No) ○ Is the method of analysis appropriate and adequately explicated? (Yes or No)

Following quality assessment (Appendix S), relevant data were extracted. A summary of this data can be seen in Appendix T, which includes authors, publication year, study title, critical interpretative synthesis criteria, characteristics of study participants, time point of study, methods of data collection and analysis, titles of categories and subcategories (as applicable), and a summary of the key findings that were relevant to the aim of the literature review.

5.3 Synthesis of findings

5.3.1.1 Summary of included studies

Of the 16 studies included, four had explored the experiences of participants diagnosed with metastatic spinal cord compression. Most of these participants had been diagnosed with previous primary cancers, and only one had a malignancy of unknown origin. All had received only radiotherapy as their treatment for metastatic spinal cord compression. The other 12 papers included participants with high-grade brain tumours, which showed similarities in terms of sudden presentation, related neurological symptoms and life-limiting prognoses. Time points for studies ranged from participants being newly diagnosed up to a year after diagnosis. Four studies included interviews with patients, carers and healthcare professionals, but data for this review were extracted regarding only patient experiences. The studies had been conducted in the UK (eight), Denmark (four), Belgium (two) and Australia (two). A summary of the coding process from this qualitative synthesis review can be found in Appendix U.

5.3.2 Synthesised findings

As stated, most of the studies that were focused on metastatic spinal cord compression included participants with existing primary cancer diagnosis. These studies were primarily focused on participants' experiences of developing metastatic spinal cord compression and the strategies they used to cope with their sudden physical and functional deterioration. In contrast, the studies that included participants with brain-tumours typically centred on people receiving a new, life limiting cancer diagnosis who had a clear primary diagnosis at presentation. While the authors acknowledged the physical and functional impacts that the new diagnosis caused, these were discussed to a lesser extent than in those studies specifically focused on metastatic spinal cord compression.

Through critical interpretive analysis, four categories were developed to describe the experiences of people transitioning to a new physical, functional and emotional status after a diagnosis of a life-limiting neurological cancer. These were: (1) the “emotional impact of dual diagnosis”; (2) “competing priorities:

immediate urgency vs. the future"; (3) "adjusting to a new physical and functional reality"; and (4) "the perception and processing of information about diagnosis and prognosis". The categories were constructed through the employment of the strategies recommended by Dixon-Woods et al. (2006): key concepts were identified, these were translated into one another, and judgements were made about the key characteristics of each concept to ensure the most appropriate representation. This process also involved explaining potential contradictions within the literature and rebuilding a general interpretation that was grounded in the findings of the individual studies. This approach ensured that the most powerful categories were identified to represent the full scope of the studies through constant comparative analysis across all the studies included in the review.

5.3.3 Emotional impact of dual diagnosis

The constructed category of "emotional impact of dual diagnosis" was developed from how participants often experienced emotional turmoil following their diagnosis. Participants commonly felt emotionally overwhelmed, distressed, sad, and anxious about their sudden physical, functional and health decline, and feared the loss of their independence and identity (Warnock & Tod, 2014). Participants described their emotional distress peaking during the treatment phase due to the sudden life-threatening diagnosis, fear of surgery and progressing dependence on others, which would affect the quality of their lives (Vedelø et al., 2024).

Although it was reported that they did not dwell on their incurable cancer diagnosis, they had a heightened awareness of their mortality (Begley et al., 2014; Molassiotis et al., 2014). Despite fear of death and the distress caused by their new diagnoses, Molassiotis et al. (2010) observed that participants had a renewed desire to live, and they focused on life opportunities after their incurable diagnosis. Some perceived treatment as important for survival and to improve their health (Nyatanga et al., 2024). Participants shared that they were constantly shifting between having hope of returning to normal and the frightening reality of an unexpected death (Vedelø et al., 2018). Although they recognised that their disease was incurable, they found that they were not ready for the involvement of palliative care services and perceived such involvement as a loss of hope (Halkett et al., 2010).

Begley et al. (2014) described how, during this time, participants were trying to make sense of their situation and to find meaning in what lay ahead. They often used emotion-focused coping strategies to create distance from the disease. They did not want to live lives that were near death, so they focused on what they could control, particularly the physical and functional aspects of their new situations (Lobb et al., 2011; Sterckx et al., 2015). Participants sought coping mechanisms to prevent loss of their aspirations and to focus on how they wanted to live their lives (Begley et al., 2014; Nyatanga et al., 2024). These study participants were living in the moment, day by day, trying to manage the uncertainty of incurable cancer and physical life changes, while wanting to prioritise their time with whom and where they most wanted to be, which was with family at home (Begley et al., 2014; Manson et al., 2017; Warnock & Tod, 2014).

During this time, participants described a feeling of emotional isolation, especially during hospital stays, due to their urgent presentation. They felt that they needed more connection and support from family and friends (Warnock & Tod, 2014). However, the researchers identified that emotional needs often went unmet because participants sometimes did not voice their fears and anxieties (Vedelø et al., 2024). Piil et al. (2015) recognised that during this highly emotive time, there was a need for relational activity. This was because there was a need to support participants in finding a balance between having hope of a physical and functional recovery, while grappling with the fear and reality of shortened and uncertain life expectancy. This emphasised the need for healthcare professionals to try to provide ‘universal togetherness’ that recognised care as a relational practice and as a demanding emotional interaction (Vedelø et al., 2018).

Family and friends and their involvement were central in supporting participants, especially during the acute hospital phase. Maintaining contact and relationships was important for helping participants feel more complete and preserve a sense of normality (Lobb et al., 2011; Nixon & Narayanasamy, 2010; Nyatanga et al., 2024;

Sterckx et al., 2015). Family members helped participants to navigate complex information, provided emotional support and were instrumental in care decisions (Begley et al., 2014; Eva et al., 2008; Nyatanga et al., 2024). Participants often relied on their families to help them prepare for discharge and to manage the practical aspects of returning home (Begley et al., 2014; Eva et al., 2008). This reliance on family was particularly evident in cases in which external support systems (e.g. community services) were lacking (Begley et al., 2014; Eva et al., 2008). Family-centred care was emphasised, with the understanding that families are crucial to the care process and should be involved in decision-making, rather than staff adopting a one-size-fits-all approach (Nyatanga et al., 2024).

In summary, the category of "emotional impact" included the new reality of starting to live with an incurable cancer diagnosis. Participants described experiencing emotional turmoil, distress, sadness and fear, especially during the treatment phase, and they sought coping mechanisms to avoid losing their aspirations for living and to retain focus on how they wanted to live. There was a constant tension between hope for recovery and fear of death, with many avoiding palliative care due to its association with giving up hope. They used emotion-focused coping and distanced themselves from their disease by focusing on their physical and functional needs as a way of trying to manage their new realities. Another challenge was emotional isolation, particularly during hospital stays; people often did not voice their fears, and this led to unmet emotional needs. This emphasises the importance of relational support from healthcare professionals, with the need for "universal togetherness" in care. The literature highlights the importance of family-centred care and states that care should be tailored to the person rather than staff relying on a one-size-fits-all approach.

5.3.4 Competing priorities: immediate urgency vs. the future

The constructed category of "competing priorities: Immediate urgency vs. the future" refers to the disconnection that happens as healthcare professionals focus on the urgency of the neurological event and the prioritisation of treatment plans while participants are trying to make sense of the loss of mobility and function, their life-limiting diagnosis and how this will impact on their lives. Participants described being in a state of chaos and crisis and going through a fast transition into an unknown journey with no time to adjust as they experienced this physical, functional life-changing event (Halkett et al., 2010; Vedelø et al., 2018).

The literature referred to treatment in the form of surgery, systemic anti-cancer therapy and/or radiotherapy, which was initiated for participants with brain tumours, whereas participants with metastatic spinal cord compression were treated with radiotherapy alone. None of the studies included people with metastatic spinal cord compression who had received spinal surgery or systemic anti-cancer therapy. None of the studies shared the experiences of people with either a brain tumour or metastatic spinal cord compression diagnosis for whom treatment was not an option. These studies highlighted that, because treatment was often initiated as an emergency to avoid further neurological deterioration, there was limited time for people and their loved ones to process the new life-limiting cancer diagnosis or the treatment options (Lobb et al., 2011). This aligns with the demands of urgent care pathways, in which the timing of treatment delivery is considered the dominant quality measure. As a result, a person's consultation at this time is often focused on the clinical urgency rather than on addressing their holistic wishes or preferences (Vedelø et al., 2018). While this approach ensures timely intervention, it can overlook the person's broader concerns during this period of crisis and uncertainty (Vedelø et al., 2018).

Participants with brain tumours recognised that they were dealing with biological, physical and psychological factors (Nixon & Narayanasamy, 2010). Lobb et al. (2011), Sterckx et al. (2015), and Vedelø et al. (2018) described that due to the abruptness of their diagnosis, many participants felt that their mild symptoms did not fit with the seriousness of a having a life-limiting brain tumour, and that this situation made the experience surreal. In contrast, participants diagnosed with metastatic spinal cord compression were primarily concerned with their sudden loss of mobility and the uncertainty around their future (Warnock & Tod, 2014). Across both groups, the unique interplay of physical, emotional, and social impacts that distinguishes these conditions from other cancers was emphasised in the studies (Eva et al., 2008; Manson et al., 2017; Nixon & Narayanasmy, 2010; Nyatanga et al., 2024; Warnock & Tod, 2014).

After their initial shock, participants became more focused on regaining a sense of normality, wanting to return home to a familiar environment and to be with family. Participants prioritised this as a way of starting to regain control over their physical and emotional states through therapies. Hammill et al. (2018) found that many participants with brain tumours felt that inpatient therapy fell short of meeting their broader needs, as it was focused on their immediate, basic self-care needs after urgent treatment. As a result, the broader physical and functional challenges of how to continue to live life were often not anticipated during their inpatient stays and were unsupported once they returned home because there was a lack of community services. This situation compromised their transition forward. This finding was also reported by Manson et al. (2017) regarding people being discharged after their diagnosis of metastatic spinal cord compression.

To summarise, the category of “competing priorities: immediate urgency vs. the future” as synthesised in the review highlights the disconnection between healthcare professionals prioritising the urgent medical management of the persons’ conditions as the person’s struggle to process their new life-limiting diagnosis. This includes diagnoses such as brain tumours or metastatic spinal cord compression, which bring significant physical, emotional, psychological, existential and social impacts. What was highlighted by the review was the lack of studies of the experiences of people for whom there were no treatment options available, the prioritisation of medical intervention over holistic care and the low availability of community support after treatment. This synthesis brings recognition that there is a need for better integration of physical, functional and emotional support after discharge, in order to ensure a smooth transition from hospital to home and to improve this experience. There is a need to work towards the achievement of a balance between the need to kickstart urgent treatment while addressing the broader needs of the person and their concerns and increasing multidisciplinary care.

5.3.5 Adjusting to a new physical and functional reality

The category of "adjusting to a new physical and functional reality" was constructed from the participants' descriptions of experiences of rapid and often severe loss of mobility, physical identity, and independence. These changes left them feeling vulnerable, powerless and having lost some control (Halkett et al., 2010; Nixon & Narayanasamy, 2010; Vedelø et al., 2018). People with these diagnoses are at the start of a transition into a rapid journey to the unknown (Vedelø et al., 2024). A major concern expressed by the study participants was how they would return to the normality of living their pre-diagnosis life, given their loss and the new challenges they were facing physically and functionally (Vedelø et al., 2024). Adjustment to their physical limitations was particularly difficult in the hospital setting, where the focus was often on acute treatment rather than rehabilitation or supportive care (Fahrenholtz et al., 2019; Manson et al., 2017; Piil et al., 2015; Warnock & Tod, 2014). Participants felt that this new physical deterioration was the reason why they had put their lives on hold (Vedelø et al., 2024). Mentally, participants were moving back in time to the past, returning to the present and then looking to the near future as a vehicle to help them cope and to adjust to their sudden physical and functional changes (Manson et al., 2017).

Participants acknowledged the distress, sadness and anxiety of what was happening (Nixon & Narayanasamy, 2010; Nyatanga et al., 2024; Vedelø et al., 2018; Warnock & Tod, 2014). They recognised that there were, in the words of one study participant, '*a lot of things I can't do anymore*', due to the adverse effects of the tumour (Lobb et al., 2011). The loss of their routines and activities they valued was a particular challenge (Halkett et al., 2010; Lobb et al., 2011; Manson et al., 2017). They tried to make sense of this altered and now unpredictable body, and they explored ways to adjust (Eva et al., 2008).

Participants exhibited resilience by taking active, problem-solving approaches, trying to improve their mobility and functional independence with the hope of restoring normality, routine and identity; not allowing the disease to take over (Eva et al., 2008; Lobb et al., 2011; Warnock & Tod, 2014). Participants recognised the need to remain adaptable to their physical and functional adjustment and to develop self-management skills to restore control (Eva et al., 2008). They viewed this as an ongoing process that involved starting to act and plan. Warnock and Tod (2014) found that, for participants with spinal cord compression, this was an important coping strategy. They recommended that healthcare professionals support these efforts and help to shape the priorities of people's care.

At the immediate point of their diagnosis, Lee (2013) described participants as developing their own 'battle plans' to continue living, which included reflecting on their past abilities as coping mechanisms. As they explored their new physical and functional boundaries, they worked to re-order and restructure by setting short- and long-term goals to support the adjustment process (Eva et al., 2008; Warnock & Tod, 2014). The participants in the studies used goals to try to return to 'normal' and to re-establish control and independence. They sought to plan ahead and look towards the future, for instance by planning holidays and challenging activities, with the hope of living for some time (Manson et al., 2017). Lobb et al. (2011) and Warnock and Tod (2014) identified that such goals were often unrealistic and that participants would often need to revise their expectations downwards in order not to disconfirm normality (Eva et al., 2008). By using this goal-setting approach, particularly through physical therapy and rehabilitation, participants gained a sense of purpose, drive, and strength that improved their psychological well-being; they felt organised, more accepting of their new limitations as they found ways to manage, which gave them hope of living, while ensuring that goals were realistic (Begley et al., 2014; Eva et al., 2008; Sterckx et al., 2015).

In all, the category "adjusting to a new physical and functional reality" revealed the profound impact of the rapid physical decline and loss of independence that study participants faced with a neurological life-limiting diagnosis. Participants struggled to adjust to their new physical limitations, particularly in the hospital setting where acute treatment took priority over rehabilitation. Despite this, many participants demonstrated resilience by setting goals to regain control, improve their mobility, and return to a sense of normality. However, the synthesis highlights that these goals were often unrealistic and required adjustment. In these situations, healthcare professionals play a crucial role in helping people to balance hope with acceptance, providing holistic care and supporting people to develop psychological resilience and set realistic goals. The findings emphasise the need for a more integrated approach to care, one that fosters active collaboration between the person, their family or friends and healthcare professionals. Such an approach is essential to address effectively the physical, emotional, and social support needs of people who are diagnosed with life-limiting neurological cancers.

5.3.6 The perception and processing of information about diagnosis and prognosis

Data within the category illustrated how participants perceived and processed the information they received. As participants transitioned rapidly into their unknown journeys, undergoing sudden changes while navigating this overwhelming experience, they often found themselves confused with the pathway processes (Vedelø et al., 2018, 2024). Within this context, the way in which information was communicated played an important role in shaping their understanding of what was happening.

Study participants said that the involvement of multiple healthcare providers in their treatment often led to fragmented care. This fragmentation resulted in the provision of deteriorated or distorted information, and this issue created communication barriers that left participants feeling frustrated, abandoned, vulnerable and misunderstood (Vedelø et al., 2018, 2024). This worsened an already difficult communication situation. Participants were highly stressed after a sudden and significant shock, which hindered their ability to process and remember the information they were receiving from healthcare professionals (Halkett et al., 2010; Lobb et al., 2011). Halkett et al. (2010), Lobb et al. (2011) and Pill et al. (2015) all recognised that the information provided about diagnosis and prognosis shocked the recipients and needed to be delivered at a pace to suit each person and personalised to their case, their preferences and the level of information that they wanted and could absorb. Study authors recommended that diagnostic and prognostic information should be delivered by a senior clinician with acceptable communication skills and the expertise of diagnosis and likely prognostic outcome (Lobb et al., 2011; Molassiotis, 2010). If the information was not delivered in this way, amid all the changes that had to take be taken in, the study participants misunderstood the terminal nature of their diagnosis, their prognosis and treatment goals, and expectations of what would happen next (Halkett et al., 2010; Lobb et al., 2011; Molassiotis et al., 2010).

If participants were unable to determine the meaning of their illness, they found it hard to develop adaptive coping strategies. Participants felt that healthcare professionals should understand the impact of uncertainty in a sudden life crisis and consider carefully the timing of when and how much information about diagnosis and prognosis was given (Halkett et al., 2010; Lobb et al., 2011; Molassiotis et al., 2010; Nyatanga et al., 2024; Piil et al., 2015; Vedelø et al., 2018). By proactively asking questions to identify a person's particular needs and wishes, it was felt that healthcare professionals could better tailor information delivery in a way that aligned with the person's self-preservation strategies (Eva et al., 2008; Vedelø et al., 2018). Although participants expressed a wish to be involved in their care, they wanted to receive information in a positive way, even when faced with a life-limiting diagnosis and uncertain physical improvement. This is a challenging demand of professionals as they try to combine hope with honesty during communication of a new life-limiting neurological cancer diagnosis (Piil et al., 2015; Warnock & Tod, 2014).

It was important that healthcare professionals consider the mode of information transfer as participants struggled to remember, and they should recognise a person's vulnerability with this aspect at this point in their experience (Nyatanga et al., 2024; Vedelø et al., 2024). At times, participants were responsible for seeking out additional information or retaining what they had been told, particularly when trying to explain their situation to family members while in hospital (Halkett et al., 2010; Vedelø et al., 2024). Some authors suggested that information should be delivered via proactive channels and tools that provide timely, tailored and consistent content. This information should be communicated collaboratively to support discussions around life changes, diagnosis, prognosis and fears, and to prepare the person for these challenges (Molassiotis et al., 2010; Piil et al., 2015;

Sterckx et al., 2015). It was recognised that people would benefit from having access to information given by professionals with the appropriate specialist knowledge and skills and continuity of access to these same professionals (Halkett et al., 2010; Hammill et al., 2018; Lobb et al., 2011; Sterckx et al., 2015; Vedelø et al., 2018, 2024).

In summary, the category "perception and processing of information about diagnosis and prognosis" highlighted how study participants with neurological life-limiting diagnoses struggled to process and understand the information that healthcare professionals provided. Key issues were identified, which included fragmented communication, during which people received inconsistent and often unclear information, leading to frustration and confusion. The emotional shock of the new diagnosis impairs a person's ability to retain and process information, and this highlights the need for personalised communication that considers the person's preferences and cognitive state. The synthesis identified the need to deliver information effectively that is proactive and tailored to the person's needs, that is communicated clearly, is consistent and empathetic. In addition, people benefit from having continuity in their care and access to specialists who can provide consistent and understandable information throughout their journeys. This synthesis emphasises the importance of personalised, ongoing communication to support individuals to cope and make informed choices about their care.

5.4 Discussion of the review

The critical synthesis of the literature is intended to increase our understanding of how people experience the transition to a new physical, functional, and emotional state following a life-limiting neurological cancer diagnosis. By comparing these experiences with those of people with metastatic spinal cord compression, the review seeks to refine or refute the emerging theory of: "Navigating the liminal space of a dual diagnosis: experiencing metastatic spinal cord compression and the sudden discovery of a newly diagnosed advanced cancer".

In summary, this critical synthesis, which was undertaken using the approach recommended by Dixon-Woods et al. (2006), highlights the complex and multidimensional experiences of people diagnosed with life-limiting neurological cancers such as metastatic spinal cord compression or a high-grade brain tumour. Four interrelated categories were identified: (1) “emotional impact of diagnosis”, (2) “competing priorities: immediate urgency vs. the future”, (3) “adjusting to a new physical and functional reality” and (4) “the perception and processing of information about diagnosis and prognosis”. These categories were constructed from a comprehensive comparison of published studies and address the multifaceted aspects of this experience, highlighting the similarities within the literature.

Together, these categories reflect the emotional distress, sudden loss of independence, conflict between the hope of recovery and the inevitable reality of their illness, and fragmented care pathways that shape the early stages of experiencing such a diagnosis. The findings highlight the need for holistic, person-centred care that integrates physical, functional and emotional support, while prioritising clear, compassionate communication. These insights contribute to the emerging theory of understanding of how people navigate the liminal space that is created by sudden neurological decline and a new life-limiting cancer diagnosis.

Overall, there is a clear need for better integration of physical, functional, psychological and emotional support through personalised care that balances medical urgency with the broader human experience. Improving how people transition through these challenges requires a healthcare response that is not only clinically effective but also emotionally and socially responsive. This qualitative review synthesis highlights key areas for future research, including the roles of multidisciplinary and community-based care after acute treatment, as well as the development strategies required to enhance communication and address existential concerns. Application of a more comprehensive and compassionate approach than occurs currently will better equip healthcare professionals to support people facing the profound disruption of a life-limiting neurological cancer diagnosis.

5.5 Strengths and limitations of the review

Using a critical interpretive synthesis approach has been valuable to understand the experiences of a person transitioning to a new physical, functional and emotional status when diagnosed with a life-limiting neurological cancer. The following sections consider the strengths and limitations of this method

5.5.1 Strengths of the review

One of the key strengths of this review was the use of critical interpretive synthesis, which enabled the integration of multiple perspectives to provide a comprehensive understanding of the subject. Use of this method allowed for an in-depth exploration of qualitative data and placed the emphasis on the subjective experiences of the affected people themselves. Such depth was crucial in understanding how people in this situation began to cope with and adapt to the profound transition brought on by this new diagnosis.

Importantly, the approach also incorporated a broad contextual lens, as it considered the social, cultural and environmental factors that shape a person’s experience. This was particularly relevant in the context of a life-limiting neurological cancer, in which the impact extends beyond the physical body to affect identity, autonomy, and interpersonal relationships. The flexibility of the method proved invaluable, as it supported an adaptive and evolving process of interpretation, allowing for continuous refinement of insights as the review progressed.

Ultimately, this qualitative review synthesis offered not only theoretical but also practical insights. The findings contribute to the guidance of future care by informing more personalised approaches that directly address the physical, functional and emotional challenges that are encountered by people facing life-limiting neurological cancer diagnoses.

5.5.2 Limitations of the review

Although valuable, the critical interpretive synthesis approach, which centres on the interpretation of personal narratives, inherently introduces a degree of subjectivity. This is because the analysis is grounded in the experiences of those who are interviewed, and therefore may not reflect a universal perspective, and there is a risk that bias shapes how findings are interpreted and presented.

The process of synthesising data from multiple qualitative studies also proved complex. At times, the integration of diverse methodologies and study contexts made it difficult to draw clear or unified conclusions. This complexity may have limited the clarity and consistency of the overall synthesis.

Another notable limitation was the issue of the generalisability of qualitative data to wider populations. Since the review was focused on personal, subjective experiences, the findings may not apply broadly to all people living with life-limiting neurological cancers.

Additionally, by narrowing the scope to qualitative research, this review excluded the medical and clinical dimensions of life-limiting neurological cancers. As a result, aspects such as disease progression and its physiological impact on functional status were not fully explored.

Finally, it was difficult to reflect the depth of the experiences of each participant as they transitioned through their discovery of having a life-limiting neurological cancer, and this brought challenges when balancing the depth of the analysis with the need for broad, more generalisable conclusions.

5.6 Summary

In this chapter, I have presented the delayed systematic literature review, which was conducted using a critical synthesis approach, in keeping with constructivist grounded theory methodology. The review explored how people experience the transition to new physical, functional and emotional states when they are diagnosed with life-limiting neurological cancers, and how this compares with the experience of metastatic spinal cord compression. From the synthesis, four core categories were constructed. In Chapter 6, I explore how the published literature contributes to and strengthens the understanding of the three conceptual categories that were developed from the primary study data. These categories were: category 1: “making sense of the bodily changes and disruption to normal life”; category 2: “focusing on living life for longer”; and category 3: “emotional consequences of a dual diagnosis”. I also discuss how the literature informs the further development of the refined emerging theory: “Navigating the liminal space of a dual diagnosis: Experiencing metastatic spinal cord compression and the sudden discovery of a newly diagnosed advanced cancer”.

Chapter 6: Discussion

In Chapter 5, I presented the findings of the delayed systematic literature review, undertaken using critical interpretive synthesis to align with the constructivist grounded theory methodology (Charmaz, 2014). In this chapter, I examine how the synthesised literature contributes and strengthens the conceptual understanding of the categories developed from the primary study data, and the emerging theory: "Navigating the liminal space of a dual diagnosis: experiencing metastatic spinal cord compression and the sudden discovery of a newly diagnosed advanced cancer."

I begin the summary of the review findings and then integrate these with the primary study data to deepen understanding of the experiences of participants' presenting with metastatic spinal cord compression as their first symptom of a previously undiagnosed, advanced cancer. I conclude this chapter with a discussion of how this integration has informed and critically shaped final theory: "When the spine speaks first": A constructivist grounded theory of people's experiences of discovering a newly diagnosed advanced cancer through metastatic spinal cord compression", and its relevance to Van Gennep's (1960) concept of liminality. This chapter also considers how the final theory relates to Van Gennep's (1960) concept of liminality, including pre-liminal, liminal, and post-liminal phases, which are elaborated later in the chapter alongside Figure 6.1. The concept of liminality supports the understanding of the transition to a new state and the experiences of participants diagnosed with metastatic spinal cord compression and a new advanced cancer.

Within this chapter, I focus on living life for longer, the emotional impact of the diagnosis, the competing priorities between urgent treatment and emotional support, and the challenges of processing complex information. Specifically, I examine how the literature strengthens and extends the primary categories, particularly focusing on emotional impact, competing priorities, processing information about diagnosis and prognosis, and efforts to live for longer within the context of rapid physical and functional change. The concept of liminality provides a way of understanding how participants navigate the uncertainty and ambiguity that are associated with both diagnoses.

The pre-liminal space reflects the time before diagnosis when participants are experiencing vague, unexplained symptoms, which lead to growing confusion and a sense that something is wrong. The liminal space encompasses the period during which there are acute physical, functional and emotional responses to both the knowledge of the metastatic spinal cord compression and the new advanced cancer diagnosis. This phase is marked by a significant shift in identity and reality, as participants try to make sense of what is happening. Many of their priorities at this phase revolves around their desire to continue to live and to regain some sense of control amidst the sudden and profound changes in their health. This phase also reveals tension between urgent medical intervention and the emotional and informational support those participants need as they grapple with the meaning of their diagnoses. The post-liminal space represents the phase after diagnosis and the initial management of their spinal cord compression. At this phase, participants either move towards palliative rehabilitation, with further cancer-controlling treatment depending on their prognosis or face the need to make decisions regarding palliative and end-of-life care. The handling of this transition is crucial in terms of care planning and decision-making, as the people affected and healthcare professionals navigate the complex, often difficult discussions surrounding quality of life, treatment options and future care goals.

6.1 Summary of the findings of the critical synthesis review

The qualitative synthesis review identified four categories: (1) “emotional impact of diagnosis”, (2) “competing priorities: immediate urgency vs. the future”, (3) “adjusting to a new physical and functional reality” and (4) “the perception and processing of information about diagnosis and prognosis”. Studies that had been focused on metastatic spinal cord compression had primarily explored the physical, functional, and emotional impacts of the diagnosis. The authors reflected on the effects and shared the coping strategies developed by participants as they navigated their conditions and moved forward. This focus was particularly relevant because, in studies on metastatic spinal cord compression, participants already had an existing primary cancer diagnosis. In contrast, in the studies involving participants with high-grade brain tumours, they were receiving and dealing with new primary cancer diagnosis. These latter studies placed more emphasis on the challenges of managing the sudden onset of acute-cancer diagnosis, which were likely to lead to progressive physical and functional changes. Key themes centred on the emotional and psychological responses to these abrupt diagnoses and how participants adapted to the uncertainty of their situations. The integration of findings from both the primary study undertaken for this thesis and the critical interpretive synthesis is discussed in more detail next, along with how this integration has informed the final theory of this thesis.

6.2 Integration of the findings from the primary study and critical synthesis review

The aim of the critical interpretive synthesis of the qualitative literature was to gain a broader understanding of the experiences of a person transitioning through the physical, functional and emotional changes that occur with a new life-limiting neurological cancer diagnosis. The critical interpretive synthesis review supported the emerging grounded theory I constructed: “Navigating the liminal space of a dual diagnosis: experiencing metastatic spinal cord compression and the sudden discovery of a newly diagnosed advanced cancer”. This review took an iterative/inductive approach; the literature review was performed following the primary data analysis and then was related to the three categories that had been constructed from the primary study. These were: category 1, “making sense of the bodily changes and disruption to normal life”; category 2, “focusing on living life for longer”; and category 3, “emotional consequences of a dual diagnosis”.

Consideration of these categories helped me to frame the understanding of how the primary study participants presented with metastatic spinal cord compression as their first symptom of a previously undiagnosed, advanced cancer. They provided insight into how participants navigated this complex situation, made sense of their physical and emotional changes, prioritised living within the context of a life-limiting illness and coped with the emotional challenges it brought, all of which contributed to an understanding of the personal meaning of their experiences. Next, these findings from the primary study data were integrated with those of the qualitative synthesis review to deepen the insights into the experiences of participants who present with metastatic spinal cord compression as the first symptom of a previously undiagnosed advanced cancer.

The qualitative synthesis review of the literature revealed key differences in the timings of the interviews between the reviewed studies and the primary study. Most participants in the published studies were reflecting on their experiences after diagnosis and treatment for metastatic spinal cord compression or high-grade brain tumours. In contrast, participants in the primary study were interviewed during the acute phase of their experiences, as they were navigating the process of being diagnosed with metastatic spinal cord compression and an advanced cancer that they had not been aware of until then. The differences highlighted the varying perspectives on the cancer journey among those who had already received the news and undergone treatment, compared with those in the midst of it.

Another notable observation was that all the published studies on metastatic spinal cord compression involved participants with existing primary cancer diagnoses prior to developing the spinal cord compression. One participant, in one of the studies, presented with metastatic spinal cord compression without a prior cancer diagnosis. Additionally, all participants across the studies had been offered treatment after their diagnoses, although there were notable differences in the types of treatment received: all participants with metastatic spinal cord compression had received only radiotherapy, and none had been offered spinal surgery or systemic anti-cancer therapy. In comparison, participants with high-grade brain tumours had typically received surgery and brain radiotherapy with or without systemic anti-cancer therapy. It was not clear from the literature whether participants with metastatic spinal cord compression went on to receive further treatment for their primary cancer after their spinal cord compression had been treated. None of the participants in any of the studies, including the primary study, were considered to be facing imminent death at the time of their interviews, so the focus was on the challenges and experiences of an active treatment phase rather than at the very end-stage of illness.

The literature provided valuable insights into the emotional impact of a life-limiting cancer diagnosis, the coping strategies that people develop, and the support they require to transition through this critical period of their experience. The literature findings revealed a number of similarities with the primary study data, with only a few notable differences. I now present the similarities and differences within the three main categories: “Emotional consequences of a dual diagnosis”, “focusing on living life for longer”, and “making sense of bodily changes and disruption to normal life”, which were constructed from the primary study data. Additionally, I discuss how the identified literature contributes to, strengthens or refutes these categories. This analysis was used to develop the final grounded theory, which was constructed from both the primary data and the findings of the critical interpretive synthesis review.

6.2.1 Emotional consequences of a dual diagnosis

There were significant similarities between the primary study data and the literature regarding the emotional impact of receipt of an acute diagnosis of metastatic spinal cord compression or high-grade brain tumour. For all participants, their diagnosis was a huge shock and emotionally overwhelming. Not only was it life-limiting, but for many, it also brought significant physical and functional impairments, regardless of whether or not the participants in the literature studies already had diagnoses of existing cancers. Following the diagnosis, participants in both the primary study and those published in the literature expressed feelings of loss of control. However, those captured in the literature review were more vocal about their fears regarding loss of identity and independence. While in the primary study, participants also acknowledged some fear, they were largely in the process of understanding and processing the meaning of these losses, rather than immediately confronting them.

At the time of the interviews in the primary study, the participants were recognising a need for change but were still reflecting on their pre-diagnosis lives, holding on to hope that they could return to a ‘normal’ routine with some minor adjustments. In contrast, the participants in the literature review were in a constant emotional shift, experiencing hope of a return to normality but also recognising the frightening reality that they faced unexpected early deaths, which caused them significant distress. The literature emphasised that a new life-limiting diagnosis led to renewed desires to live and to focus on fulfilling missed opportunities. The primary study data similarly acknowledged the participants’ diagnoses as life-limiting, but the participants did not express the same fear of death. They recognised this as an inevitable part of life over which they had no control, and certainly the older participants in the interviewed group had considered that death might occur soon, even before they had received their diagnoses, but they would not have chosen to pursue this path prematurely.

Family and friends played central roles in providing emotional support throughout this experience, in both the primary study and those taken from the literature. They were crucial, especially during the inpatient phase, which was described as a lonely and challenging time. Family support helped participants to remain positive and to navigate complex information and care decisions. However, participants feared being a burden on their loved ones. The literature heavily focused on family as the primary emotional support network, but did not explore the role of friends, even for participants who were single and could not rely on a broader family network. In the primary study, three male participants were in this situation, and this was shown to be a distinct experience compared with those of participants with partners and children. These single participants had to become dependent on others and share private aspects of their lives, which they would not have chosen to do pre-diagnosis. They had no choice, especially while in the hospital, and needed assistance with daily tasks such as paying bills, managing a house, and maintaining their care. Unfortunately, this type of support was not provided by healthcare professionals, whose focus was mainly clinical.

Maintaining hope and positivity was difficult, although essential for the participants in both the primary and literature studies. Family and friends played crucial roles in sustaining this hope. However, an interesting point was how the introduction of palliative care services was perceived. While for some this was helpful in managing pain and symptoms, for others the introduction was seen as a signal that took hope away, and this finding was similar in both the primary study and those published in the literature.

6.2.2 Focusing on living life for longer

The category of "focusing on living life for longer" reflected the participants' efforts to transition through a combination of physical, functional, and emotional shifts while dealing with their new life-limiting cancer diagnoses. During this phase, participants were primarily focused on whatever they could do to extend their lives, which often involved working to improve their physical function and finding practical solutions to adjust to a new 'normal'. Both the primary study and those in the literature review described a sudden, overwhelming transition into an unknown journey, in which participants were thrust into life-changing events with little time to adjust to the reality of life-limiting diagnoses.

For both groups, the desire to live was central. In the literature review studies, all participants had received radiotherapy for metastatic spinal cord compression, although the plans for treatment to control their primary cancer were not clear. Although those in the primary study had not yet received treatment, the primary study data reflected a similar focus on survival, with participants determined to do whatever they could to live as long as possible.

Another significant priority for participants, particularly while they were inpatients, was returning home to be with their families. In both the primary study and the literature, participants emphasised focusing on how to get home and resume their former lives as much as possible. They approached this transition by prioritising attempts to resolve their physical and functional challenges, hoping to return to their pre-diagnosis normality. As a coping strategy, both groups moved into action and were solution focused. In the literature review studies, many participants had set short- and long-term goals, although these goals were often unrealistic. Over time, they tended to revise their goals and expectations downwards in an attempt to maintain a sense of normality. In contrast, participants in the primary study showed a greater acceptance that living from that point onward would involve some level of disability, which they were willing to accommodate in order to live longer. The authors of the published studies expanded on this, suggesting that the proactive drive to improve physically stemmed from the desire to return to pre-diagnostic functioning. However, the literature also highlighted the difficulties participants faced in adjusting to their physical limitations. The focus of acute therapy was often on meeting their basic needs to facilitate their discharge, rather than preparing them for how to live with their new and increased physical limitations once home. Additionally, the literature explored the finding that the participants did not anticipate their increased number of physical and functional challenges while they were inpatients, and that this led to struggles with adjusting to their altered bodies and finding new ways to cope once discharged, especially in cases in which community services offered limited support.

Both the primary and literature review studies found that participants experienced information overload and difficulty retaining large volumes of information, largely due to feeling unprepared and being sleep-deprived, and the effects of pain medication. Both groups found it difficult to distinguish among the multiple healthcare teams that attended to them and their roles in the care process. The literature extended this point, suggesting that the involvement of multiple care providers created fragmented care, leading to a deterioration in communication, which left participants feeling frustrated, abandoned, vulnerable, and misunderstood. While there were elements of this in the primary study data, participants were still in the process of making sense of these issues, as this was happening in real time for this group.

Family members were identified as crucial in supporting participants, especially in terms of remembering essential information and providing emotional support, as discussed in previous sections. This role was particularly important as participants navigated the complexities of their treatment and ongoing care.

6.2.3 Making sense of bodily changes and disruption to normal life

The key difference between the literature and primary study data was in the participants' diagnostic experiences. In the literature, participants had either existing cancer diagnoses or clear radiological diagnoses of a primary brain tumour. In contrast, participants in the primary study were still awaiting confirmation of primary cancer diagnoses. At the time of the primary study, all participants, apart from one, had not been referred formally to a primary disease group, and their prognosis remained uncertain. They were confused about the extent of their disease and struggled to understand its meaning.

In the primary study, decisions regarding how to manage the participants' metastatic spinal cord compression were made based on the extent of the disease and spinal stability, and this situation caused misunderstanding and confusion for the participants. This finding reflects the timing of the study. Participants were in the midst of navigating two overlapping journeys: one that was focused on their physical and functional deterioration caused by metastatic spinal cord compression, and the other centred around trying to make sense of a new and advanced cancer diagnosis, the origin of which, for most, was still unknown.

Participants in the primary study were in a state of limbo, waiting for further investigations, biopsies, or histology results, or for the news that there would be no further investigations or treatments pursued. This uncertainty about both their diagnoses and whether or not they would be offered further treatment left participants in a difficult emotional state and space, unsure of what their futures held and struggling to connect their physical symptoms with unclear diagnoses and prognoses.

6.3 The final grounded theory

In this thesis, the final grounded theory represents the highest level of analytic abstraction, integrating the refined categories and relationships developed across earlier analytic phases into a coherent conceptual account of participants' experiences of discovering a newly diagnosed advanced cancer through metastatic spinal cord compression.

After the critical synthesis review, I revisited the primary data to examine the initial codes and categories through a new lens (Charmaz, 2014). Figure 6.1 illustrates the newly refined final grounded theory: "When the spine speaks first": A constructivist grounded theory of participants' experiences of discovering a newly diagnosed advanced cancer through metastatic spinal cord compression. This theory was further developed through the integration of the insights from the critical synthesis review to ensure close alignment with the primary study data. It describes how participants navigate the complex and shifting experience of metastatic spinal cord compression in conjunction with the news of a previously undiagnosed, advanced cancer. The theory is grounded in the concept of liminality and emphasises how understanding of this transitional phase can guide healthcare professionals in the provision of holistic support with the right skills at the right time.

This final grounded theory represents the integration of the early conceptual model (Figure 4.1) and the emerging liminality-informed theory (Figure 4.2) into a more analytically developed explanatory theory.

This chapter critically engages with this final grounded theory and its relevance to Van Gennep's (1960) concept of liminality. It explores the spaces that participants navigate: the pre-liminal space (past/no longer), the liminal space (in-between), and the post-liminal space (new). Although these spaces are presented conceptually, participants' experiences were not linear, with ongoing movement, overlap, and fluctuation between processes within and across these spaces.

The introduction of the concept of liminality supports the understanding of the transition to a ‘new normal’ and experiences of participants diagnosed with metastatic spinal cord compression and a newly diagnosed advanced cancer.

Within this chapter, I focus on living life for longer, the emotional impact of the diagnosis, the competing priorities between urgent treatment and emotional support, and the challenges of processing complex information. The concept of liminality helps to explain how participants navigate the uncertainty and the ambiguity that are associated with both diagnoses.

The pre-liminal space reflects the time before diagnosis when people are experiencing vague, unexplained symptoms, which were associated with growing confusion and sense that something is wrong. The liminal space encompasses the acute physical, functional and emotional responses to both the knowledge of the metastatic spinal cord compression and a new advanced cancer diagnosis. This phase is marked by a significant shift in identity and reality, as participants try and make sense of what is happening. Many of their priorities at this stage revolve around their desire to continue to live and regain some sense of control amidst the sudden and profound changes in their health. This phase also reveals tension between urgent medical intervention and the need for emotional and informational support by participants who are grappling with the meaning of their diagnoses.

The post-liminal space represents the phase following diagnosis and the initial management of their spinal cord compression. At this phase, people either move towards palliative rehabilitation, with further cancer controlling treatment depending on their prognosis, or face the need to make decisions regarding palliative and end-of-life care. The handling of this transition is crucial in terms of care planning and decision making, as the participants affected and healthcare professionals navigate the complex, often difficult discussions surrounding quality of life, treatment options and future care goals.

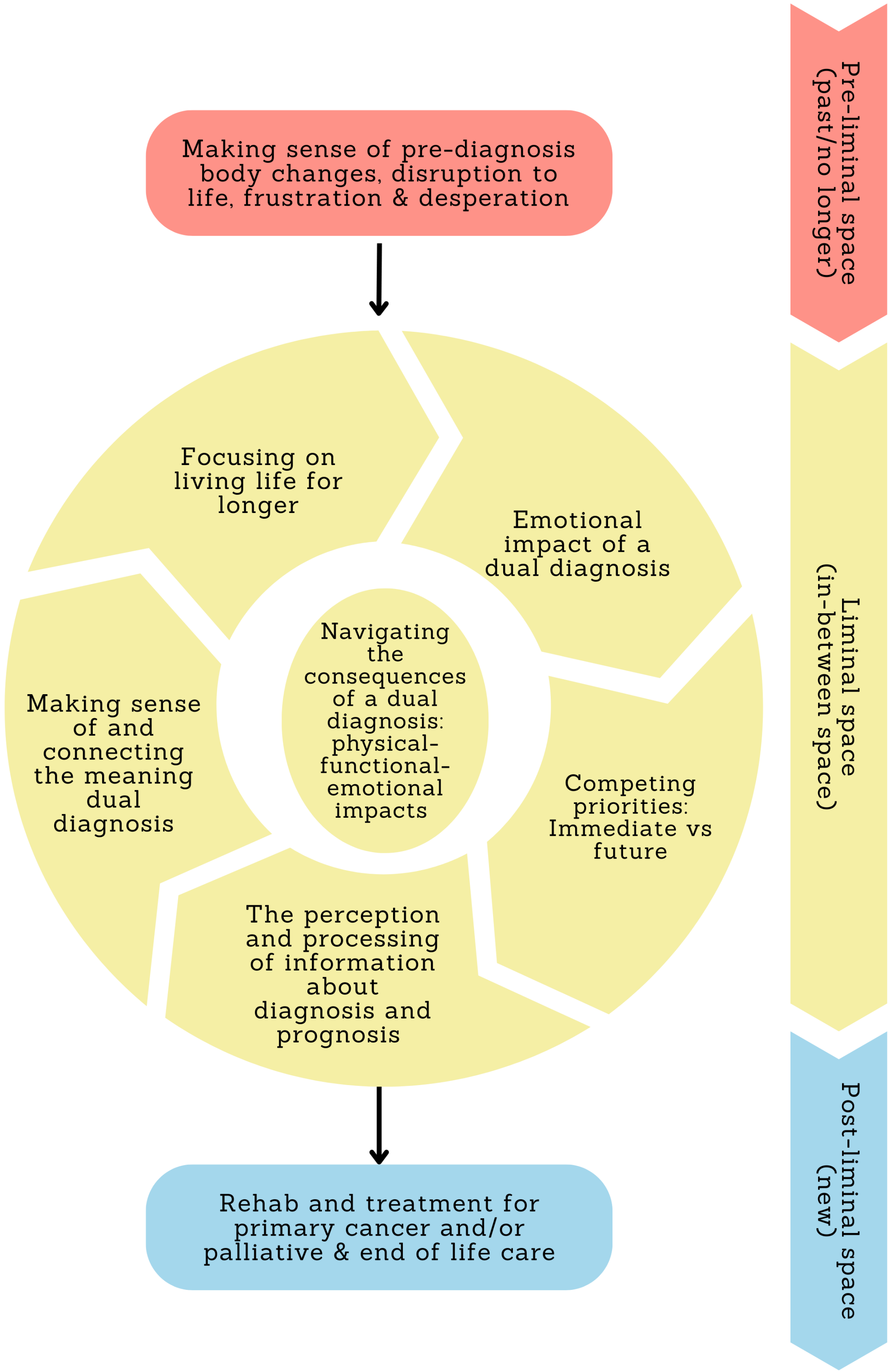

Figure 6.1: *Final Grounded theory:* “When the Spine Speaks First”: A Constructivist Grounded Theory of People’s Experiences of Discovering a Newly Diagnosed Advanced Cancer Through Metastatic Spinal Cord Compression.

6.4 Contribution to knowledge

This study contributes new understanding to the experiences of people who present with metastatic spinal cord compression as their first symptom of a new advanced cancer. It offers an original final grounded theory, illustrated in Figure 6.1, that integrates the insights from both the primary study and the critical interpretive synthesis review of the literature. This final grounded theory helps to highlight how people navigate the liminal space in which they shift from active and fully functioning people to those grappling with life-limiting illness and disability. This study reveals that healthcare professionals can play a vital role in recognising the liminal space and supporting the transition by offering tailored, compassionate care that addresses not only the physical and functional but also the emotional changes that people face as they build their understanding of the meaning of both diagnoses during this time.

Following integration with the critical interpretive synthesis, the original three categories were refined and extended, resulting in five final conceptual categories that better captured the processes evident across the combined evidence base.

The new constructivist grounded theory “When the spine speaks first”: of people’s experiences of discovering a newly diagnosed advanced cancer through metastatic spinal cord compression is constructed from five revised and refined conceptual categories: of:1) “Focusing on living life for longer”; 2) “emotional impact of dual diagnosis”; 3) “competing priorities: immediate urgency vs. the future”; 4) “the perception and processing of information about diagnosis and prognosis”; and 5) “making sense and connecting the meaning of the two diagnoses of metastatic spinal cord compression and a new advanced cancer”.

Together, these categories provide a deeper theoretical understanding of how people interpret, adapt to, and emotionally respond to this dual diagnosis, and offer new insights for enhancing future clinical practice, person-centred communication and supportive care.

6.4.1 Pre-liminal space (past/no longer): life before diagnosis

The pre-liminal space represents a transitional period in which participants in this study experienced subtle changes in their bodies but did not fully understand the significance. This phase involved an acute shift as they moved into the liminal space of diagnosis. As illustrated in Figure 6.1, this phase was reflected in both the literature and the primary study data.

The pre-liminal space refers to the period in the participants' lives before they were diagnosed with both metastatic spinal cord compression and an advanced cancer of which they were previously unaware. They described their lives during this period as "routine" and "normal", characterised by active, everyday living without significant health concerns. However, many participants began to notice subtle bodily changes, such as aches, pains, and disruptions to their regular activities. These changes were not initially recognised as signs of cancer, and the participants did not suspect that these symptoms could indicate something serious.

Despite these physical disruptions, participants remained unaware of the underlying causes, and the changes in their bodies went unrecognised by healthcare professionals as metastatic spinal cord compression, which was gradually affecting their ability to function normally. This phase was marked by an increasing awareness that something was changing in their bodies, but the cause remained unclear. The absence of other symptoms or an obvious illness left participants in a state of uncertainty. They could not pinpoint what was happening, and the lack of clear answers from healthcare professionals added to this confusion.

As participants continued to experience these disruptions in their lives, they were unprepared for what lay ahead. The movement into the liminal space of a new cancer diagnosis, along with the immediate onset of disability, was unforeseen. This phase represents the period between their past life and the changing reality associated with their diagnosis. The pre-liminal space was one of growing disability and a heightened sense that something was "not right", yet there was no clear explanation from healthcare professionals until the progressive neurological symptoms emerged. This left participant feeling frustrated and desperate, as it was only when it was too late to alter their course that the true cause of their symptoms became apparent.

6.4.2 The liminal space (in-between)

The liminal space or ‘in-between’ state is one in which old identities and roles are disrupted, but new ones are not yet fully formed. This space in the final theory is formed by the physical and practical subcategories, in which the study participants pursued cancer treatment and formulated the aim of wanting to live as long as possible following this new life-limiting cancer diagnosis. Framing this experience as a liminal space helps to explain the transition from health and independence to illness and disability. It highlights the complexities that this group faces, not only in terms of survival, but in redefining what it means to live while navigating this dramatic life change.

6.4.2.1 Category: Focusing on living life for longer

As illustrated in Figure 6.1, “focusing on living life for longer” represents a core process within the liminal space, through which participants orientate their actions towards survival, function, and future possibility.

The category of “focusing on living life for longer” captures how participants are orientating their thoughts and actions during this early transition towards new disability and life-limiting cancer diagnosis. In this space, participants showed a strong desire to live longer, through active engagement in efforts to improve physical function, pursue further treatment and find practical ways to adjust to a new normal. All of these aims helped participants to maintain hope and positivity. The subcategories of handling physical and practical challenges and pursuing cancer treatment reflect this proactive, goal-driven response to their sudden and overwhelming life change. Participants were solution-focused, seeking to regain control through rehabilitation and goal setting with the hope of returning to normal and their families, and to have cancer treatment. Although these goals were unrealistic, the creation of them represented a coping mechanism to maintain hope and a sense of purpose.

6.4.2.2 Category: Emotional impact of a dual diagnosis

Within the liminal space (Figure 6.1), the emotional impact of the dual diagnosis operates alongside physical and functional disruption, shaping how participants make sense of their new reality.

The category of “emotional impact of a dual diagnosis” encompasses the emotional toll that participants experience when dealing with metastatic spinal cord compression and the diagnosis of a new, advanced cancer. The category was constructed from the subcategories of waiting in limbo while trying to maintain hope and positivity, and how this experience had affected them both as people and for their families and friends.

All participants described their new diagnoses as a huge shock, which was emotionally overwhelming. For some, the life-limiting diagnosis also brought significant physical and functional impairments. After diagnosis, participants immediately experienced loss of control, identity and independence. While they recognised that this diagnosis would lead to life changes, many held on to the hope that they could return to their pre-liminal space of activity and routine, returning to their pre-diagnosis ‘normal’ with minor adjustments. During this time, there was a constant shift between hope of returning to normal and awareness of the painful reality of the diagnosis. Participants acknowledged that their diagnosis was life-limiting but found it hard to accept that death might come so soon; they recognised that death was inevitable part of life but were not prepared for it to come so suddenly and unexpectedly.

Maintaining hope and positivity, while difficult, remained an essential coping strategy. Family and friends were key sources of support, particularly while participants were inpatients; they helped the study participants to navigate complex information, to make decisions, and to deal with life outside the hospital. This synthesis highlighted that healthcare professionals underestimate the roles that family and friends play for people in these situations, as they are central in providing emotional support, helping with decision-making, and managing the practical aspects of care, especially when external support systems are lacking.

Although palliative care teams helped manage pain and symptoms, the introduction of palliative care was seen by some participants as a loss of hope, as it brought the reality of their life-limiting diagnosis.

6.4.2.3 Category: Competing priorities: immediate vs. the future

In Figure 6.1, “competing priorities” captures the tension between clinical urgency and participants’ emotional and informational needs, which influenced how they moved between processes during the acute phase.

The category refers to the disconnect that occurs when healthcare professionals focus on the urgency of the neurological event caused by the metastatic spinal cord compression, while participants struggle to make sense of their physical and functional state and life-limiting diagnosis. Participants described their experience as being in a state of chaos and crisis while undergoing a fast transition into and through an unknown journey, leaving little time to adjust.

Due to the acute nature of the metastatic spinal cord compression, healthcare professionals prioritised urgent treatment plans for it. However, there was also a critical need to support participants to understand the meaning of their physical and functional changes and how these changes would impact their lives. The challenge participants faced in understanding this was compounded by the uncertainty of unconfirmed primary cancer diagnosis and prognosis. This created a difficult conflict between the priorities of the participants and healthcare professionals, as the requirement for urgent medical intervention clashed with the need for emotional and information support.

6.4.2.4 Category: The perception and processing of information about diagnosis and prognosis

As represented in Figure 6.1, participants’ perception and processing of information shaped meaning-making and decision-making across the liminal space, particularly during periods of uncertainty and information overload.

The category was constructed through participants' accounts of how they perceive and processed what was communicated to them. As participants and healthcare professionals focused on active management of the metastatic spinal cord compression, participants were overwhelmed. Many had been reassured initially that their symptoms were not serious, only to be confronted with the extreme reality of a life-limiting diagnosis. This dramatic shift in understanding created a challenge as participants found it hard to correlate the two perspectives.

Participants found it difficult to process the large amounts of information they received, particularly when multiple professionals from various care settings, primary, community, and acute care, were involved. This fragmentation of care led to distorted and inconsistent information that left participants confused. Their ability to process the information was further compromised by sleep deprivation and the effects of pain medication.

For participants to better navigate this liminal space, information should be delivered proactively and tailored to their needs via tools in a timely and consistent manner. Essential information should be provided in a simple and easy-to-understand format that allows participants to discuss their diagnosis, disease extent, and life changes. Ideally, this should be provided by a healthcare professional with the specialist knowledge and skills to offer participants the opportunity to ask questions about both their cancer diagnosis and their metastatic spinal cord compression. While participants expressed a desire to be actively involved in their care, they also wanted to hear positive news, which could be challenging given the urgency of treating the spinal cord compression.

6.4.2.5 Category: Making sense of and connecting the meaning of metastatic spinal cord compression and a new advanced cancer diagnosis

In the final grounded theory (Figure 6.1), connecting the meaning of metastatic spinal cord compression and newly diagnosed advanced cancer represents a key meaning-making process through which participants sought coherence in the dual diagnosis.

For people who present to the medical profession with metastatic spinal cord compression as the first symptom of an advanced cancer, the liminal space is where they try to focus on living and regaining some control in the face of uncertainty. Despite the emotional impact, the maintenance of hope and positivity becomes a key coping strategy. People were challenged by the competing priorities between their understanding of their diagnosis and the perspectives of healthcare professionals. They struggled to make sense of the extent of their cancer while also grappling with the impact of their metastatic spinal cord compression. This stage represents a critical transition, in which people seek meaning and understanding amidst the complexities of their condition, balancing emotional, physical, and practical aspects of their lives. In this space, they are prioritising what matters most, trying to determine how to spend their remaining time and where they wish to be as they navigate the uncertainty ahead.

6.4.3 Post-liminal space (new space)

6.4.3.1 Palliative rehabilitation, treatment, or palliative and end-of-life care

As illustrated in Figure 6.1, the post-liminal space represents the space that develops following the most intense disruption of the liminal space, in which participants begin to re-orient themselves to the reality of their dual diagnosis and the altered conditions of their lives.

The post-liminal space refers to the phase that follows liminal space. While most participants in the primary study had not entered this phase, the literature suggests that it is where participants begin to process and adjust to the reality of their dual diagnosis of metastatic spinal cord compression and advanced cancer. The participants in the primary study would transition into this space as they engaged in making sense of and connecting the meaning of both diagnoses. The transition would occur while navigated the immediate physical, functional, and emotional challenges, which would allow them to plan for future care. This care could be palliative rehabilitation, treatment, or palliative or end-of-life care, depending on the extent of disease and potential prognosis, which in some cases might never be fully confirmed. In such cases, both the healthcare professional and the person need to accept that pursuance of further diagnostics is unlikely to alter the course of care and will be futile.

The integrated findings of the study show that what is critical during this phase is personalised care. People who present with metastatic spinal cord compression are often treated similarly to meet their urgent clinical needs and to address immediate treatment targets. However, each person's unique needs must be met. Care discussions should be holistic, addressing not only their physical and functional needs but also their emotional well-being. This holistic approach enables more meaningful conversations around treatment options, quality of life, and personal priorities.

People must have the chance to have difficult yet essential conversations about the extent of their disease, the rationale behind the management of their metastatic spinal cord compression, and the possible, immediate treatment goals (NICE, 2023). These discussions should involve oncologists and specialists who are experienced in managing people with spinal metastases and metastatic spinal cord compression. In addition to medical discussions, people must be offered emotional support and guidance in order to help them understand their diagnoses, regardless of the disease stage they are at (Clayton et al., 2005). Although these conversations may be challenging, they are essential for ensuring that informed decisions are made, and that people feel supported through their journey.

In this post-liminal space, people must be supported to navigate the realities of their advanced cancer diagnosis and treatment for their metastatic spinal cord compression while they adjust to the significant changes that they must face in their lives. People who receive this dual diagnosis should be provided with holistic care, open and supportive communication, and personalised management so as to help them to move through this space. By addressing not only the medical aspects of treatment but also their emotional needs, healthcare professionals can offer holistic care that aligns with the person's goals. This approach enhances the quality of their life and provides optimal care as their disease progresses.

6.5 Positioning the final grounded theory within existing theory

This section positions the final grounded theory (Figure 6.1) within existing theoretical literature and demonstrates how it extends earlier conceptual development (Figures 4.1 and 4.2).

Eva et al. (2008) explored how people with metastatic spinal cord compression experienced and constructed their understanding of disability. Two central concepts from their study are particularly relevant to this thesis. First, they highlight the tension between acknowledging and avoiding recognition of disability. While some people openly confront their physical limitations, others minimise or avoid them. Importantly, Eva et al. (2008) argue that this is not necessarily denial; rather, it may function as a protective coping mechanism that supports identity and autonomy in the face of a life-altering diagnosis.

Eva et al. (2008) introduce a concept of "positive illusions," a form of hopeful thinking or unrealistic optimism, which can serve as an adaptive psychological strategy. Rather than viewing this optimism as avoidance of reality, they suggest that it enables people to maintain a sense of control and emotional stability in the context of progressive illness. This perspective aligns with research in health psychology that emphasises the value of maintaining hope and psychological flexibility in the face of serious illness (Taylor & Brown, 1988). It also challenges traditional clinical assumptions that full acceptance of disability is always necessary or helpful (Charmaz, 1991).

These existing insights extend the findings of this thesis, particularly concerning the emotional complexity for participants who receive a dual diagnosis. They reinforce the idea that making sense of a life-limiting condition involves emotional processes, and that adaptive strategies such as selective acknowledgement and optimistic thinking may play important roles in sustaining resilience and hope during times of significant uncertainty (Folkman & Moskowitz, 2000).

Building on this, the final grounded theory developed in this thesis: "When the spine speaks first": A constructivist grounded theory of people's experiences of discovering a newly diagnosed advanced cancer through metastatic spinal cord compression extends Eva et al.'s (2008) work by introducing the concept of liminality, as originally defined by Van Gennep (1960). While Eva et al. (2008) explored how people adapted to and managed disability over time, the grounded theory presented here focuses specifically on the initial presentation of metastatic spinal cord compression as the first symptom of a previously undiagnosed, advanced cancer, which, taken together, are marked by clinical urgency, personal disruption, and emotional consequences.

A key contribution of the grounded theory developed in this thesis is the positioning of liminality as a central concept. Liminality refers to a transitional phase in which people exist between two states, no longer who they were, but not yet who they will become (Turner, 1977; Van Gennep, 1960). This is especially relevant to the diagnostic moment, when people face rapid changes to their health status, identity, and anticipated future. The simultaneous emergence of neurological deterioration and a new cancer diagnosis places people in a disorienting "in-between" space, physically, functionally, and emotionally.

Another difference lies in the dual nature of the diagnosis. While Eva et al. (2008) focused solely on disability that was related to metastatic spinal cord compression, this thesis considers only metastatic spinal cord compression as the first presentation of a previously undiagnosed advanced cancer. This adds a layer of complexity to the person's experience. The urgent clinical demands of metastatic spinal cord compression (such as pain, paralysis, or loss of function) occur alongside the emotional processing of a life-limiting cancer diagnosis. These overlapping crises create competing priorities: immediate action to address physical symptoms, and the need to understand and emotionally absorb the long-term implications of cancer. This intersection of acute and life-limiting illness increases the liminality of experience.

The final grounded theory presented in Figure 6.1, "When the Spine Speaks First," constitutes a substantive mid-range theory because it offers an interpretive and conceptually coherent explanation of how participants make sense of, and respond to, the dual diagnosis of metastatic spinal cord compression and newly identified advanced cancer. Consistent with Charmaz's constructivist grounded theory, this theory is grounded in the situated experiences of participants while achieving an analytic level that moves beyond description to conceptualise the underlying processes shaping their actions and meanings (Charmaz, 2014; Birks & Mills, 2015). It is considered substantive because it is rooted in a particular population and clinical context, explaining a process as lived by people experiencing this specific dual diagnosis rather than aiming for universal, formal application. At the same time, it is a mid-range theory because it sits between narrow empirical description and highly abstract grand theory: its conceptual categories and their relationships provide transferable insights that may inform understanding and practice in similar clinical situations. Thus, the final grounded theory synthesises the analytical development illustrated across the conceptual model (Figure 4.1) and emerging theory (Figure 4.2) into a theoretically integrated account.

Building on this theoretical positioning, the resulting final grounded theory offers a mid-range substantive theory that explains how participants begin to navigate this initial crisis, re-evaluate their priorities, and construct meaning in the midst of disruption. It adds to the body of knowledge on metastatic spinal cord compression by shifting attention from long-term adaptation to the immediate moment of transition, a point in time that is often under-recognised in clinical settings yet is profoundly significant for people. This final grounded theory also has practical implications. By highlighting the nuanced and layered experiences of people with a dual diagnosis, it offers healthcare professionals insight into how best to support people's own coping strategies who are within this vulnerable space to regain a sense of wellbeing (Walshe et al., 2017). It suggests that tailored communication, compassionate presence, and attention to both emotional and functional needs can help to guide patients through this turbulent period of reorientation (Beach et al., 2006; Clayton et al., 2007).

In summary, while the theories introduced by Eva et al. (2008) provide essential insights into long-term adaptation and identity work in the context of metastatic spinal cord compression, the final ground theory developed in this thesis contributes a new layer of understanding through its focus on the initial moment of diagnosis. It introduces liminality as a central concept to capture the profound sense of disruption that people experience when faced with the dual crisis of sudden neurological deterioration and a new, life-limiting cancer diagnosis. It offers a new understanding of the physical, functional, and emotional disturbances that occur during this period. By shifting attention from long-term adjustment to the acute experience of diagnosis, this study extends and refines existing theory, challenges assumptions about illness acceptance, and offers practical insights for supporting people during one of the most critical and under-recognised parts of the cancer journey. This has implications not only for theory development but also for the improvement of clinical care and communication at the point of diagnosis.

6.6 Summary

In this chapter, I have described the integration of the primary study data and the literature synthesis. This process involved revisiting the initial codes from the primary data; ensuring that they still took priority over the critical interpretive review findings but were considered as part of the final theory construction. This integration led to the development of the revised constructivist grounded theory of: “When the spine speaks first”: A constructivist grounded theory of people’s experiences of discovering a newly diagnosed advanced cancer through metastatic spinal cord compression. I have outlined how the theory contributes to existing knowledge and its position in the broader literature. In the final chapter, I conclude the thesis by summarising they study’s strengths and limitations and discussing its implications for practice, policy, education, and future research.

Chapter 7: Conclusion

The rising incidence of cancer in the UK, particularly among older adults, has drawn increasing attention to emergency cancer presentations, as one-in-five cases are diagnosed via this route (Elliss-Brookes et al., 2012). People diagnosed in this way are more likely to present with advanced disease, have fewer treatment options, and experience poorer outcomes. Among such oncological emergencies, metastatic spinal cord compression is particularly concerning. An increasing number of people are presenting with metastatic spinal cord compression as the first symptom of a previously undiagnosed, advanced cancer. This creates a complex and distressing situation that is characterised by acute neurological deterioration, diagnostic uncertainty, and the sudden realisation that the person has a life-limiting illness.

Early recognition and intervention are crucial to avoid irreversible neurological damage and preserve function. However, when metastatic spinal cord compression presents in the absence of a known primary cancer, people often encounter delayed diagnosis, fragmented care pathways, and limited access to specialist support. It has been highlighted that there is limited research in this area, following the recent release of the NICE guideline update for spinal metastases and metastatic spinal cord compression (NICE, 2023).

This study aimed to capture the specific time frame during which people develop symptoms, receive a diagnosis, and undergo initial management and decision-making following the discovery of metastatic spinal cord compression as the first symptom of a new advanced cancer. To offer insight and meaning into this period, it was essential to understand what was evolving for people physically, psychologically, and emotionally, and how they navigated the transitions occurring during this time. Through the use of a constructivist grounded theory approach (Charmaz, 2014; Mills et al., 2006), this study has co-constructed meaning from participants' experiences and generated new insights, thereby contributing to the development of a substantive theory that could guide future research and inform improvements in care for this population.

The findings of the primary study led to the development of several emerging categories and subcategories, which were co-constructed through iterative coding and constant comparative analysis. These contributed to the development of the conceptual model: “Navigating the consequences of a dual diagnosis: The physical, practical and emotional impacts of facing metastatic spinal cord compression and a Newly Diagnosed Advanced Cancer”. This, in turn, introduced the concept of *liminality*, the relevance of which was highlighted in understanding this unique experience, and which formed the basis for the emerging theory: “*Navigating the liminal space with a dual diagnosis: metastatic spinal cord compression and a previously undiagnosed advanced cancer.*” This emerging theory captures the transitional state people experience as they confront both the immediate physical consequences of metastatic spinal cord compression and the existential impact of a new, life-limiting diagnosis. It reveals the interaction between clinical realities, shifting identity, and the search for meaning in a context of profound uncertainty.

A delayed, critical interpretive synthesis of the literature was conducted in keeping with the constructivist grounded theory methodology (Dixon-Woods et al., 2006). This review examined how people experience transitions following diagnosis with a life-limiting neurological cancer and compared these experiences with those of metastatic spinal cord compression. Four core categories were constructed: 1, the emotional impact of dual diagnosis; 2, competing priorities-immediate urgency versus future planning; 3, adjusting to a new physical and functional reality; and 4, the perception and processing of information about diagnosis and prognosis.

These findings were then integrated with the literature synthesis to shape and refine the final theory: “When the spine speaks first”: A constructivist grounded theory of people’s experiences of discovering a newly diagnosed advanced cancer through metastatic spinal cord compression. This theory draws on Van Gennep’s (1960) concept of liminality, which illustrates the transitional spaces that people inhabit during change: the pre-liminal (the past/self that is no longer), liminal (the in-between), and post-liminal (the unknown future). The concept of liminality proved critical to the understanding of the complex, layered experiences of those diagnosed with metastatic spinal cord compression and a new advanced cancer.

I now discuss the strengths and limitations of the whole study, as well as its implications for practice, policy, education, and research. Ultimately, this work is intended to inform person-centred care, shape policy development, and guide the creation of future clinical guidelines. By identifying and critiquing the lack of qualitative research in this area, in which the majority of studies are focused on people with an existing cancer diagnosis rather than those who experience metastatic spinal cord compression as the first symptom of an advanced cancer (Eva et al., 2008; Lee, 2013; Manson et al., 2017; Warnock & Tod, 2014), this study contributes valuable human perspectives that are essential for improving care, support, and outcomes. It is crucial to hear the voices of people who encounter metastatic spinal cord compression in this way, to address a significant blind spot in the literature and, with it, to deliver an urgent call to recentre care around the person at the moment of crisis, when empathy, clarity, and timely support are most needed.

7.1 Strengths of this study

This constructivist grounded theory study has explored the unique experiences of people who present to the medical profession with metastatic spinal cord compression as the first symptom of an advanced cancer. Given the complex, subjective, and context-specific nature of this experience, I have evaluated the strengths of this study using the qualitative standards of rigour, which are: credibility, auditability, fit, resonance, and usefulness. Application of these standards enhances rigour and transparency, which are important in grounded theory, as the theory is co-constructed from the data rather than imposed in line with pre-existing theories (Charmaz, 2003, 2014; Chiovitti & Piran, 2003).

Credibility refers to the extent to which the findings are true to life and trustworthy from the perspectives of both participants and readers. In this study, several research methods were used to enhance credibility. I used a flexible interview guide, which allowed participants to guide the direction of the conversation. This ensured that the research focus was aligned with what mattered most to the participants. As the interviews progressed, it became clear that participants were primarily concerned with the sudden experience of metastatic spinal cord compression and the implications of a new advanced cancer diagnosis, rather than that they had a malignancy of unknown origin, which I had initially anticipated. This led to the redefining of the research question, in accordance with the emergent, iterative nature of grounded theory (Charmaz, 2014). In addition, people with lived experience were consulted at different stages of the research process. Their insights helped in the shaping of the study design and interpretation of the emerging findings and ensured that the analysis remained relevant and reflective of real-world experiences, thereby increasing the overall credibility of the research.

The participants' language, their own words and expressions, were consistently used throughout the coding process. This helped to preserve the authenticity of their experiences and ensured that the emerging categories were grounded in the data (Strauss & Corbin, 1990). Participant validation was sought from a layperson with lived experience of metastatic spinal cord compression and from one participant after their interview to confirm that the emerging categories resonated with their own experiences and interpretations.

Research reflexivity was integral throughout this study. The analysis and co-construction of meaning was intensive, involving multiple listening and readings of transcripts, concurrent memoing, and keeping a reflexive journal. I constantly questioned and reflected critically on my coding and category decisions to increase the transparency of the analytical process. Finally, I used triangulation methods in which I compared interview data, existing literature, and my own interpretations to demonstrate how these sources related to each emerging category. This ensured that the developing grounded theory remained firmly rooted in participants' perspectives and situated within existing knowledge (Thornberg & Dunne, 2019).

Auditability refers to the transparency and traceability of the research process—the ability of others to follow the same analytical steps. In this study, auditability was supported through detailed documentation, including memoing, coding processes, and theoretical sampling decisions, which together formed a clear audit trail. I followed a transparent methodology by documenting participant selection, data collection, and analytical decisions in a step-by-step manner, allowing others to understand the logic of the research process (Carpenter, 1995). I also justified sampling decisions, such as recruiting younger, single men after initially interviewing older participants with strong family support, to explore potentially different experiences. This enhanced variation strengthened the robustness of the emerging theory.

The interrelated criteria of fit, resonance, and usefulness were used to evaluate the quality and relevance of the new theory. ‘Fit’ assesses how well the theory reflects the data; ‘resonance’ considers how deeply it captures participants’ experiences; and ‘usefulness’ examines its applicability to practice, policy, or research. The theory developed in this study is a substantive theory situated within a specific clinical context (Carpenter, 1995). It is mid-range because it moves beyond description to conceptualise underlying processes, while remaining closely grounded in a specific population and clinical situation.

The credibility of the final grounded theory, “When the Spine Speaks First,” rests on the systematic and rigorous application of constructivist grounded theory methods, including constant comparison, iterative coding, analytic memo-writing, and theoretical sampling. These processes ensured that the theory remained closely connected to participants’ accounts while developing sufficient analytic depth to explain the underlying processes of navigating a dual diagnosis of metastatic spinal cord compression and newly diagnosed advanced cancer (Charmaz, 2014). Credibility was further strengthened through detailed engagement with the data, reflexive examination of the researcher’s role in co-constructing meanings, and the integration of participants’ words and experiences into the analytic categories and final theoretical account.

The transferability of the theory lies in its mid-range nature: although rooted in the specific clinical context and population studied, the conceptual processes it describes, such as navigating uncertainty, responding to sudden bodily disruption, and managing the emotional and practical consequences of an unexpected, advanced cancer diagnosis, may be relevant to people in comparable clinical circumstances. Rather than claiming universal applicability, the theory provides a conceptual lens that can be meaningfully applied to similar settings, patient groups, or diagnostic journeys, enabling practitioners and researchers to assess its resonance and usefulness within their own contexts. In this way, the theory achieves both credibility and context-sensitive transferability while remaining faithful to the interpretive foundations of constructivist grounded theory.

The findings resonated with both participants and professionals. One participant confirmed that the categories and emerging theories reflected their experiences. When shared with colleagues, the categories and relationships were recognised as credible and relevant. Usefulness was demonstrated through the theory's ability to provide practical insights into the challenges faced by people diagnosed with advanced cancer through the discovery of metastatic spinal cord compression. This study highlights the physical, functional, and emotional impacts of such a diagnosis and offers implications for clinical practice, policy, education, and research. According to Charmaz (2014), a grounded theory is of high quality when it provides useful interpretations that improve understanding or stimulate action in real-world settings.

7.2 Limitations of this study

Limitations of this study

The recruitment of participants proved challenging due to the complexity of the metastatic spinal cord compression management pathway. Potential participants frequently presented at various local hospitals with initial symptoms but then were urgently transferred for surgical assessment or radiotherapy or were discharged home before recruitment teams had the opportunity to approach them. A key recruitment site was the regional neurosurgical/spinal centre; however, this may have limited the scope of recruitment as people who attended this centre were more likely to be considered surgical candidates. Consequently, this group often had less extensive disease and few comorbidities, which may partly explain the underrepresentation of people who were closer to the end of their lives and for whom treatment for the metastatic spinal cord compression may not have been considered appropriate.

The initial plan was to recruit from additional regional sites. However, this became increasingly complex due to the involvement of multiple hospitals and the urgency of clinical decision-making and transfers. As this was a PhD study, I was time restricted and had limited resources to support extensive coordination across sites.

Further barriers to recruitment were at a clinical level. Acute oncology nurses occasionally acted as gatekeepers, and on two occasions, they declined to introduce information about the study to potential participants, expressing concern that participation might cause unnecessary distress. In addition, some clinical nurse specialists did not consider that the introduction of research studies to potential participants was part of their role. These factors may have contributed to a reduced representation of the wider metastatic spinal cord compression population, particularly those who had been given a new advanced cancer and had complex psychosocial needs.

Finally, a longitudinal study may have provided deeper insight into participants' evolving experiences over time than did this study. Comprehension of how people's coping mechanisms develop, how they make sense of their diagnosis after the initial shock, and whether further primary cancer treatment was possible or not, may have added valuable depth to the study and recommendations.

Given these limitations, particularly the recruitment challenges and underrepresentation of certain groups, the transferability of the findings is necessarily bounded; while the final grounded theory offers conceptual insights applicable to similar clinical contexts, it should be interpreted with awareness of the specific population and service configurations from which it was derived.

7.3 Implications for clinical practice, policy, private organisations, charities and research

7.3.1 Implications for clinical practice

7.3.1.1 Early recognition and diagnosis/advocacy for early intervention

Findings from the primary data and wider literature underscore that in many cases, metastatic spinal cord compression is misdiagnosed or mismanaged, often due to systemic barriers or misinterpretation of the initial presenting symptoms, such as non-specific back pain. Early signs may be dismissed as benign causes, or people are wrongly reassured that this is the case, and this situation delays appropriate referral and treatment. This study highlights the need for increased clinical awareness and advocacy to support earlier recognition and diagnosis. It is essential that people are encouraged to report new or progressive physical symptoms and to ensure that healthcare professionals are equipped to interpret these red flags. Proactive intervention before progression to metastatic spinal cord compression may help to preserve neurological function, expand treatment options, and improve quality of life.

7.3.1.2 The need to enhance collaborative working between clinical services

The study highlights the need to improve collaboration between clinical services that care for people with metastatic spinal cord compression, and more so when this is their first symptom of an advanced cancer. Current care is often fragmented, with limited coordination among oncology, acute oncology, spinal surgery and therapy teams, and among palliative, primary, and community care providers. An integrated approach is needed to ensure the provision of timely person-centred care, whether to support recovery or to plan for end-of-life. Clearer pathways and better communication across services may improve outcomes and correlate with a person's values and needs. Inclusion of a central point of coordination to communicate information is recommended.

7.3.1.3 Person-centred and tailored management options

This study suggests that people who present with metastatic spinal cord compression as the first sign of an advanced cancer experience a sudden loss of mobility and function, alongside pain and emotional shock, and uncertainty. These physical, functional, and emotional disruptions are often overlooked in standardised, protocolised care. Participants describe gaps in timely diagnosis, but also in post-treatment support, particularly around physical, functional, and emotional adjustment. This highlights the need for person-centred care plans that go beyond clinical urgency to include support that aligns with a person's holistic needs.

7.3.1.4 Professional-level communication and information practices

Staged and timed communication

Professionals should provide timely, small, and staged conversations that acknowledge the cognitive and emotional overload associated with a sudden dual diagnosis. Information should be prioritised, paced, and revisited over time rather than delivered in a single encounter.

Consistency and continuity of professional communication

Consistency of messaging should be supported through the identification of a lead clinician or small core team responsible for key conversations, helping to reduce confusion, prevent contradictory information, and support therapeutic continuity.

Active checking of understanding and shared meaning-making

Professionals should actively check understanding, invite questions, and revisit information frequently, recognising that information processing is often compromised during acute physical deterioration and emotional distress. With consent, family and friends should be included to support shared understanding.

Acknowledging uncertainty and emotional dimensions of care

Clinicians should acknowledge uncertainty openly, explaining what is known, what remains unclear, and what will happen next. Alongside clinical updates, space should be intentionally created for emotional conversations, particularly during the liminal period when people feel suspended between shock and decision-making.

Collaborative and flexible goal setting

Professionals should engage collaboratively in realistic and flexible goal setting, recognising that goals may function as coping strategies that support meaning and hope even in the context of functional decline. Goals should be reviewed and renegotiated as circumstances change.

These practice-level recommendations arise directly from participants' accounts and highlight the fundamentally relational and communicative work required of professionals to support people living within the liminal space identified in the final grounded theory.

7.3.2 Implications for healthcare policies

7.3.2.1 Referral pathways

The study highlights the need for urgent and clearly defined referral pathways for the assessment and diagnosis of people who present with new or worsening back pain that may suggest the presence of an underlying cancer. Early and structured intervention, specifically the timely identification of spinal metastases before progression to metastatic spinal cord compression, has the potential to prevent neurological deterioration, reduce the level of long-term disability, expand the list of available treatment options, and reduce the pressure on overburdened emergency departments.

7.3.2.2 Addressing the gaps in support services

A key finding of this study was the significant gap in support services that are available to people diagnosed with metastatic spinal cord compression. The availability of such services often depends on the person's primary cancer diagnosis and overall prognosis. This variation can lead to inconsistent care and unmet needs, particularly in the early stages of diagnosis and adjustment. There is a pressing need for more robust systems and policies that prioritise holistic, person-centred care. These approaches should not only address the physical and functional needs of the person but also consider the emotional and practical challenges that they, their family, and friends face. These support structures must be strengthened to improve continuity and the overall care experiences of those who must navigate this complex, life-altering diagnosis.

7.3.3 Implications for private organisations and charities

7.3.3.1 Private organisations

Increasingly, people seek diagnostic investigations via private providers; one participant in this study did, and a number of others stated that they had considered this route. Private providers may increase their focus on rapid diagnostics and interventions for people who present with symptoms of spinal metastases and metastatic spinal cord compression, but these providers must have pathways, guidelines and policies that cater for the immediate needs of this population, particularly when their care must be transferred back to NHS organisations for support with their ongoing investigations and subsequent treatment of their new cancer.

7.3.3.2 Charity involvement

Charities are a key in the development of holistic support programmes and resources that are tailored for those diagnosed with advanced cancer and who present with metastatic spinal cord compression. These resources include psychological, emotional, and financial support as well as education materials for people and their families. Charitable organisations, such as Macmillan can play a key role by launching awareness campaigns to educate the public and healthcare providers about spinal metastases and metastatic spinal cord compression. These campaigns should also address the implications of the condition for people with a new or existing diagnosis of cancer in order to foster greater understanding and promote early identification.

7.3.4 Implications for education

7.3.4.1 Raising awareness through education and training resources

People in this study who had presented to various healthcare settings with spinal metastases and subsequent metastatic spinal cord compression encountered significant challenges at their first point of contact, both administrative and clinical, when seeking appointments and answers to their escalating symptoms and life disruption. These early contacts often failed to raise concern that the symptoms could suggest an undiagnosed, advanced cancer. This highlights the need for improved education and training across the healthcare workforce to raise awareness and to promote earlier recognition of potential red flag symptoms. All first point of contact professionals, both those in administration and clinicians in generalist and specialist cancer healthcare services, should have access to appropriate training resources. For example, adoption of the Acute Oncology level 1 and 2 Passports, which were developed by the UK Oncology Nursing Society and the UK Acute Oncology Society Education and Training Group (2024), should be made mandatory across UK healthcare organisations to ensure timely and effective responses to potential oncological emergencies. All healthcare professionals, regardless of speciality, should be equipped to deal with potential oncological presentations, including those who may first present to general practice, emergency departments, orthopaedics or neurology (National Chemotherapy Advisory Group, 2009; NHS England, 2014).

7.3.5 Implications for research

There is a clear need for further research to explore both the experiences and clinical outcomes for those presenting with spinal metastases and metastatic spinal compression, particularly across different disease groups, malignancies of unknown origin, and cancers of unknown primary. This is because diagnostics, treatments, behaviours, and trajectories of each disease group may vary significantly. Focused research is essential to better understand the distinct needs of these groups and to ensure that their care is tailored appropriately. Additionally, there is a need to explore the impact on families and friends, who often experience a sudden and significant increase in responsibility due to the abrupt neurological decline and loss of function of their relative or friend. This aspect is under-researched but is important for developing supportive interventions that recognise the wider network of non-professional care that this population requires. Furthermore, there is a pressing need to explore the professional nursing and therapy requirements of people with metastatic spinal cord compression, to support quicker and smoother transitions from hospital to home, whether for ongoing palliative rehabilitation or palliative and end-of-life care. It is vital to ensure that people have access to timely and appropriate therapy interventions in order to maintain dignity, function, and quality of life during this critical period.

7.3.6 What I have learnt

As a constructivist researcher, I have developed knowledge and skills that enhance both my research practice and my clinical work. I have learned how to use my professional experience to co-construct meaning with participants and to focus on creating knowledge together rather than remaining detached or neutral. I now better understand how to minimise bias by setting aside preconceptions and allowing the data to “speak for itself” as I resist the urge to force early theoretical conclusions.

At times during the analysis of both the primary data and literature, I felt that I was drowning in the data, particularly when trying to make sense of the emerging patterns. However, I came to appreciate the richness and complexity of the process. Being embedded in this area of practice meant that I was already familiar with the literature, but by using a delayed literature review, I was able to position my findings within the wider theoretical landscape in a meaningful way. This allowed me to refine, rather than simply confirm, existing ideas and to offer a unique contribution to this field. This process strengthened my theoretical sensitivity by sharpening my capacity to identify and interpret what was conceptually significant in the data and to develop emerging analytic ideas without prematurely imposing external explanatory theories (Charmaz, 2014; Morse et al., 2009).

Having a dual role as a clinician and researcher strengthened my development of reflexivity. I became more aware of how my clinical lens shaped the way I interpreted the data, and I learned to balance insider knowledge with research objectivity. This reflective process deepened my understanding of theory development and highlighted the value of integrating research into clinical practice.

Through this study, I have realised the significance of physical recovery, goal setting, and returning to normal life for people who present with metastatic spinal cord compression. Previously, I had underestimated the importance of these elements due to the urgency of clinical care. My dual role as a clinician and researcher revealed how my focus on immediate intervention often overshadowed the person's longer-term needs and hopes. This challenged my assumptions and highlighted the importance of supporting not only acute treatment but also what happens next: person-centred care that acknowledges a person's desire for control, normality, and purpose beyond the initial crisis.

As part of this reflexive process, I also developed a more critical appreciation of basic social processes within grounded theory. Within grounded theory, basic social processes refer to patterned actions and interactions through which people respond to and manage a central concern over time; they are explanatory analytic constructions that account for movement, adaptation, and consequence rather than static thematic description (Glaser, 1978; Strauss & Corbin, 1998). Consistent with Morse's conceptualisation of social processes as analytic constructions that are not necessarily evident at the outset but are progressively developed through iterative engagement and increasing levels of abstraction (Morse, 1994; Morse et al., 2009), such processes were not immediately visible in this study. This was particularly the case given the complexity, acuity, and rapid progression associated with metastatic spinal cord compression alongside newly diagnosed advanced cancer. Early analytic attention was therefore oriented primarily towards capturing the immediacy and disruption of participants' experiences.

However, through sustained iterative coding, constant comparison, and analytic memo-writing, a more coherent processual understanding became possible across successive analytic phases (Charmaz, 2014; Glaser, 1978). The conceptual model (Figure 4.1) initially articulated key dimensions of participants' accounts, which were subsequently integrated within the emerging theory (Figure 4.2) as patterns of action, meaning, and consequence were increasingly conceptualised. This analytic progression supported a shift from descriptive categorisation towards interpretive explanation.

The final grounded theory (Figure 6.1) articulated a coherent basic social process centred on how participants navigated disruption, uncertainty, and shifting identities in the context of metastatic spinal cord compression and newly diagnosed advanced cancer. The construction of this process required an increasingly refined theoretical sensitivity, enabling me to move beyond surface-level variation in individual responses to theorise the underlying social and interpretive dynamics shaping participants' experiences (Charmaz, 2014; Morse et al., 2009; Strauss & Corbin, 1998).

Engaging in this level of analytic work deepened my understanding of grounded theory not only as a systematic method of analysis, but as an interpretive practice requiring sustained reflexivity, conceptual risk-taking, and theoretical openness. Overall, this study has strengthened my capacity to think theoretically, to critically interrogate my analytic assumptions, and to recognise the deeper social processes embedded within experiential accounts, contributing to my development as both a qualitative researcher and a clinician.

7.4 Conclusion

In this constructivist grounded theory study, I have identified a gap in our understanding of people's experiences of presenting with metastatic spinal cord compression, and this study contributes to establishing a body of knowledge to address this gap. Through the study, I have explored people's experiences of discovering a newly diagnosed advanced cancer through metastatic spinal cord compression, and how they navigate these complex and shifting experiences of the physical, functional, and emotional changes they undergo. By conceptualising these experiences through the concept of liminality, this study offers valuable insights into how healthcare professionals can provide more holistic, empathetic, and tailored support than is currently provided. Through the primary data and wider literature, I have provided a final grounded theory of: "When the spine speaks first": A constructivist grounded theory of people's experiences of discovering a newly diagnosed advanced cancer through metastatic spinal cord compression. This theory offers a comprehensive understanding of the challenges faced by people in this transitional phase and can be used to guide future research and clinical practice to improve the care and support provided to this vulnerable population.

Appendices

Appendix A: Recruitment Support Information (Acute oncology & MSCC co-ordinators)

Recruitment Support for MSCC Co-ordinators / Acute Oncology Teams
(V3_1/10/22_**IRAS ID 317014)**

My name is Clare Greenbaum. I am a postgraduate researcher undertaking the PhD in Palliative Care programme at Lancaster University, Lancaster, United Kingdom.

Summary of Study:

Study Lead	Clare Greenbaum
Study Title	Exploring the experiences of people who present with metastatic spinal cord compression with a malignancy of unknown origin.
Study Design	Qualitative: Grounded Theory Approach
Study Participants	People diagnosed with metastatic spinal cord compression with a malignancy of unknown origin
Planned Size of Sample	12-18 participants
Planned Period of Study	November 2022 – December 2023
Research Question / Aims	Question: What are the experiences of people who present with metastatic spinal cord compression with a malignancy of unknown origin Aims: To develop a grounded theory to explain the experiences of people who present with metastatic spinal cord compression with a malignancy of unknown origin

MSCC Co-ordinators: If you receive MSCC referrals for people who meet the following eligibility criteria, please ask the local acute oncology team to approach, introduce study to potential participant, issue participant information sheet and assist in the completion of the expression of interest form and send in electronically to **c.greenbaum@nhs.net** / c.greenbaum@lancaster.ac.uk

Inclusion Criteria

- People with MSCC or impending cord compression with neurology of epidural spinal cord compression scale (ESCC) Grade 1C-3
- People where the primary cancer has not been identified or histologically confirmed (MUO or pCUP)
- Aged 18 or older

Exclusion Criteria

- Spinal cord compression of non-malignant origin
- People with a current known primary malignancy prior to developing an MSCC

Please contact within 48 hours of admission:

Study lead contact details:

Name: Clare Greenbaum

Division of Health Research

Faculty of Health and Medicine

Health Innovation One

Sir John Fisher Drive

Lancaster University

Lancaster LA1 4AT

Email: c.greenbaum@lancaster.ac.uk / c.greenbaum@nhs.net Tel: 07807341306

Appendix B: Participant information sheet

Participant Information Sheet (V5_17/01/23_IRAS ID 317014)

Study Title: Exploring the experiences of people who present with metastatic spinal cord compression with a malignancy of unknown origin.

My name is Clare Greenbaum. I am a postgraduate researcher undertaking the PhD in Palliative Care programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

As part of my PhD programme, I am undertaking a study to explore the experiences of people who present with metastatic spinal cord compression where no primary cancer site has been identified which is known as malignancy of unknown origin. The purpose of this study is to gain a greater understanding of your experiences, understanding and expectations of what this time is like for you, in order to review future practice & policy in this area. This study is sponsored by Lancaster University.

Why have I been approached?

You have experienced a recent diagnosis of metastatic spinal cord compression, with no primary cancer diagnosis when you presented to hospital. The study team would like to hear about your experiences.

Do I have to take part?

No. It's completely up to you to decide whether you take part or not. Your care will not be affected by a decision to take part or not.

What will I be asked to do if I take part?

You will be asked to take part in a detailed interview that may take approximately 60 minutes. This interview will be audio-recorded by Clare Greenbaum using an interview recorder with microphone. You can take a break as you need during the interview (for example if you are tired) or can refuse to answer any of the questions if you wish. The information will be used by the researcher to attempt to describe your experiences of presenting with metastatic spinal cord compression with no primary cancer diagnosis. However, if you receive a diagnosis prior to being interviewed you will not be able to take part in the study.

In the event you lost capacity to consent prior to interview then it would not be appropriate to continue. However, if this is due to a short-term reason for example infection or a delirium then identifiable data will be retained and if they regain capacity within one month of presenting with metastatic spinal cord compression and they have not received a confirmed primary cancer diagnosis then you would be given them the opportunity to re arrange the interview if you would like to.

Will my data be Identifiable?

The information you provide is confidential. All data (electronic and paper) collected for this study will be stored securely at Lancaster University and only the Chief Investigator and those working on the study who are authorised by the Chief Investigator on an individual basis will have access to the data.

- Audio recordings will be destroyed and/or deleted once the project has been submitted for examination/publication.
- Hard copies of transcribed data and demographic data will be kept in a locked cabinet.
- The files on the computer will be encrypted (that is, no-one other than the researcher will be able to access them) and the computer itself password-protected for 10 years after they have been transcribed, and the final thesis is submitted and then deleted.
- At the end of the study, hard copies transcripts and demographic data will be kept securely in a locked cabinet for ten years. At the end of this period, they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- As there are only a small number of participants involved in the study your experiences maybe recognised by others from the transcripts. A confidentiality agreement for the transcription of the interviews will be completed to ensure any data transcribed will not he disclosed to a third party.
- All your personal data will be confidential and will be kept separately from your interview responses.

Where can I find out more about how your information is used?

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I may have to break confidentiality and speak to your General Practitioner. If possible, I will tell you if I have to do this.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our
web page: www.lancaster.ac.uk/research/data-protection

What will happen to the results?

The results will be summarised and reported in a PhD thesis and may be submitted for publication in an academic or professional journal of Oncology and Palliative Care. Findings will be presented locally to oncology and spinal surgery teams to which participants, families and carers are invited.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet. If the researcher has any concerns regarding your medical or nursing care then they will have a duty to report this to the clinical team in charge of your care.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct personal benefits to taking part.

However, this research is intended to further our understanding of the experience of patients undergoing who present with metastatic spinal cord compression as their first of sign of cancer of unknown primary and how they may be better supported in the future.

Can I withdraw from the study?

You can leave the study (without explanation or penalty) if you wish to; this is only possible before the interview data will be analysed, as otherwise, it will be difficult to extract post analysis. If you do wish to withdraw post interview, we would ask you to do this within one week post your interview.

Who has reviewed the project?

This study has been reviewed and approved by HRA and the NHSREC. Lancaster University sponsorship office has approved this.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:
Chief Investigator contact details: Name: Clare Greenbaum
Division of Health Research Faculty of Health and Medicine Health Innovation One
Sir John Fisher Drive Lancaster University Lancaster LA1 4AT
Email: c.greenbaum@lancaster.ac.uk

Supervisor:

Dr Yakubu Salifu
Lecturer, International Observatory on End-of-Life Care (IOELC), Division of Health Research, Faculty of Health and Medicine, Lancaster University

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:
Dr Ian Smith Tel: (01524) 529282
Research Director; Email: i.smith@lancaster.ac.uk Faculty of Health and Medicine
Lancaster University Lancaster
If you wish to speak to someone outside of the Palliative Care Doctorate Programme, you may also contact:
Dr Laura Machin Tel: +44 (0)1524 594973
Chair of FHM REC Email: l.machin@lancaster.ac.uk Faculty of Health and Medicine
(Lancaster Medical School) Lancaster University Lancaster
LA1 4YG

Contacting local Patient Advice and Liaison Service (PALS)

The Christie NHS Foundation Trust: Tel: 0161 446 8217 or Email: the-christie.pals@nhs.net

Clatterbridge NHS Foundation Trust: Tel: 0151 556 5203 or Email: ccf-tr.pals@nhs.net

Lancashire and South Cumbria NHS Foundation Trust: Tel 01772 676 028 or Email:

pals@lscft.nhs.uk

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, please contact the Chief Investigator or the following resources may be of assistance:

Your GP
Macmillan Cancer Support http://macmillan.org.uk/How can we help or telephone 0808 808 00 00

Thank you

We would like to take the opportunity to you for taking the time to consider, and potentially participate, in this study. Your contribution will be greatly appreciated.

Appendix C: Expression of interest form

Expression of Interest Form (V3_1/10/22_IRAS ID 317014)

Project: Exploring the experiences of people who present with metastatic spinal cord compression with a malignancy of unknown origin
Have you received a patient information sheet about the project: YES or NO (circle)
Please return this form to a member of your medical or nursing team, the Lancaster University study lead at the UK address below will be in contact with you to discuss the project, answer and questions you may have about the research and whether you would like to take part.

Please complete one or all methods of contact you prefer and leave blank if you do not wish to be contacted in this manner.
Contact mobile phone: Email:
Home phone: Work phone:
Study lead contact details:
Name: Clare Greenbaum
Division of Health Research Faculty of Health and Medicine Health Innovation One
Sir John Fisher Drive Lancaster University

Email: c.greenbaum@lancaster.ac.uk Tel: 0161 956 1730

Appendix D: Participant consent form

Consent Form (V4_12_22/IRAS317014)

Study Title: Exploring the experiences of people who present with metastatic spinal cord compression with a malignancy of unknown origin.

Please initial each statement:

1. I can confirm that I have read the participant information sheet (Version___, Date____) and fully understand what is expected from me within this study.	
2. I have been able to ask questions about the study, and these were answered in a way that I understand and am happy with.	
3. I understand that my participation is voluntary and whether or not I decide to take part will have no effect on my relationship with my healthcare team.	
4. I understand that I am not obliged to take part in this study and can withdraw my participation until the interview data is analysed.	
5. I understand any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researchers may need to share this information with the research team.	
6. I understand that my interview will be audio-recorded and then made into an anonymised written transcript stored securely at Lancaster University.	
7. When interviewed I can also refuse to answer a question and ask to stop taking part at any time without having to give an explanation.	
8. I understand some anonymised quotes from the study may be used in reports and academic papers, but these will not be shared in other ways.	
9. I understand that Lancaster University archive written material after the study has finished.	
10. I understand that information from the study will be used in reports, conferences and training events.	
11. I understand that written material will be kept for 10 years after the research/thesis report.	
12. I understand that the information collected will be pooled with other participants' responses, anonymised and may be published.	
13. I agree to take part in the above study.	

Name of participant: ____

Signature ______________________________________

Date ____________________________ (Day/month/year)

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Signature of Researcher/person taking consent________________________

Date __________**(**Day/month/year)

One copy of this form will be given to the participant and the original kept in the files of the researcher at ……. (Add name of your organisation here)

Appendix E: Participant demographic data tool

Participant data tool (V3_1/10/22_IRAS ID 317014)

Demographic data	**Sex:** Male or Female Age:
Previous cancer diagnosis and were discharged from follow-up services	Previous cancer diagnosis: YES or NO IF yes what type of cancer: Discharge date from cancer follow-up:
Marital status	Single Married Partner Widowed
Performance status pre and post MSCC	**Performance status Pre:** 0 or 1 or 2 or 3 or 4 or 5 Performance status Post: 0 or 1 or 2 or 3 or 4 or 5
Employment status	Employed Unemployed Retired

Study lead contact details:
Name: Clare Greenbaum
Division of Health Research Faculty of Health and Medicine Health Innovation One
Sir John Fisher Drive Lancaster University Lancaster LA1 4A

Appendix F: Interview topic guide

Participant Interview Guide (V3_1/10/22_IRAS ID 317014)

Topic Guide

Introduction and opening questioning

Interviewer will provide a summary of the purpose of the study, the study events and why the study is being completed.

How do you feel today? Is there anything you would like to say before we start the interview?

- Exploring what brought the participant into hospital
- Exploring the experience of MSCC
- Exploring the understanding if what is happening at the moment
- Experience of finding out you have a cancer
- Experience of knowing you have a secondary cancer but not knowing where the primary cancer is

Closing the interview

Is there anything you want to tell me, it may be important to you, something that we haven't talked about?

How do you feel now? What was your experience of the interview?

The interviewer will thank the participant for taking part in the interview

Appendix G: Lancaster University Sponsorship approval

TO WHOM IT MAY CONCERN 1st August 2022

Dear Sir/Madam

LANCASTER UNIVERSITY AND ALL ITS SUBSIDIARY COMPANIES

We confirm that the above Institution is a Member of U.M. Association Limited, and that the following covers are currently in place:

EMPLOYERS' LIABILITY

Certificate No.	Y016458QBE0122A/080
Period of Indemnity	1st August 2022 to 31st July 2023
Limit of Indemnity	£50,000,000 any one event unlimited in the aggregate
Includes	Indemnity to Principals
Cover provided by	QBE UK Limited and Excess Insurers

PUBLIC AND PRODUCTS LIABILITY

Certificate of Entry No.	UM080/05
Period of Indemnity	1st August 2022 to 31st July 2023
Includes	Indemnity to Principals
Limit of Indemnity	£50,000,000 any one event and in the aggregate in respect of Products Liability and unlimited in the aggregate in respect of Public Liability
Cover provided by	U.M. Association Limited and Excess Cover Providers led by QBE UK Limited

If you have any queries in respect of the above details, please do not hesitate to contact us. Yours

faithfully

Paul Cusition

For U.M. Association Limited

TO WHOM IT MAY CONCERN 1st August 2022

Dear Sir/Madam

LANCASTER UNIVERSITY AND ALL ITS SUBSIDIARY COMPANIES

We confirm that the above Institution is a Member of U.M. Association Limited, and that the following cover is currently in place:

PROFESSIONAL INDEMNITY

Certificate of Entry No.	UM080/05
Period of Indemnity	1st August 2022 to 31st July 2023
Limit of Indemnity	£5,000,000 any one claim and in the aggregate except for Pollution where cover is limited to £1,000,000 in the aggregate
Cover provided by	U.M. Association Limited

If you have any queries in respect of the above details, please do not hesitate to contact us. Yours

faithfully

Paul

Paul Cusition
For U.M. Association Limited

Appendix H: Northwest Research Ethics Committee (NHSREC) approval

NHS
Health Research
Authority

Northwest - Greater Manchester West Research Ethics Committee

Barlow House

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

3rd
Floor 4
Minshull Street
Manchester

M1 3DZ

13 January 2023

Mrs Clare Greenbaum 4
Hurst Green Gardens
Culcheth
Warrington WA3
4FX

Dear Mrs Greenbaum

Study title:	**Qualitative: Grounded Theory Approach Exploring the experiences of people who present with metastatic spinal cord compression with a malignancy of unknown origin.**
REC reference:	**22/NW/0372**
IRAS project ID:	**317014**

Thank you for your letter received on 18.12.22, responding to the Research Ethics Committee's (REC) 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.

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.

The REC identified the following recommendation to be issued to the research team. Please note that fulfilling this recommendation is not a condition of the final decision for this application. This recommendation is provided to support the research team and encourage good research practice.

Recommendation: the members of the REC strongly recommend considering posting a summary of the study findings to a suitable website (with details of such within the participant information sheets).

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions/recommendations of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study: Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

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 management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database, and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, ‘clinical trials’ are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-sum maries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

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).

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, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) 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/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Interview schedules or topic guides for participants [Interview topic guide]	V3	01 October 2022
IRAS Application Form [IRAS_Form_26102022]	317014/1588451/37/558	26 October 2022
Other [Dept risk assessment]		31 August 2022
Other [Distress Protocol]	V3	01 October 2022
Other [Transcriber confidentiality agreement]	V3	01 October 2022
Other [Recruitment support document]	V3	01 October 2022
Other [Potential Participant data form]	V3	01 October 2022
Other [Expression of Interest form]	V3	01 October 2022
Other [Post ethics review information]	*Submitted on 18/12/2022	
Participant consent form [Participant Consent Form]	V4	12 December 2022
Participant information sheet (PIS) [Participant Information Sheet]	V4	14 December 2022
Research protocol or project proposal [Study/Research Protocol]	V4	14 December 2022
Summary CV for Chief Investigator (CI) [CV]		
Summary CV for student [Student_CV]		

Summary CV for supervisor (student research) [Academic Supervisor CV]		
Summary CV for supervisor (student research) [CV_ academic supervisor_2]		
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Sponsor insurance]		01 August 2022

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.

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 Learning -We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:

https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 317014 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely, Aoife Harrington pp Mrs Julie Grindey Vice Chair

Email: gmwest.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Non-CTIMP Standard Conditions of Approval

Copy to: Ms Becky Gordon
Lead Nation
approvals@hra.nhs.uk

Appendix I: Health Research Authority (HRA) approval

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Mrs Clare Greenbaum
4 Hurst Green Gardens
Culcheth
Warrington
WA3 4FX

Email: approvals@hra.nhs.uk

23 January 2023

HRA and Health and Care Research Wales (HCRW) Approval Letter

Dear Mrs Greenbaum

Study title:	**Qualitative: Grounded Theory Approach Exploring the experiences of people who present with metastatic spinal cord compression with a malignancy of unknown origin.**
IRAS project ID:	**317014**
REC reference:	**22/NW/0372**
Sponsor	**Lancaster University**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set, and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation.

The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below

Your IRAS project ID is **317014**. Please quote this on all correspondence.

Yours sincerely, Theodora Chortara Approvals,Specialist

Email: approvals@hra.nhs.uk

Copy to: *Ms Becky Gordon*

Appendix J: Distress Protocols

Distress Protocol 1 (Participant)

Protocol for managing distress in the context of a study interview (Drauker et al 2009)

Distress	• A participant indicates they are experiencing a high level of stress or emotional distress OR • Exhibit behaviours suggestive that the interview is too stressful such as uncontrolled crying, shaking etc
Stage 1 Response	• Stop the interview • Study lead (health professional) will offer immediate support Assess mental status: • Tell me what your thoughts you are having? • Tell me what you are feeling right now? • Do you feel you are able to go on about your day? • Do you feel safe?
Review	• If participant feels able to carry on; resume interview / discussion • If participant is unable to carry on – go to stage 2
Stage 2 Response	• Discontinue interview • Encourage the participant to contact their GP or mental health provider OR • Offer, with participant consent, for the study lead to do so OR • With participant consent contact a member of the health care team treating them for further advice/support
Follow-up	• Follow participant up with a courtesy call (if participant consents) OR • Encourage the participant to call either if he/she experiences increased distress in the hours / days following the interview

Distress Protocol 2 (Interviewer/Study Lead)

The protocol for managing distress in the context of a study interview management (McCosker et al 2001)

Pre-Data Collection	• The study lead should consider the potential physical and psychological impact on themselves of the participants description of life experiences • The study lead should consider how many interviews could be undertaken in a week • The study lead should be aware of the potential for emotional exhaustion
Data collection stage	• If the topic in potentially sensitive/distressing data collection the study lead could consider a 2nd interviewer for the study • Regular scheduled debriefing sessions with an appropriate designated supervisor • May be encouraged to journal their thoughts and feelings which may then become part of the fieldwork notes in some study approaches
Analysis	• Is alerted prior to transcription review of potentially “challenging” or “Difficult” interviews • Has regular schedule debriefing sessions with an appropriate designated supervisor
Follow-up	• Encourage the study led to access a study mentor if he/she experiences increased distress in the hours / days following transcription

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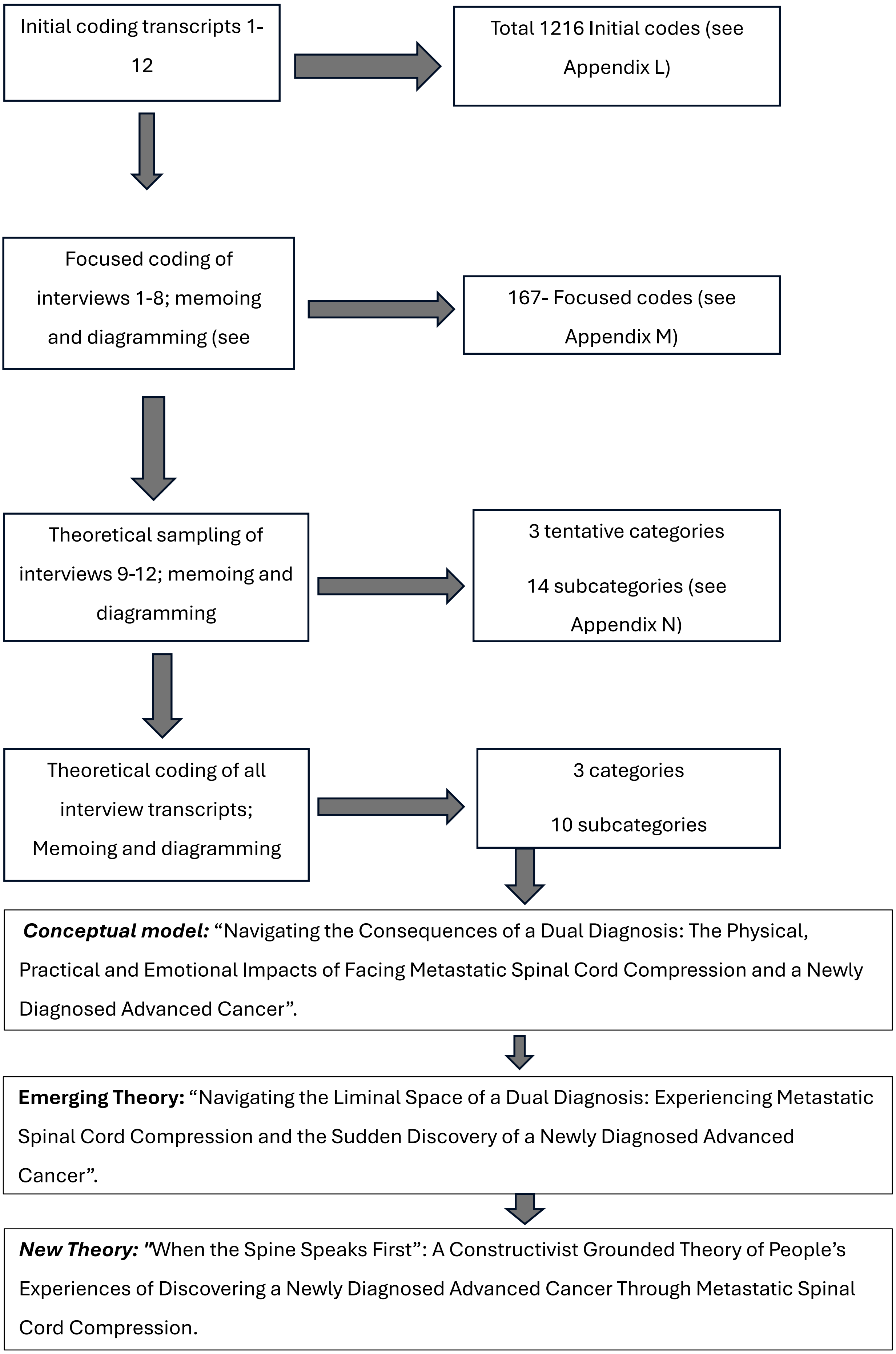
Distress Protocol 3 (Transcriber/Study Lead)

The protocol for managing distress in the context of a study interview transcription (Gregory et al 1997)

Pre-data collection	• The transcriber should be considered in any study proposal, with a clear indication of how this person will be provided with a 'safe' working environment while also maintaining the 'quality' of the study
Ethical review stage	• Be included in the ethical clearance process • Is informed of the nature of the research and the type of data
Pre-transcription	• Is alerted prior to the transcription of potentially 'challenging' or 'difficult' interviews • Has regular scheduled debriefing sessions with a named member of the study team
During transcription	• Has prompt access to an appropriate person for crisis counselling • Has a clearly documented termination from the transcription process that includes resolution of personal issues which arose as a consequence of the work • May be encourages to journal their thoughts and feelings which may then become part of fieldwork notes in some study approaches
Follow-up	• Follow transcriber up with courtesy call (if transcriber consents) • OR • Encourage the transcriber to call if he/she experiences increased distress in the hours/days following transcription

Appendix K: Data analysis process



Initial coding transcripts 1-12

Total 1216 Initial codes (see Appendix L)

Focused coding of interviews 1-8; memoing and diagramming (see

167- Focused codes (see Appendix M)

Theoretical sampling of interviews 9-12; memoing and diagramming

3 tentative categories

14 subcategories (see Appendix N)

Theoretical coding of all interview transcripts; Memoing and diagramming

3 categories

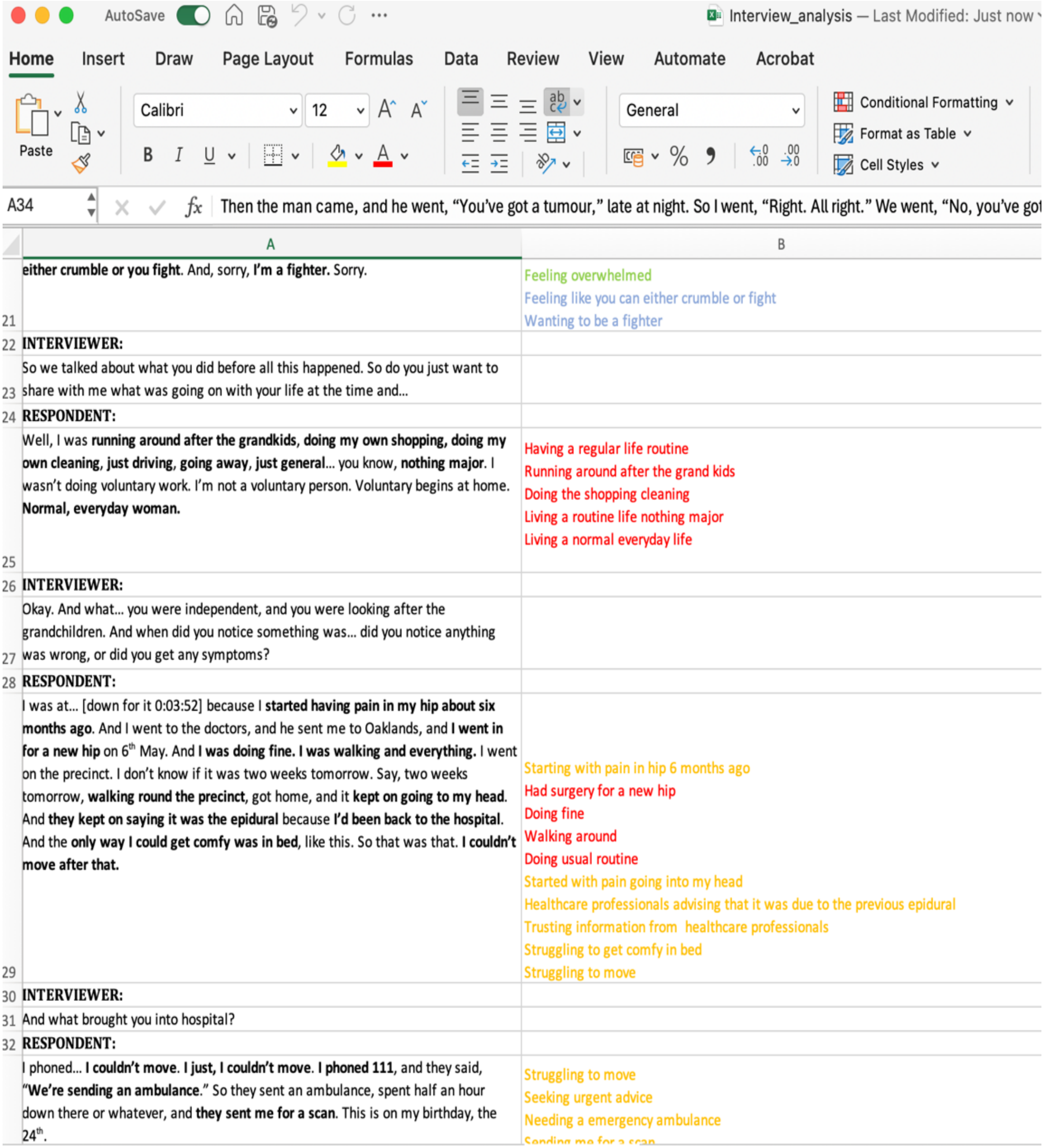
10 subcategories

Conceptual model: "Navigating the Consequences of a Dual Diagnosis: The Physical, Practical and Emotional Impacts of Facing Metastatic Spinal Cord Compression and a Newly Diagnosed Advanced Cancer".

Emerging Theory: "Navigating the Liminal Space of a Dual Diagnosis: Experiencing Metastatic Spinal Cord Compression and the Sudden Discovery of a Newly Diagnosed Advanced Cancer".

New Theory: "When the Spine Speaks First": A Constructivist Grounded Theory of People's Experiences of Discovering a Newly Diagnosed Advanced Cancer Through Metastatic Spinal Cord Compression.

Appendix L: **Initial coding** of the transcript sample



A34 Then the man came, and he went, "You've got a tumour," late at night. So I went, "Right. All right." We went, "No, you've got

	A	B
21	**either crumble or you fight**. And, sorry, **I'm a fighter.** Sorry.	Feeling overwhelmed Feeling like you can either crumble or fight Wanting to be a fighter
22	**INTERVIEWER:**	
23	So we talked about what you did before all this happened. So do you just want to share with me what was going on with your life at the time and…	
24	**RESPONDENT:**	
25	Well, I was **running around after the grandkids**, **doing my own shopping, doing my own cleaning**, **just driving**, **going away**, **just general**… you know, **nothing major**. I wasn't doing voluntary work. I'm not a voluntary person. Voluntary begins at home. **Normal, everyday woman.**	Having a regular life routine Running around after the grand kids Doing the shopping cleaning Living a routine life nothing major Living a normal everyday life
26	**INTERVIEWER:**	
27	Okay. And what… you were independent, and you were looking after the grandchildren. And when did you notice something was… did you notice anything was wrong, or did you get any symptoms?	
28	**RESPONDENT:**	
29	I was at… [down for it 0:03:52] because I **started having pain in my hip about six months ago**. And I went to the doctors, and he sent me to Oaklands, and **I went in for a new hip** on 6th May. And **I was doing fine. I was walking and everything.** I went on the precinct. I don't know if it was two weeks tomorrow. Say, two weeks tomorrow, **walking round the precinct**, got home, and it **kept on going to my head**. And **they kept on saying it was the epidural** because **I'd been back to the hospital**. And the **only way I could get comfy was in bed**, like this. So that was that. **I couldn't move after that.**	Starting with pain in hip 6 months ago Had surgery for a new hip Doing fine Walking around Doing usual routine Started with pain going into my head Healthcare professionals advising that it was due to the previous epidural Trusting information from healthcare professionals Struggling to get comfy in bed Struggling to move
30	**INTERVIEWER:**	
31	And what brought you into hospital?	
32	**RESPONDENT:**	
	I phoned… **I couldn't move**. **I just, I couldn't move**. **I phoned 111**, and they said, "**We're sending an ambulance**." So they sent an ambulance, spent half an hour down there or whatever, and **they sent me for a scan**. This is on my birthday, the 24th.	Struggling to move Seeking urgent advice Needing a emergency ambulance Sending me for a scan

Appendix M: Codebook of **focused codes**

Groups:	**Focused codes**
Life pre diagnosis	1. Reflecting on having an active life 2. Recognising age-related changes 3. Having a regular routine 4. Enjoying life 5. Being independent 6. Feeling content with life **7.** Having a life plan
Presenting with MSCC	8. Recognising a change in function 9. Recognising a change in regular routine 10. Experiencing severe pain 11. Recognising symptoms weren't normal 12. Minimising urgency of situation (HCP's) 13. Feeling frustrated with accessing assessment 14. Focusing on age-related changes 15. Seeking answers about increasing physical symptoms 16. Seeking answers about functional changes 17. Trusting HCPS to explain process, investigations and diagnosis 18. Focusing on rehabilitation 19. Failing to improve physically 20. Recognising the need for urgency 21. Feeling desperate 22. Feeling relieved when emergency services arrived 23. Feeling unprepared for outcome of investigations 24. Dismissing initial symptoms (participant) 25. Feeling relieved when admitted into specialist hospital 26. Recognising risk from previous cancer diagnosis (HCP's) 27. Receiving a diagnosing without investigations
Presenting with increasing symptoms	28. Fearing a cancer diagnosis 29. Reflecting on events leading to diagnosis 30. Minimising urgency of symptoms 31. Having an awareness, it could be cancer 32. Needing to trust in HCP's knowledge 33. Recognising a physical change
Diagnosis	34. Feeling shocked 35. Feeling devastated 36. Seeking knowledge and understanding about diagnosis (MSCC, Metastatic cancer, MUO) 37. Trying to understand the meaning of diagnosis (MSCC, metastatic cancer, MUO) 38. Misunderstanding diagnosis 39. Misunderstanding cause of physical deterioration 40. Finding it difficult to understand it all 41. Struggling to remember information 42. Understanding that cancer is not curative 43. Dealing with the uncertainty (cancer and function)

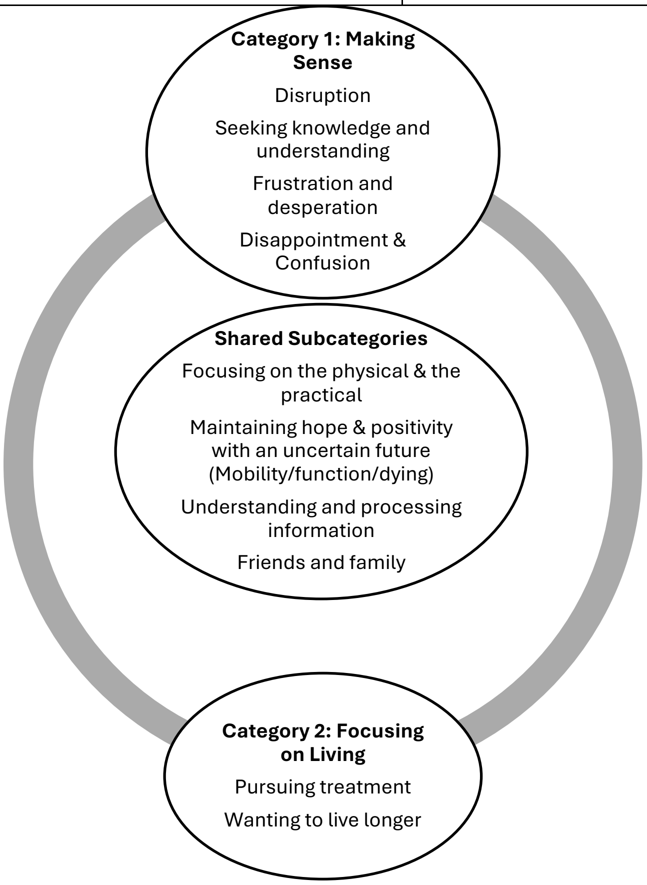
	44. Having things explained by experts 45. Needing terms/language explained 46. Needing time to absorb information 47. Needing to wait for results 48. Recognising life will change 49. Wanting to fight 50. Focusing on living 51. Needing to be involved with decision-making (moving forward) 52. Feeling angry (younger participants)
Treatment	53. Pursuing any treatment to live 54. Focusing on treatment 55. Seeking knowledge and understanding about treatment options 56. Trying to understand treatment aims (primary and MSCC) 57. Trying to understand decision-making 58. Wanting HCPs to understand wishes regarding treatment 59. Trusting HCPs with treatment decisions 60. Wanting to be included in decision-making about treatment 61. Understanding treatment aims are to control cancer 62. Needing to wait for histology (further cancer treatment) 63. Misunderstanding treatment decisions (cancer and MSCC)
Future	64. Wanting to live life 65. Focusing on returning to normal (function/routine) 66. Wanting to carry on 67. Wanting to walk again 68. Wanting to return to independence 69. Wanting to reach goals 70. Recognising change in function 71. Trying to adapt to change 72. Seeking new ways to adapt 73. Recognising life changes are needed 74. Feeling uncertainty 75. Fearing a level of disability 76. Needing some organisation 77. Wondering what life will be like 78. Pacing thoughts 79. Trying to make changes to live longer 80. Focusing on quality of life **81.** Taking information in stages
Seeking knowledge and information	82. Seeking knowledge about new symptoms 83. Seeking knowledge about change in function 84. Seeking expert knowledge and understanding about diagnosis (cancer and MSCC) 85. Trying to understand the meaning cancer and MSCC 86. Seeking to understanding what is happening about next steps 87. Recognising complexity of situation 88. Needing to understand purpose of spinal instructions 89. Wanting things to be explained in more detail 90. Seeking knowledge to understand options

	91. Needing information in more detail 92. Appreciating expert knowledge 93. Trusting healthcare professionals to interpret expert knowledge 94. Needing expert guidance with information and decision-making 95. Needing information at appropriate level 96. Feeling confused with information 97. Needing time to process information 98. Needing the opportunity to ask questions 99. Needing support to explain to family 100. Seeking cancer information from family and friends 101. Recognising medication and fatigue can impact on processing information 102. Feeling overwhelmed with information 103. Struggling with verbal information 104. Needing information to be repeated 105. Receiving information from multiple sources 106. Feeling confident with expert knowledge 107. Trying to understand different terms/language (cancer/MSCC)
Mortality and dying	108. Choosing not to die 109. Acknowledging death an inevitable part of life 110. Having no control over dying 111. Accepting mortality is increasing with age 112. Facing death is more of a reality when diagnosed with cancer
Family and friends	113. Focusing on family 114. Recognising the importance of family and friends 115. Wanting family to be involved 116. Relying on family and friends 117. Feeling dependent on family and friends 118. Depending on each other 119. Looking after each other 120. Acknowledging contentment with family
Hope	121. Hoping to get better 122. Hoping to live longer
Positivity	123. Trying to be positive
NHS staff	124. Trusting in healthcare professionals with knowledge and information 125. Angry with lack of understanding and compassion 126. Appreciating HCP's trying to do something 127. Appreciating support from HCP's 128. Being introduced to the right HCPs at the right time 129. Appreciating patient/empathetic nursing staff 130. Needing to communicate to your needs 131. Wanting to be treated as a whole person 132. Appreciating specialist support 133. Recognising the importance of being treated with dignity and respect 134. Having multiple HCP's/teams involved
Mobility	135. Wanting to improve physically 136. Moving from independence to dependence

and function with MSCC	137. Wanting to be independent again 138. Wanting to walk again 139. Focusing on physiotherapy 140. Acknowledging the need to adapt 141. Seeking new ways to adapt 142. Recognising limitations 143. Wanting to make progress 144. Wanting to do more 145. Accepting more help will be needed 146. Accepting level of disability to live longer 147. Feeling uncertain about future
NHS systems /Pressure	148. Finding access to assessment teams difficult 149. Demanding to be seen 150. Feeling desperate 151. Having no control 152. Having to wait for investigations 153. Recognising NHS pressures impact on communicating information 154. Having to accept and conform 155. Having multiple professionals involved 156. Needing coordination
Inpatient	157. Having lack of control 158. Having to accept and conform 159. Feeling dependent on ward staff 160. Needing more time with physio 161. Needing to understand medical and NHS processes 162. Feeling abandoned at times 163. Needing to understand hospital routines 164. Feeling lonely 165. Needing contact with family and friends 166. Feeling secure when admitted to specialist centre 167. Feeling secure to seek answers

Appendix N: Example of exploring tentative subcategories and categories

Category	Previous subcategories	New subcategories
Making Sense	1. Disconnection 2. Disruption 3. Seeking knowledge and understanding 4. Frustration 5. Desperation	1. Disruption 2. Seeking knowledge and understanding 3. Frustration and desperation 4. Disappointment & Confusion
Focusing on living	6. Pursuing treatment 7. Waiting 8. Positivity and maintaining hope	5. Pursuing treatment 6. Wanting to live longer
Shared	9. Getting physically better 10. Recognising & Negotiating change 11. Regaining control 12. uncertainty 13. Understanding and processing information 14. Friends and family	7. Focusing on the physical & practical 8. Maintaining hope & positivity with an uncertain future (Mobility/Function and dying) 9. Understanding and processing information 10. Friends and family



Appendix O: Examples illustrating the development of category 1: 'Making Sense of bodily changes and life disruption'

Participant	Interview Transcript	Initial code	Focused code	Theoretical memo	Sub-categories	Category
10	Working. Socially, I like playing golf. In the summer, I play it, like, two or three times a week. (P10 L14)	Enjoying an active life	Reflecting on having an active life Having a regular routine Recognising changes (physical and life routine) Minimising urgency Experiencing severe pain	All participants started with sharing how this experience started pre-diagnosis, they frequently reflected on the past what they could do then how things changed so much from their normal, and they struggled to make sense and communicate these changes. The increasing changes/symptoms brought disruption	**Disruption**	**Making Sense of Bodily Changes and Life Disruption**
2	It was just everyday...I won't say, well it is the same....my brain has always been active...jump in the car...have a natter with my friends of 40 odd years. Seems a dull life when you mention that, but that's way it has always been' (P2 L8)	Having a daily life routine				
6	Oh, God. It's a massive change. You couldn't get a more massive change if you wanted, could you? (P6 L219)	Recognising change				
8	it's a bad back. It can get better. (P8 L153)	Minimising symptoms				
4	'I had to sleep downstairs because me and my wife used to sleep in the same bed, as most couples do, but it became exceedingly painful to get out of bed with my back, as if it was pinned and needles giving me hell' (P4 L47)	Changing routine				
9	Went to my GP and I said, "Oh, I've got this pain and it's getting me down. I can't walk as far as I used to walk." But he didn't really do anything about it. He just said, "Just continue doing what you do with the gel and take the painkillers and everything." (P9 L9)	Seeking answers to functional	Seeking answers about increasing physical symptoms Seeking answers about increasing functional changes Recognising the need for urgency	The tried hard to seek answers, it was clear to see how hard participant had tried to seek answers to what was happening to them. Often, they were no 'urgent route' for them to access this often led to being reassured that their symptoms were benign in nature. However, they persisted as they were not seeing any sign of their situation resolving and they were so far from their normal, functioning routine.	**Seeking Answers**	
7	I got in touch with the GP, because I thought, "My hip now has taken over from my shoulder." So, went to see the GP, kind of, said I knew my background, because years ago, I used to have a bad back. (P7 L17)	Seeking answers to physical symptoms				
4	'I think they said it sounded like mobility problems, no energy, no energy problems, things like that, which it should be better, you know, you don't run marathon' (P4 L54)	Minimising urgency of symptoms				
1	'So, when I phoned the doctor this time, he said "Oh, I'll refer you to the OT's" and he gave be a date about three weeks down the line' (P1 L 74)	Lacking urgency				
1	The OTs wanted to get me walking. They'd only give me 10-15 minutes a day it seems, because I wasn't responding that well (P1 L82)	Failing to improve physically	Failing to return to normal Feeling frustrated with accessing information / systems Feeling desperate	As participants recognised, they were not returning to their normal, they were failing to improve, elderly participants were often channelled down rehabilitation to resolve their reduced mobility they became even more frustrated with healthcare systems they found it hard to communicate the changes as they were not clinical unwell. This led to desperation when they neurology and significantly deteriorated and they needed emergency access to services	**Frustration and Desperation**	
6	I'm on the floor. I can't move on the floor, but I am conscious. I am... whatever, so I'm not priority. But they did come, I think, within a reasonable time. I mean, the ambulance crew were absolutely amazing (P6 L137)	Feeling frustrated with systems				
9	At last, I was relieved because I could not do it. I had a very bad night one night at home and I could not do it anymore. (P9 L35)	Feeling desperate				

Appendix P: Examples illustrating the development of the category 2: ‘Focusing on Living for Longer’

Participant	Interview Transcript	Initial code	Focused code	Theoretical Memo	Sub-categories	Cate-gory
1	‘I can’t sit in a wheelchair, although hopefully the physios are going to work on that’ (p1 L18)	Hoping physios will help with physical improvement	Wanting to improve physically Wanting to make progress Seeking new ways to adapt Regaining control Accepting level of disability Returning to a normal routine Having dignity and respect from HCP’s	At this stage participants saw their reduced physical function as the barrier to them moving forward from MSCC rather than the metastatic cancer diagnosis As above they saw their reduced physical function as a barrier to them returning to their ‘normal life’, so they were focusing on improving their function as a priority They were willing to comprise ‘normal’ in order to live longer and return to living their pre-diagnosis life With the deterioration with function and loss of independence participants felt more confident when HCPs were patient, recognised that this was new for them, took time to allow them to try to be independent which increased self-confidence. Dignity and respect were a huge factor particularly with personal care. It was extremely hard for participants be dependent for these private things that MSCC had brought like bowel and catheter care	**Focusing on the physical and the practical changes**	**Focusing on Living Life for Longer**
5	I might be in a wheelchair, which is fair enough. But I’ll be here. I’ll still be me. (P5 L277)	Accepting a level of disability to continue to enjoy life				
6	But I’m really happy that I’m making progress. (P6 L347)	Recognising a long way to go to improve function				
8	*Yes, I cannot get over how frail I am, how weak I am. The weakness hit me yesterday and it’s terrible to think my body reducing to that and. And I’ve got a very long way to go. (P8 L208)*	Recognising physical deterioration				
6	It boosts me on, as well. It boosts me on to get well. They talked to me with dignity. They talked to me with respect and boosts me to move on.’ (P6 L342)	Being treated with dignity and respect				
1	‘I felt that I could be helped and certainly I hoped I could be helped. And I mean I do a lot of things’ (P1 L15)	Wanting and hoping to be helped by healthcare professionals	Focusing on treatment Pursing treatment to live	Participants recognised that receiving cancer treatment would mean living longer		

5	So maybe it'll be... and a tablet a day, or I'll have to come in and have a blood transfusion, or I'll have to... so what? I'm here. (P5 L124)	Pursing treatment whatever form to be here	Trusting HCPs to know wishes about treatment	They wanted to focus on treatment as a positive route to getting better and surviving longer Some participants did not understand that there was no treatment option post radiotherapy as there had been a focus on having treatment for MSCC? they assumed or misunderstood or it had not been explained that there was no further treatment due to their extensive disease and poor performance status. Whereas in participants where disease had not spread further they also assumed from conversations that once histology had been confirmed there would be more treatment offered.? balancing hope and reality		
2	*Until we get the biopsy report and can plan a way ahead with chemotherapy, we're not going anywhere immediately.' (P2 L50)*	Pursuing chemotherapy treatment				
7	If I can live, and they can zap me and blast me, and put a load of shit in me, to just keep me waking up every day, I'll do it. (P7 L86)	Willing to take any treatment to live				
6	I think I was probably slightly off with the fairies by this time because I'm so in bloody pain and things. (P6 L106)	Feeling unable to remember due to pain	Feeling overwhelmed with information Feeling confused with multiple teams Feeling confused with information Recognising medication and fatigue impacts on processing	Receiving information and processing information was challenging, often participants were on their own when the medical ward round attended them, many teams reviewing with different priorities, often people had moved across several hospital sites, exhausted, cogitatively impaired due to analgesia	**Understanding and processing of information**	
10	It's not easy to think of these things at the time, especially when you've had to take quite a bit of morphine to get in. (P10 L274)	Feeling the effects of medication on cognition				
8	but it was very, very difficult, wasn't it? You had about seven or eight nights of indescribable, that level, no sleep. And of course, that's kind of affecting your mental state. (P8 L75)	Feeling impact of no sleep on mental state				
9	somebody came to me today with a folder. (Laughs) Oh yes. Pain and whatever. She came to me today twice and she said about the pain, yeah, and all the different types of things that can help with the pain. But before she does all that, she's got to take some bloods on Monday to check my renal function and if I really need it, I can have it. Yeah, and it's going to be a patch instead of oral. (P9 L139)	Feeling confused with which team did what				
10	Yeah, it gets confusing sometimes, especially round, yeah, drugs. Yeah, I mean, local hospital is sending you stuff, the GP, and cancer hospital (P10 L106)	Feeling confused with systems				
1	'It was disappointing. I was surprised that as far as I know, this wasn't getting any better' (P1 L30)	Knowing cancer wasn't getting any better	Acknowledging death as an inevitable part of life	Participants had a powerful desire to continue to live life and look forward regardless of their stage of cancer prior to primary cancer being found	**Wanting to Live Longer**	
4	'Well, I know in my age group people, you know, sometimes die through cancer' (P4 ??)	Knowing that people in older age group die through cancer	Having no control over dying			

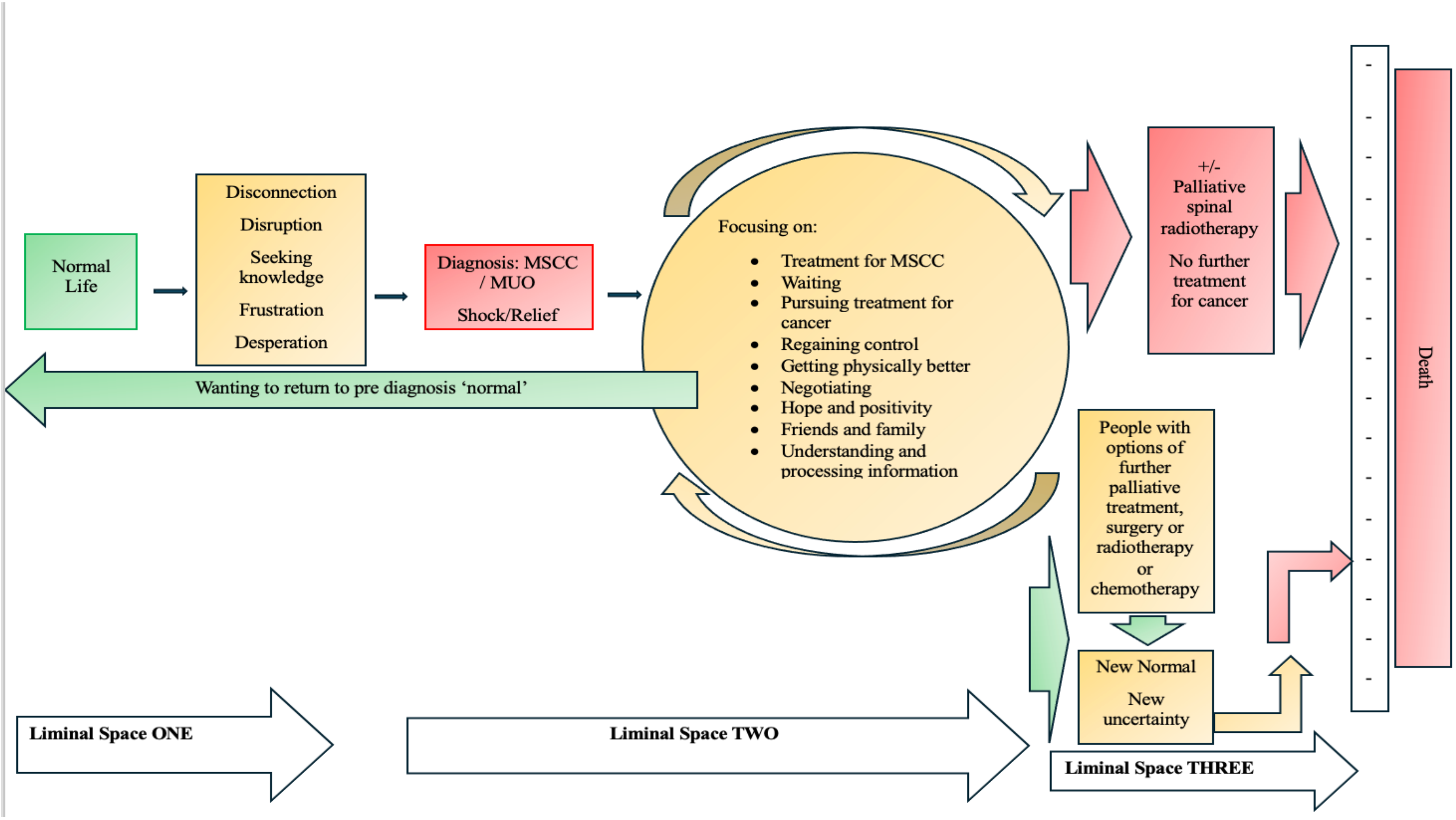
5	*I'm just going to live the life that I've been living. (P5 L168)*	Wanting to live the life I had	Accepting mortality is increasing with age Facing death is more of a reality with a cancer diagnosis	The were looking forward planning almost forgetting their new advanced life-limiting cancer diagnosis, this did not cause concern at this stage, this was not a barrier to their future whereas the physical and functional deficits were.		
10	Well, I think it's pretty much straightaway they told me I wouldn't be cured from it. Yeah, I think the plan is just to give me as much quality of life as possible. (P10 L110)	Knowing the cancer was not curative				
1	'It can't be very long, I'm not happy about it, but what can you do?' (P1 L46)	Accepting no control over dying				
3	'But I just thought, "Well, okay, I've not got many years, but I'd like to carry on a bit longer" you know' (P3 L105)	Hoping to live longer				

Appendix Q: Examples illustrating the development of the category 3: 'Emotional consequences of a Dual Diagnosis'

Participant	Interview Transcript	Initial code	Focused code	Theoretical memo	Sub-categories	Cate-gory
9	Yes, sometimes, yeah. I don't think too deep. I just take it step-by-step. (P9 L147)	Taking it step-by-step	Needing to wait for histology Waiting to hear what next Waiting in the system	I sensed during early interviews that none of the participants were frustrated with waiting for results of primary cancer or what happens next, which was different to their frustration while they were waiting to have MSCC diagnosed. They seem comfortable with this period of waiting, this period of 'limbo' almost that they prefer the unknown? in denial of the life-limiting cancer diagnosis.	**Waiting in Limbo**	**Emotional consequences of a dual diagnosis**
7	I feel like I'll be in a limbo stage forever, whatever time I've got (P7 L234)	Feeling in limbo				
8	But we're at the beginning of a long path. Anyway, it's unknown. I don't know where I'm going or what I'm going to do. No idea what sort of treatment they might be thinking of, if any. (P8 L212)	Having to wait to see what happens next				
12	So, everyone's waiting for this, they're all just poised and waiting (P12 L332)	Waiting for histology				
11	But they're coming to you and they're telling you that, "We're not sure yet until we get the results." (P11L293)	Waiting in the unknown				
6	*I'm trying to stay as positive and looking forward as I can. I want to make the most recovery that I can possibly make. (P6 L320)*	Focusing on looking forward	Trying to be positive Hoping to get better Hoping to live longer	All were positive and had hope of controlling the cancer and returning to a normal they were still processing the extent of their disease in some cases, and some found it difficult accept without a confirmed primary cancer	**Maintaining Hope and**	
12	*So, I know I'm a long way from being back to normal, but I can get up the stairs and down the stairs and into bed and out of bed and make a cup of tea. I'm far happier now to deal with the next stage than… like I say, hopefully, it just comes back, it's behind*	Hoping to get back to normal				

	us and we'll sort it out. But whatever it is, I'm ready to have a go at it because I'm up and about (P12L348)		Wanting to fight	Participants with extensive disease were still positive and had hope, they either didn't understand or had not processed the information that had been given that there was not further treatment post radiotherapy for MSCC? was this due to shock or denial or just not explained in a way that they didn't understand? Difficult to question this further at times as research and may cause distress		
4	Well, it gave me hope of getting better. I didn't sort of write myself off straight away, I've got cancer, I can get better.' (P4 L113)	Hopping to get better				
1	Try to be as positive as possible, which is not easy' (P1 L136)	Trying to be as positive as possible				
5	I'm fighting for me and my little family (P5 L76)	Wanting to fight	Focusing on family Recognising the importance of family and friends Relying on family and friends Wanting family to be involved Feeling dependent on family and friends Looking after each other Needing to be together	Family and friends were central through this transition Contact was essential for their well-being and to engage with normality They were their drive to get better They did not want to be a burden Key with supporting to move through transition ? Key differences in single/younger group? who were their support unfamiliar territory with trusting friends	**Family and Friends**	
8	I want all the information about me to be channelled through my daughters because they care about me more than anybody else in this world and they will do nothing to bring me home (sic). They will only wish me good. And they will prevent harm if they can. So, it's open door for them. (P8 L19)	Wanting my daughters to be involved				
3	'Come out (of surgery) and seeing my kids, seeing xxxx and xxxxx and the two grandchildren' (P3 L117)	Focusing on family				
2	It's difficult to explain, because I've always been an active person, my friends of 40 years. So, things like that, I won't say I'm beginning to miss, but's it's been pushed to one side' (P2 L42)	Needing contact with friends				
4	'I think my mobility has to be better, well, I know it does, I'd be a burden on xxxxx, do you know what I mean? It would drain her; she would probably become ill with doing everything' (P4 L153)	Feeling dependent on family				
2	'Now, he has got the keys to the house, so he has been moving the car to the house from the airfield, putting the shopping in, cleaning up.' (P2 L63)	Being dependent on friends				
4	'It's just hard being separated when things like this are going on' (P4 L345)	Finding it hard being separated				

Appendix R: Examples of diagramming



Appendix S: Dixon et al. (2006) Critical Interpretive Synthesis Quality Appraisal of included studies

Author (year), country **Research question or aim**	**Journal**	**Type of paper QL = qualitative; GT = grounded theory)**	**Are the aims & research objectives of the research clearly stated**	**Is the research design clearly specified & appropriate for the aims and objs of the research?**	**Do the researchers provide a clear account of the process by which their findings were produced?**	**Do the researchers display enough data to support their interpretation & conclusions**	**Is the method of analysis appropriate & adequately explained?**
Warnock & Tod (2014) **(UK)** To explore the experiences, concerns and priorities of patients newly diagnosed with advanced malignant spinal cord compression and had significant problem with mobility at presentation*	**Journal of Advanced Nursing**	**QL other**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Manson et al. (2017) **(UK)** To explore the experiences in the days and weeks following discharge home post discharge and treatment for metastatic spinal cord compression*	**Supportive Care in Cancer**	**QL other**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**

Eva et al., (2008) (UK) The study aims to ascertain the constructions placed upon disability by patients with MSCC*	**Palliative Medicine**	**QL other**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**

(Lee, 2013) **(UK)** A case study analysis to explore the perceptions and experiences of patients, carers and/or family members and healthcare professionals in the management of metastatic spinal cord compression*	**PhD Thesis**	**QL other**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Vedelø et al. (2024) **(Denmark)** A Fast transition: a case study of patient's experiences during the diagnostic and surgical treatment phase of accelerated brain cancer pathway*	**Scandinavian Journal of Caring Sciences**	**QL other**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Nixon & Narayanasamy (2010) **(UK)** To identify the spiritual needs of neuro-oncology patients form a patient's perspective and how nurses currently support patients with spiritual needs*	**Journal of Clinical Nursing**	**QL other**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Sterckx et al. (205) **(Belgium)** To better understand how patients with high-grade glioma experience life with a brain tumour and to explore their professional care needs*	**European Journal of Oncology Nursing**	**GT**	**Yes**	**Yes**	**Yes**	**Yes**	**YEs**
Nyatanga et al. (2024) **(UK)** To understand the impact of living with a primary brain tumour and identify adjustments the patients make in order to cope with their condition*	**International Journal of Palliative Care**	**QL other**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**

Halkett et al. (2010) **(Australia)** To understand patients' experiences of High-Grade Glioma and identify and describe information and support needs along the disease trajectory*	**Patient Education and Counselling**	**GT**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Fahrenholtz et al. (2019) **(Denmark)** To gain understanding and knowledge of patients' experience of being diagnosed with a severe disease and their view of a rehabilitation process*	**British Medical Journal**	**QL other**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Lobb et al. (2011) **(Australia)** To seek the views of patients and their caregivers on their experience of being diagnosed with high-grade glioma*	**Journal of Neuro-oncology**	**GT**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Piil et al. (2015) **(Denmark)** A longitudinal exploration of rehab and supportive care needs To elucidate the experiences and needs for rehabilitation and supportive care in patients with High-Grade Glioma and their caregivers*	**American Association of Neuroscience Nurses**	**QL other**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Begley et al. (2014) **(UK)** Listening to patients with cancer: using a literary based research method to understand patient focused care*	**British Medical Journal**	**QL other**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**

Vedelø et al. (2018) **(Denmark)** To identify and describe patients' experiences and care needs throughout the diagnostic phase of The Danish integrated brain cancer pathway: A case study*	**Journal of Clinical Nursing**	**QL other**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Hammill et al. (2018) **(Australia)** To understand the effects of brain cancer symptoms and treatments on occupational participant or about the role that occupational therapy can plan for people with brain cancer*	**British Journal of Occupational Therapy**	**QL other**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Molassiotis et al. (2010) **(UK)** To further understand the symptom experience and the impact of symptoms in daily life in people treated for brain tumours A longitudinal exploratory study*	**European Journal of Oncology Nursing**	**QL other**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**

Appendix T: Summary of Key categories, subcategories and findings from included studies

Author (year), country **Research question or aim**	**Participants**	**Methods of data collection and analysis**	**Relevant** categories in qualitative studies Key findings **relevant to the aim of this literature review**
Warnock & Tod (2014) Experiences, concerns and priorities of patients newly diagnosed with advanced MSCC with significant mobility issues	10 Patients MSCC with previous diagnosis of prostate, breast or lung cancer	**<u>Qualitative</u>** Semi-structured interviews Framework analysis **Time point:** After completion of radiotherapy before discharge home	**Relevant categories:** Thinking through the implications of MSCC, meeting the challenges **Emotional response:** Distress, sadness anxiety, anger/frustration with delayed diagnosis **Concerns:** Loosing mobility & independence, challenges getting home, practical challenges**,** uncertainty cancer progression & mobility **Coping strategies:** Action focused, emphasising ability to cope & improvements achieved, testing own limits, maintaining a positive outlook, not dwelling on future, improving mobility & independence, taking hope from uncertainty **Support needs:** healthcare professionals teach new skills, opportunities to test limits, being honest/leaving room for hope, family involvement in meeting priorities of care
Manson et al., (2017) (UK) To explore the experiences in the days and weeks following discharge home post discharge and treatment for metastatic spinal cord compression	11 Patients MSCC with previous diagnosis of breast, prostate, thyroid and lymphoma	**<u>Qualitative</u>** Semi-structured interviews Framework analysis techniques **Time point:** Experiences at 1, 3-4 weeks post discharge home following diagnosis of MSCC and radiotherapy treatment, all patients	**Relevant categories:** Time – past, present, near future and distant future, ongoing adjustment involves continuous emotional/physical/social **Emotional responses:** Frustration, feeling loss (independence, /control, /valued/ activities)**,** hopes, fears, uncertainty about future (prognosis/treatment outcomes)**,** in limbo, close to family, familiar environment, impact on family **Coping strategies:** Getting home, balancing hope/realism**,** reminiscing past abilities, strength to face current/future challenges, resuming normal routines**,** maintaining positive outlook/identifying short term and long-term goals**,** living day by day

		had a known primary cancer diagnosis	**Support needs:** Challenges not anticipated in hospital, lacking support community services, need to aid in living well with limitations/provide support during the transition from hospital to home

Eva et al., (2008) **(UK)** The study aims to ascertain the constructions placed upon disability by patients with MSCC	9 Patients MSCC (breast, prostate, kidney, thymus and myeloma) 6 carers 29 Health care professionals	**<u>Qualitative</u>** Semi-structured interviews Within case analysis informed by George & Bennett's account of processing tracing, and between case analysis was modelled on the constant comparative method of Glaser and Strauss **Time point:** interviews at intervals through course of illness to end-of-life 15 days – 2 years and 6 months, all had previous diagnosed primary cancer. All had radiotherapy for MSCC. (9 patients, 6 carers and 29 staff	**Relevant categories:** acknowledging the problem, not acknowledging the problem, managing the tension **Emotional responses:** Not to burden others, resisting a disabled identity **Coping strategies:** Acknowledging that future plans, need to accommodate altered circumstances**,** reordering/restructuring, maintaining a sense of normality, waiting for information, self-protection/positive illusion, claiming competence, self-management, new skills, avoiding confronting the problem new condition, adjusting expectations downwards, finding possibilities, activities/pleasures to look forward to **Support needs:** Healthcare professionals should help set realistic, achievable goals to support this transition

Lee (2013) **(UK)** A case study analysis to explore the perceptions and experiences of patients, carers and/or family members and healthcare professionals in the management of metastatic spinal cord compression	Phase 1: 25 healthcare professionals Phase 2: 8 Patients (various primary diagnosis/not specified) 6 carers 42 healthcare professionals	**Qualitative** Semi-structured interviews 1-1(patients) Thematic inductive data approach **Time point:** patients interviewed twice over 6 months, all had radiotherapy, mixed previous cancer diagnosis and 2 participants Unknown primary (Carers and HCPS interviewed, very difficult to separate data findings)	**Relevant categories:** Negotiating care pathway, facing uncertainty, trying to make sense of it all, trusting healthcare professionals/make the right decisions, timely information, conversations about the future, trade off, battle plan, perception of demands of care, finding support out there, determining the final moments
Vedelø et al., (2024) (Denmark) A Fast transition: a case study of patient's experiences during the diagnostic and surgical treatment phase of accelerated brain cancer pathway	4 Patients Malignant brain tumour (awaiting grading at time of interviews) **Time point:** Observing patients for 32 days post diagnosis over hospital stays	**Qualitative** Field observations Semi-structured interviews Four steps of systematic text condensation	**Relevant categories:** A fast transition into unknown journey **Emotional response:** Vulnerability, fear of dependency, becoming a burden, overwhelmed/sudden/shock diagnosis, high stress (Information processing challenges)**,** symptoms not aligning to expectation of life-limiting brain tumour, putting life on hold, unfamiliar dependency**,** not voicing feelings, fears /needs could be easily overlooked & unmet **Support needs:** Proactive/continuous care approach through diagnostic phase, emotional support, consider individual information preferences**,** types of information delivery (written or oral)**,** continuity across care providers given complex paths
Nixon & Narayanasamy (2010) (UK) To identify the spiritual needs of neuro-oncology patients form	21 Patients High-grade glioma (19) Meningioma (1)	**Qualitative** Critical incident technique questionnaire Thematic content analysis	**Relevant categories:** Biological, psychological, and spiritual needs are interconnected, with spirituality providing meaning, purpose, and a sense of normality **Emotional response:** may seek spiritual support, identify their needs as emotional rather than spiritual, especially in relation to fear,

a patient's perspective and how nurses currently support patients with spiritual needs	Grade **II** glioma (1)	**Time point:** 19/23 above grade **III** brain tumours who had all been treated with radiotherapy and/or chemotherapy questionnaire given at follow-up clinic	anxiety, loneliness, distress, loss of control, similar to other cancer patients, thoughts about meaning of life, end-of-life decisions and discussions of beliefs, need for connection **Coping strategies:** Religious needs, need to talk, reassurance, solitude, denial, having plans for future **Support needs:** Varied spiritual support, not all patients desire spiritual support, may find it beneficial, nurses need to be aware/respond to these spiritual needs, maintaining family relationships is crucial, importance of family-centred care during treatment
Sterckx et al., (2015) (Belgium) To better understand how patients with high-grade glioma experience life with a brain tumour and to explore their professional care needs	17 Patients High-grade glioma	**Qualitative** Semi-structured interviews Qualitative Analysis Guide of Leuven Grounded theory approach **Time point:** During hospital visits for treatment or follow-up post diagnosis	**Relevant Categories:** Shocked, surreal response to diagnosis, active exploration of person's needs, loss/grief, empowerment, hope, information, access to care **Emotional response:** Shock, confusion, disbelief, diagnosis changes life drastically, feeling surreal, struggling to grasp, feeling of loss (abilities and self-esteem), loss of connection, leading to grief, disregarded by family caregivers/professional care givers/healthcare systems, felt on side lines of own life, living with uncertainty, anxiety, hoping to live as long as possible, talking about end-of-life **Coping strategies:** Therapy brought hope, spending time with family, expressed great inner strength, tried to maintain hope **Support needs:** Pivotal professional care needs to consider information, communication, accessibility, supportive of patients with a life-changing diagnosis, hearing positive, hopeful, encouraging words/health care professionals, acknowledge individuals/strive to empower to enhance their personal strength
Nyatanga et al., (2024) (UK) To understand the impact of living with a primary brain tumour and identify adjustments the patients make in order	11 Patients Primary brain tumours (High-Grade, palliative or approaching	**Qualitative** Semi-structured interviews Coding and thematic analysis	**Relevant categories:** adjustment, loss of independence, support, health and symptoms **Emotional response:** Various types of loss, immediately dependent on others, uncertainty about illness **Coping strategies:** Leads to inevitable adjustment to maintain day to day life, must develop coping mechanisms to preserve their

to cope with their condition	end-of-life diagnosis)		aspirations for living, personalised interventions, optimise independence, restore some control over their lives. **Support needs:** People value support others felt support was inadequate family-centred care, integral to decision-making, psychological support oncology/palliative care nurses are in key positions to explore psychological concerns and offer tailored support
Halkett et al., (2010) (Australia) To understand patients' experiences of High-Grade Glioma and identify and describe information and support needs along the disease trajectory	19 Patients High-Grade Glioma	**Qualitative** Semi-structured interviews Grounded theory/constant comparative method	**Relevant categories:** Feelings of uncertainty around prognosis and quality of life, need for individualised information, dependence on carers, communication with healthcare professionals around prognostic, uncertainty/disease progression, communication barriers **Emotional Response**: sudden transition to a poor prognosis with physical deficits, immediately impacts lifestyle, rapid functional decline in contrast to other metastatic conditions, dependence on carers, striving to maintain independence, feeling loss of control, uncertainty about quality of life **Support needs:** information needs & preferences, positivity versus realism, continuity in information, reliable contact-treating doctor essential for ongoing support/care, information needs change over time, needs that differ from other patients with terminal malignancy with disease progression, brain tumours may have unique needs
Fahrenholtz et al. (2019) **(Denmark)** To gain understanding and knowledge of patients' experience of being diagnosed with a severe disease and their view of a rehabilitation process	5 Patients (men only) Newly diagnosed glioma (ungraded at point of study)	**Qualitative** Semi-structured interviews Phenomenological interpretive analysis **Time point**: newly diagnosed primary glioma who had completed the rehabilitation intervention (6 weeks physical therapy in the	**Relevant categories:** coping with a new life situation, motivating and maintaining elements, experience of the benefit of the rehabilitation programme **Emotional response:** Chaotic life change, struggling due to abrupt onset of symptoms, unreal experience **Coping strategies:** emotional coping distancing from disease, problem-solving strategies, more active in health behaviour, passive and emotion, motivational aspect, competitive, crucial to self-efficacy and benefit, interventions impact on quality of life, potential to increase patients' resources to manage their situation

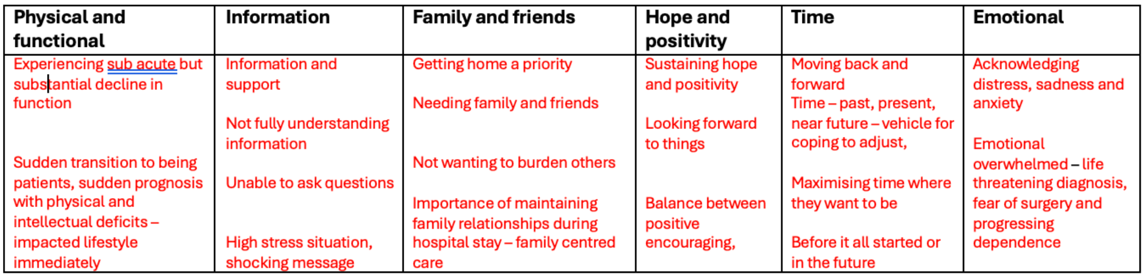
		period concurrent with chemoradiation)	
Lobb et al., (2011) (Australia) To seek the views of patients and their caregivers on their experience of being diagnosed with high-grade glioma	19 patients – High-Grade Glioma 21 caregivers	**Qualitative** Semi-structured interviews Grounded theory/constant comparative method	**Relevant categories:** Shock at hearing diagnosis, trying to understand process prognostic information while still in shock, perception of hope being taken away, importance of individualising prognostic information, clinicians lack communication skill**s** First communication of prognosis of needs care and negotiation Illustrates the persons inability to process detailed prognostic information when in initial shock/distress Importance of balancing honesty, hope when communicating poor prognosis
Piil et al., 2015 (Denmark) A longitudinal exploration of rehab and supportive care needs To elucidate the experiences and needs for rehabilitation and supportive care in patients with High-Grade Glioma and their caregivers	30 Patients – High-Grade Glioma 33 Caregivers	**Qualitative** Semi-structured interviews (five time points along a 1-year disease & treatment: interview 1) surgery/diagnosis, 2) oncological treatment, 3 & 4) treatment response scans/oncological treatment, 5) after standard treatment Thematic analysis	**Relevant categories:** individual strategy for acquiring prognostic information, shared hope, adjustment to limitation**s** **Emotional response:** Devastating impact on daily life, prognostic information can increase distress – needs to be tailored approach based on individual preference **Coping strategies/support needs:** Individual preferences/timely/paced of delivery of prognostic information, supporting individual needs, as symptoms progress need information/guidance for supportive care interventions, healthcare professionals need to support hope, caregivers crucial in supporting through adjustment process
Begley et al., (2014) (UK) Listening to patients with cancer: using a literary based research method to understand patient focused care	4 Patients High-Grade Glioma	**Qualitative** Semi-structured interviews Academics in facilitated workshop agreed major themes within the patient experience	**Relevant categories:** accountability, identity, life context, time, language, rigour and emotion **Concerns:** Pressure on family **Emotional response:** Loss of identity unique **Coping strategies:** Focuses less on diagnosis, more on making sense of their past and future, defining personal goals, maintaining sense of purpose, living the moment, not dwelling on past or future, how I want to live

			Support needs: Communication to be sensitive, consider personal preferences crucial to understanding experience
Vedelø., (2018) (Denmark) To identify and describe patients' experiences and care needs throughout the diagnostic phase of The Danish integrated brain cancer pathway: A case study	4 Patients MRI Verified primary/secondary malignant brain tumour	**Qualitative** Case study design Semi-structured interviews Participant observation Systematic text condensation **Time point:** During admission, brain surgery and discharge	**Relevant categories:** fast transition into an unknown journey, not voicing feelings, fears or needs, possible unmet needs, needing proactive continuous supportive care approach throughout diagnostic phase **Concerns:** Consultations focused heavily on diagnostic/treatment pathway, progressing dependence, unfamiliar dependency, putting life on hold **Emotional response:** Fear, fragmented care- frustration, abandonment, existential limbo, struggled to maintain positive attitude balancing hope/reality of early death, vulnerable in hospital, higher levels of distress in treatment phase requiring urgent/effective plans that respect their vulnerability. **Support needs:** Emotional interaction, recognition of vulnerability, need to be seen/heard/respected, compassionate/consistent care, proactive, tailored care, ongoing stable relationships/communication/information, to feel in control/ supported
Hammill et al., (2018) (Australia) To understand the effects of brain cancer symptoms and treatments on occupational participant or about the role that occupational therapy can plan for people with brain cancer	16 Patients (with nominated support/caregiver participant if required) Brain Cancer (life-limiting diagnosis) patients on treatment	**Qualitative** Single semi-structured interview Thematic analysis	**Relevant categories:** Disconnection with occupational therapy services, poor understanding/limited access to occupational therapy, impacting ability to adjust to functional changes **Concerns:** 'there's a lot I can't do anymore' due to tumour/treatments **Coping strategies:** "You just adjust with adversity," accepting altered occupational participant levels **Support needs:** Person-centred approach addressing all aspects of function, changes in priorities, holistic approach to support active participation /meaningful occupation through disease progression

Molassiostis et al., (2010) (UK) To further understand the symptom experience and the impact of symptoms in daily life in people treated for brain tumours A longitudinal exploratory study	9 Patients Glioblastoma (9) Glioma (1) Astrocytoma (1)	**<u>Qualitative</u>** Semi-structured interviews **Time point:** Longitudinal, soon after, 3,6,12 months post diagnosis)	**Relevant categories:** Impact of social restrictions, loss of independence, awareness of mortality, renewed perspective on life, misunderstanding terminal prognosis **Emotional responses:** Shock, renewed perspective on live, due to increased awareness of mortality, desire to enjoy life **Coping Strategies:** Improvement/reorganisation coping techniques, attempting independence/maintaining social contacts helps to feel less burdensome **Support needs:** Better information about disease progression, less medical jargon, recognition of inattention, impact on persons' expectations/optimism, tailored to person, regular assessment/understanding avoiding frustration/improve satisfaction

Appendix U: Coding process from critical synthesis review

Example of initial codes and 6 provisional categories



Physical and functional	Information	Family and friends	Hope and positivity	Time	Emotional
Experiencing sub acute but substantial decline in function Sudden transition to being patients, sudden prognosis with physical and intellectual deficits – impacted lifestyle immediately	Information and support Not fully understanding information Unable to ask questions High stress situation, shocking message	Getting home a priority Needing family and friends Not wanting to burden others Importance of maintaining family relationships during hospital stay – family centred care	Sustaining hope and positivity Looking forward to things Balance between positive encouraging,	Moving back and forward Time – past, present, near future – vehicle for coping to adjust, Maximising time where they want to be Before it all started or in the future	Acknowledging distress, sadness and anxiety Emotional overwhelmed – life threatening diagnosis, fear of surgery and progressing dependence

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Formation of final 4 categories

Systematic Review: Literature coding

Key:

Eva et al (2008). Patients' constructions of disability in metastatic spinal cord compression.

Fahrenholtz., et al (2019). *Finding 'the inner drive' for a rehabilitation process: a small-scale qualitative investigation among male patients with primary glioma.*

Lee, S. H. (2013). A case study analysis to explore the perceptions and experiences of patients, carers and/or family members and healthcare professionals in the management of metastatic spinal cord compression.

Lobb, et al. (2011). Patient and caregiver perceptions of communication of prognosis in high-grade glioma.

Molassiotis et al (2010). Symptom experience in patients with primary brain tumours: A longitudinal exploratory study.

Nixon & Narayanasamy, A. (2010). The spiritual needs of neuro-oncology patients from patients' perspective.

Piil, et al (2015). Daily Life Experiences of Patients with High-Grade Glioma and Their Caregivers. A longitudinal Exploration of Rehabilitation and Supportive Care Needs.

Sterckx et al (2015). Living with a high-grade glioma: A qualitative study of patients' experiences and care needs.

Vedelø, et al., (2024). ***A fast transition: A case study of patients' experiences during the diagnostic and surgical treatment phase of an accelerated brain cancer pathway*****.**

Vedelø et al., (2018). ***Patients' experiences and care needs during the diagnostic phase of an integrated brain cancer pathway: A case study*****.**

Warnock, C & Tod, A. (2014). A descriptive exploration of the experiences of patients with significant functional impairment following a recent diagnosis of metastatic spinal cord compression.

Hammill et al., (2018) To understand the effects of brain cancer symptoms and treatments on occupational participant or about the role that occupational therapy can plan for people with brain cancer.

Manson et al., (2017)
To explore the experiences in the days and weeks following discharge home post discharge and treatment for metastatic spinal cord compression.

Begley et al., (2014) Listening to patients with cancer: using a literary based research method to understand patient focused care.

Nyatanga et al., (2024) To understand the impact of living with a primary brain tumour and identify adjustments the patients make in order to cope with their condition.

Nixon, A., & Narayanasamy, A. (2010). The spiritual needs of neuro-oncology patients from patients' perspective. Journal of Clinical Nursing.

Halkett, G. K. B., Lobb, E. A., Oldham, L., & Nowak, A. K. (2010). The information and support needs of patients diagnosed with high-grade glioma. Patient Education and Counselling.

Category One: Emotional impact

Feeling lonely, need for connection	• Need for connection/loneliness
Acknowledging distress, sadness and anxiety	• Living with uncertainty and anxiety
Emotionally overwhelmed	• *Struggling with overwhelming emotions due to this sudden life-threatening diagnosis, fear of brain surgery and progressing independence* • *When dealing with new life situation use both - Emotion-focused coping dealing with difficult emotions associated with receiving a severe diagnosis – distancing themselves from disease* • Emotionally overwhelmed • Putting life on hold • Unfamiliar dependency • Emotional support • Need to talk
Starting an unknown journey	• *Uncertainty about cancer progression and changes in mobility* • A fast transition into and unknown journey • Emotionally overwhelmed • Unfamiliar dependency • **Feelings of uncertainty** • Uncertainty about prognosis in HGG • Uncertainty about how the diagnosis would affect their quality of life • *Feelings of uncertainty around prognosis and quality of life.*
	• ***Making sense of what had happened and giving meaning to what was to come***
Giving meaning to what is to come	• Uncertainty around not knowing nursing diagnosis and what after treatment might entail – fluctuating experience – never totally disappearing during illness – goal to manage • Need to develop nursing interventions that focus on raising awareness and managing, mitigating uncertainties – as they prepare, plan and receive diagnosis and treatment Thoughts about meaning of life
Wanting to hold onto their identity	• *Retaining an image of themselves as resourceful, able to cope* • ***Not a disabled identity – for the majority of patients with MSCC their illness and disability will not last long enough to become life itself***

Needing continuous monitoring of care needs – patient and family	• Continuous monitoring of patients and families care needs – at beginning of diagnostic phase • *Proactive continuous care approach throughout diagnostic phase to support this group*
Not voicing feelings or fears – which means likely to be unmet	• *Patients did not voice their feelings, fears or needs – so maybe overlooked, unmet*
Higher levels of distress during treatment phase	• ***Higher levels of emotional distress in treatment phase than in later stages of disease – HCPs sensitive and attentive to patients care needs***
No spiritual needs **Religious needs**	• Difficulty understanding concept of spiritual needs – for some central search for meaning, distress, fear, loss of control – consistent with other cancer patients • Spirituality is the part of a person that provides meaning and purpose, planning for future/re-stablishing sense of normality • No spiritual needs • Religious needs
Balancing hope and reality while trying to perceive the unknown reality of life-limiting diagnosis	• Shared hope – finding ways to handle their changed life situation a need for balancing hope – fostering realistic hope and creating unrealistic expectations • Life on hold when diagnosis received • *Not thinking too far ahead – sustaining hope and maintaining positivity, maintain moral* • ***Living in the moment***
Needing family and friends	• Spending time with family • *Social contacts*
Maintaining family relationships during hospital stay – family-centred care	• Need to ensure that patients are supported in maintaining family relationships during their stay – family-centred care imperative in cancer
Support to include family as inextricably connected to patient	• *Any support should include spouses or partners as they are inextricably connected to patient living with illness* • *Family disease – central to care and decision-making – move away from one-size-fits-all approach*

	• *Caregivers play significant role in supporting the patients along the trajectory – caregivers need to be provided with special support and practical assistance especially as symptoms progress* • Dependence on carers due to cognitive deficits, loss of balance and inability to drive communication barriers due to complex language deficits
Not wanting to be a burden on others	• ***Not wanting to burden others*** • ***Pressure on family***

Category Two: Competing Priorities	
Life changing, chaotic, time of crisis – fast transition into an unknown journey	• *Experiencing their changing life situation as chaotic* • ***Restrictions on social movement – physical weakness - repercussions on the patient's everyday life***
Symptoms not fitting with seriousness of situation	• Hard to identify themselves as being ill – due to abruptness, symptoms subtle in contrast to severity of disease • *Described experience of diagnosis unreal* • Feeling emotionally overwhelmed, instant shock – sudden diagnosis, symptoms not correlating with symptoms of brain tumour • *Patient related these to the fact their initial symptoms were so subtle or absent at diagnosis – knowledge of seriousness did not fit with how they were feeling at diagnosis*
Disconnection of priorities with professionals, patient and family	• *Main concerns related to reduced mobility, loosing independence and impact on their family and getting home* • Varying levels of distress that affects quality of life – support should be tailored to specific needs to help ameliorate the distress and enhance quality of life • *Specialised care model providing more proactive and individualised patient tailored care* • *Recognising care as a relational activity demanding emotional interaction – providing patients with a universal sense of togetherness*

	• Disconnection was found between occupational therapy services and occupational needs • Anticipating the future with MSCC • Theme 2: Shared hope
Enhancing physical and functional therapies with broader than just self-care which is balanced with a realistic goal and motivational focus supporting how they want to live their life with the time they have left and the place where they want to be	• *Interventions to improve mobility, get them home – takes timely planning and coordination across MDT between hospital and community services* • *Hopes identified as a set of priorities which should be central to care pathway with newly diagnosed MSCC, including the importance of developing services that support rehabilitation, family involvement and discharge planning* • *Service needs to support living well with limitations they face* • ***HCPS should look to develop goals which are reasonable and achievable*** • *Hope in terms of regaining meaningful activities – inner strength* • *Physical aspects – widely addressed by clinical services, not clear the psychological impact was not clearly understood or provided for – not always knowing themselves what they were experiencing and what support is available to them* • *Specific support customised to the needs of each person with the diagnosis* • Hopes, fears, coping mechanisms, optimising independence, support loved ones – and interventions to help enhance quality of life while restoring some level of control of peoples remaining life • ***How do I want to live*** • Need to enhance occupational participation through the journey of brain cancer • Adjustment of occupational priorities and approaches to participation was evident as participants capacities diminished • *Occupational therapy infrequently available, participants did not feel it was relevant to their priorities* • *Active process of adjusting to functional changes by altering priorities and approaches to occupations identified* • *Earlier stages participants focused more on maintain self-care and productive occupations* • *As diseased progressed and occupational participant restrictions increased, social and leisure occupations required greater importance* While progression might be consistent for most people individual priorities along this journey appeared • *Negative experience of occupational therapy – poor understanding of role and often not referred* • *Developing a systematic approach to assessment and addressing all areas of functioning, occupation types and environmental factors appear to be a priority* • *Preparing to support the person to be actively maintaining and alter meaningful occupations as impairment increases and priorities change is highly important*

	- *Requiring a change in focus from self-care occupations to a broader range of social, leisure, closure and legacy occupations* - Helpful actions and behaviours from healthcare professionals - Accessibility and availability of professional caregivers - Adjustment to symptom limitations
Acting in accordance with pathway demands when providing urgent management plan/treatment	- *At this point HCPs have to act accordingly to the demands of pathway, providing urgent an effective plan of action – just as important they respect patients' vulnerability and needs in a time of crisis* - *Support services to support transition from hospital to home*
Treatment initiated rapidly – no time to adjust	- *Treatment often initiated rapidly leaving little time for patients and relatives to adjust to diagnosis and treatment options*
Diagnosis and treatment planning becomes focus of consultation and quality measure on timeframe of pathway	- *When diagnostic and treatment planning becomes focus of patient consultations – dominant quality measurement is on the time frame of pathway elements,*
Getting home being a priority	- Challenges of palliative discharges – maximising time where they want to be – valuable goal - *Value of inpatient rehab sooner Getting home priority, challenges once home, community support, getting back to normal, in limbo, having goals*
Overlapping of biological, psychological and spiritual factors	- *Many identified psychological needs are not spiritual needs – emotional support. Overlapping biological, psychological and spiritual – all interconnected* - *Highlights physical, emotional and social impact of MSCC* - *While adjustment was individual there were common elements that characterised how people lived and made sense of their illness* - *Challenges included physical, psychological concerns, anxiety, worry, loss of independence, future uncertainty – all impacting on quality of life* - Need for care as a relational activity with an emotional engagement may not be realised

	• Brain cancer and treatments have far reached impacts on a person's function, resulting in reduced occupational participation and increasing need of environmental supports • *Dynamic interaction between the adverse effects of brain cancer and treatment on the person's active adjustments to functional decline and participants restrictions* • ***Physical exercise and environmental changes – domain coping techniques a heightened awareness of the need to psychologically and physically readjust to the diagnosis*** • ***Adjustment*** • *Capturing how patient made changes to physical, psychological and practical aspects of their life*

7.4.1.1 Category 3: The physical and functional challenges

Feeling immediate loss of mobility, independence, identity, control, vulnerable, powerless – unique to this group - HCPs should be respecting of this **7.4.1.2**	• *Acknowledging distress, sadness and anxiety but emphasis on their ability to cope, being actioned focused to improve situation* • Feeling vulnerable while hospitalised • Loss of self-control while in hospital • *Dealing with loss seems to affect self-esteem, sense of meaningless, loss of abilities source of grief* • *Loss of nature of support – lots of different types of losses need to develop coping mechanisms quickly to avoid losing daily aspirations for living* • *Loss of control – struggling to maintain independence and continue daily activities* • ***Feeling a loss of identity and uniqueness*** • Loosing mobility **Past:** • What I was able to do, use to happen, Loss of independence, routine, valued activities Feeling of loss Loosing connection **Loss of independence** • Eliciting tow broad concepts; tangible and perceived loss • *'There's a lot of things that I can't do anymore': adverse effects of tumour and treatments*
Recognising there are challenges &	• *Recognised the problems they faced but emphasising ways they could cope and remain hopeful* • ***Lack of independence, problems with everyday life – often around driving with brain tumours***

uncertainty ahead with physical and functional changes	• *Turning point in transitions*
Needing to understand new physical and functional boundaries	• ***Trying to make sense of an altered and unpredictable body*** • Driving inflicts independence **Acknowledging the problem** • **Exploring boundaries**
Needing to be flexible to adjustment, develop self-management skills to restore control	• *Flexibility – evolved over time as adjustment to challenges faced* • *Adjustment is ongoing process as they become aware of limitations and challenges for both and family* • *Accepting they needed to deal with problems they were facing* • *Taking action and making plans – important coping strategies – supporting them in these efforts should shape priorities of care* • ***Practical consequences require self-management skills to be learnt, functional boundaries to be explored, useful information sought*** • ***Holding on to established identity, keeping a sense of normality*** • *or problem-solving coping style take active decision not to let the disease affect their everyday lives performing activities as usual, proactive health behaviour, general psychological well-being* • *Social support from professionals working with the patients* • *Dissatisfied with focus of occupational therapy interventions – need to take a person-centred approach to care* • Improving mobility and independence • Developing ideas and solutions for overcoming the challenges of getting home • Taking the "right approach" to MSCC • Battle plan You adjust with adversity': accepting altered occupational participations levels.
Reordering and restructuring	• **Reordering and restructuring**
In present Short-term goals, getting back to normal, treatment, in limbo	• *Sadness, distress at physical limitations faced but managed to set goals, have hopes for immediate future* • *Patients concern past abilities, strengths to present challenges/future goals* • • ? improve mobility, function, independence? community rehab • **Sense of purpose, drive for personal and specific goals** • ***Walking to their daily life and found an improvement in the psychological and contentment levels – as time moved on more organised, accepting their limitations and finding new ways of managing them*** **Present:**

	• Wanting to get home • Needing to be close to family, familiar environment • Control • Challenges not anticipated in hospital • Frustration with reduced function • Impact on family • Lacking support from community services **Near future:** • Short-term goals • Getting back to normal • Goals related to cancer (treatment, symptom control) • In limbo • Plans for the future/sense of normality
Distant future – hopes, thoughts fears about future, long-term goals (holidays, challenging activities	**Distant future:** • Hopes, thoughts, fears about future • Long-term goals (holiday, challenging activities) • Uncertainty with incurable cancer not having prognosis or treatment outcomes (living day by day)
Existential recognition – supporting self-confidence and symptom experience	• *Existential recognition – found to help self-confidence and symptom experience*
Looking forward to things	• *Gained enjoyment from finding things to look forward to* • ***Moving to a new identity supports with embracing the idea of competence, resourcefulness, events and activities, pleasures to look forward to***
Welcomed positivity, but could be a struggle to maintain positive attitude	Hearing positive, hopeful, encouraging words from Health care professionals
Identifying short-term goals and being motivated	1. *Enhancements of the patients' resources including their motivation* 2. *Therapy brought hope* 3. *Motivating and maintain elements* 4. Experience of the benefit of the rehab

	5. Physical exercise and environmental changes *Expectations*
Having hope in regaining meaningful activities gave inner strength	*Hope in terms of regaining meaningful activities – inner strength* • Inner strength – to take action and control
Not focusing on living a life near death, but recognising death is inevitable	• *Months to years rather that specific time frames – being specific received as hope reducing*
Treatments perceived as important for survival	• Treatments perceived as important for survival and to improve their health
Want to developing coping mechanisms for losses to avoid losing aspirations for living	• *Examples of uncertainty not all negative – use this as potential source of hope regarding prognosis and mobility*
Not dwelling on cancer diagnosis	• ***Not dwelling on diagnosis of cancer***
Focusing on how I want to live	• *Living a life near death not a prominent theme in experience* • *All patients aware of death was inevitable, strong hope of having extra time, feeling of hope central to their experience, hope important even when terminal – should be nurtured by care givers* • *Re-evaluating their futures*
Having a heightened awareness and renewed perspective on life	• ***Renewed perspective in life as a result of heighten awareness of mortality, desire to live and enjoy opportunities of life post diagnosis***
Shifting between hope of returning to normal and the frightening reality of an unexpected early death	• *Constantly shifting between hope of returning to a normal and frightening reality of an unexpected early death* • Determining the final moments • *Talking about end-of-life*

Not wanting to be a burden on others	• **Concern about dependence** • *Perception of demands of care* • *Receiving help as support but also as burden*
Support received, hoped for, deemed inadequate	• Finding support out there • **Support** • Capturing actual support received • Support that was hoped for • Support that was deemed inadequate • Lack of support all together
Social and family contacts can help with feeling more complete, maintain normal life	• ***Social contacts: attempted to maintain independent life. Helped them feel more complete and less of a burden on others***
Hoping to live as long as possible	• Hoping to live as long as possible
Fearing dependency and being a burden	• *Unfamiliar dependency – fear of dependency, not wanting to burden others* • *Periods of continued good cogitative and physical function with a rapid functional decline in the terminal phase of the illness* • *Dependency on carers while other tried to maintain independence* • **Dependence on their carer**

Category 4: The perception and processing of information	
Awareness of actional and potential – rapid sequences of changes	• *Being aware of actional and potential* • *Shock diagnosis* • *Struggling to grasp meaning of diagnosis*
Fragmented, multiple healthcare providers, distorted and deterioration of communication and information – frustration, abandonment, vulnerability	• *Distortion and deterioration of information when conveyed through complex trajectories, number of care providers, professions and shifts – transfer between hospitals* • *Feeling vulnerable in hospital due to setting – need to be recognised as equal human beings by HCPS attending* • Turnover of healthcare providers – resulting in fragmented care – frustration, feeling of abandonment – in patients feeling vulnerable several healthcare centres involved • *Importance of consistence information throughout trajectory – can be challenging* • Fragmented care – feelings of uncertainty and loss of control

Needing to provide difficult and significant information	• ***Dependence on their carer*** • ***The need for information*** • *The need for information relating to prognosis* • *The need for information to be provided in different types of medium* • *Continuity in the provision of information* • *Balancing hope and reality while trying to perceive the unknown reality of brain cancer*
Increasing uncertainty and distress when not understanding the pathway	• Not knowing what to expect
Difficulty understanding their disease in order to meet their needs to support what happens next	• *Not fully understanding information given, unable to ask questions to realising severity while sitting with neurosurgeon* • High stress situation, shocking message, leads to crisis situation – hampering ability to process and remember information • *Patient related these to the fact their initial symptoms were so subtle or absent at diagnosis – knowledge of seriousness did not fit with how they were feeling at diagnosis* • ***Patients need better information particularly prep information on what to expect during course of their disease*** • Conversations about the future • *Timely information* • *Trying to make sense of it all*
Tolerating information at pace, incremental – via different media for not remembering and respecting vulnerability	• Proactive telephone follow-up consultations, facilitating discussions on altered life situations, fears of loss • *Need PI according to individual preferences: allowing to tolerate amount of information and at a pace in which information can be assimilated* ***Not what they say it's how they say it***
Timing of information about diagnosis and prognosis, while eliciting how much an individual requires	• *Provision of information not a simple task – some want it to tell it as it is while others wanted positive information – minimum* • *Importance of clinicians informing patients of types of information they can provide and eliciting how much information patient requires* • *Importance of timing of communicating, diagnosis and prognosis in this setting* • *Preferences and beliefs of HCPS- when consultations entailed prognostic information – where not prepared – feeling of uncertainty, loosing sense of control, unpreparedness – diminished ability to act and invite family* • Shock diagnosis – incremental doses of information written resume of key statements from consultations – provide support

	when not remembering, respect patient vulnerability – fulfil needs for immediate information • Theme 1: Individual strategy for acquiring prognostic information
Misunderstandings of illness diagnosis, prognosis and treatment goals and expectation due to rapid experience	• *Reviewing essential information collaboratively and addressing post consultation questions* • *Frequent misunderstandings about their illness prognosis and goals of treatment* • *Pre-final diagnosis patients experienced distress due to uncertainty about the diagnosis and treatment – due to not knowing the care pathway and the future entail* • **Patient understanding should be assessed regularly to avoid similar cases of anger and increased satisfaction with care** • **Expectations – reflected on notion that they misunderstood the terminal nature of their condition** • **optimism and fighting spirit believing the cancer in curable *in some it was due to medical jargon by HCPs and others it was due to inattention or shock of diagnosis resulted in misregistering of information*** • *Information needs*
Prognostic information when appropriate for it to be meaningful	• Significant correlation between accurate PI and reduced psychological distresses • *Hope changes over time, why prognostic information must be provided according in individuals preferences – how much the patient is ready to know in order for it to be meaningful*
Needing information strategy, focusing immediate outcomes then full discussion once	• *Needs information about diagnosis and prognosis, timing of such information ? immediate post diagnosis – not in a position to take prognosis* • *Verbal and written information – treatment, support services what happens as disease progresses, timing an issue as not ready for palliative care, perceived as loss of hope* • **Waiting for information** • Need for information from healthcare professionals
initial information is absorbed ideally when histology is available or when decision not proceed with further cancer treatment	• *Information given strategy – focus on safety outcomes of surgery – commit to full discussion of results and prognosis when histological confirmation available*
Relying on family to remember and taking	• Turing to relatives to remember information, take responsibility for practical instructions

responsibility of information and practical instructions	• *Patients valued presence of carer when receiving information – needs to be simply and positively*
Giving responsibility to seek out additional information	• Patient responsible for seeking additional information as outpatients • Life on hold when diagnosis received
Having access and continuity with information from people with appropriate specialist knowledge and skills within	• *Repeatedly offering follow-up information and emotional support after OP consultations delivering diagnostic information – experience continuity in terms of information* • *Receiving info from and having accessibility to HCPs were major needs* • Patient highlighted importance of being able to discuss treating doctor and their need to have someone they could contact when needed • *Continuity of communication with HCps was essential for obtaining information and support* • *Readily available contact person – key role in addressing patients' needs* • Detailed discussions of prognosis – senior clinician with detailed knowledge of disease characteristics – limited experience – should avoid damaging discussions of median survival • *Complex care needs and experience a particular state of vulnerability during diagnostic phase – trust with skilled healthcare providers participants experienced existential recognition and alleviation of emotional distress* • *Limited access and lack of knowledge have hindered occupational therapy oncology and palliative care* • *OT do not adequately promote the potential contribution that the profession can make to people with life-limiting illness or other healthcare professionals due to OT own lack of knowledge of their role in this area*
Proactively providing channels and tools to provide and review timely essential, simple consistent information collaboratively to allow the facilitation of discussions with altered life changes, diagnosis, prognosis and fears	• *Importance of HCPs involving patients in their care* • *Proactively providing information to patients as well as providing them with tools and channels to obtain information – meets their information needs but counters their feeling of powerless* • PI may facilitate EOL planning but may increase distress • *Adjustment – devastating impact on everyday life – same time need access to information about symptoms and support to how to manage* • ***Individual patient information preference style should be taken into consideration when providing difficult and significant information to patients*** • Sharing emotions and concerns with healthcare professionals

	• *Feelings of uncertainty around prognosis and quality of life.*
Understanding preferences for prognosis information can act as a catalyst in promoting adjustment, while managing a life crisis	• Preferences for PI can act as catalyst in promoting adjustment to HGG diagnosis • *PI needs to be based upon strategy that accounts for individuals preferences and approaches to managing life crisis* • *Strategy referred to as prognostic awareness defined as patients capacity to understand the prognosis and the likely illness trajectory* • Low prognostic awareness are too emotionally burdened and postpone dealing with the mortality until a future point
Recognising information and support needs change over time	• *Patient information and decision-making preferences change over time – wanting and then not wanting to know- importance of individualising information and eliciting concerns vital to the communication process* • *HCP's need to clarify patients information and support needs and be aware that these change over time (covers emotional and practical support needs)*
Being recognised as a human being, being seen, heard and understood, respected as an individual – personal rather than distant professional relationship, based on trust can compensate for lack of information – when ability to retain and within overwhelming situation in self-preservation	• *Evaluating social interactions with HCPS – based on being seen, heard, understood and respected as individuals* • *Feeling of being recognised seemed to have a huge influence on patients experience of the consultations and the information provided in care pathway* • *Patient required HCPs to engage in personal relationship function – not just for practical tasks – wanted capability, confidence and confidence – show compassion* • *Stable trustful relationships – enabled patients to use self-preservation strategies – avoiding information they do not feel ready to master – instead trusting surgeon to completely take over* • Relationship based upon trust may compensate for lack of information – due to self-preservation strategies or cogitative deficits or impaired ability to attain information due to the over whelming situation • HCPS took professional distance, not engaging in personal relationship – expressed feeling disappointment, frustrated and alone • Personal relationship – allows for medic to easily identify the individuals information needs and preferences of the patient • *Establishing professional relationships* • Participants' perceptions of the relationship with healthcare providers

Guideline development for information-based discussion and joint decision-making – what to expect, prepare regardless of HCP & team – enhance control & continuity	- *Proactive – involve providers to pose questions that identify the patients' individuals need and wishes to ensure information is provided according to the patients different self-preservation strategy* - Shock diagnosis – incremental doses of information written resume of key statements from consultations – provide support when not remembering, respect patient vulnerability – fulfil needs for immediate information - *Development of guideline for information based on discussion and joint decision-making should be told to expect and prepare – regardless of physician – enhance ability to act and feel in control – precise document in notes – continuity* - Opportunities to communicate and ask questions - Difficulties with communicating effectively
Wanting to be involved in own care	**Communication with health professionals** - Involvement in decision-making
Clinicians trying to combine hope with honesty	- Clinicians find it difficult to combine hope with honesty
Wanting to hear positive messages	- *Participants describe how HCP's had provided negative information about diagnosis and consequences of MSCC*

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