National Institute for Health and Care Excellence

Draft for consultation

Metastatic spinal cord compression

[C] Information and support

NICE guideline number tbc

Evidence reviews underpinning recommendations 1.1.14 and 1.2.1 to 1.2.13 (except 1.2.8) in the NICE guideline

March 2023

Draft for consultation

These evidence reviews were developed by NICE

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The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

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ISBN:

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Information and support

Review question

What information and support is valued by adults with suspected or confirmed spinal metastases, direct malignant infiltration of the spine or associated spinal cord compression, and by their families, and carers?

Introduction

People with suspected or confirmed spinal metastases, direct malignant infiltration of the spine or associated spinal cord compression have a variety of information and support needs. They need information about their symptoms, treatment options and prognosis, while also requiring support for the emotional and physical consequences of spinal metastases and cord compression. These needs will be ongoing and changing, for example during treatment or at discharge from hospital, and there may be times when there is an urgent need for information or support, for example at the onset of new symptoms.

Summary of the protocol

See Table 1 for a summary of the Population, Phenomenon of Interest and Context (PICo) characteristics of this review.

Table 1: Summary of the protocol (PICo table)

Population	• Adults with confirmed or suspected ○ metastatic spinal disease ○ direct malignant infiltration of the spine and their families & carers • Adults with suspected or confirmed spinal cord or nerve root compression because of ○ metastatic spinal disease ○ direct malignant infiltration of the spine and their families & carers
Phenomenon of Interest	Themes will be identified from the literature but may include: • Uncertainty about prognosis • Information about when to present (for example in high-risk patient groups) • Patients may struggle with identification of symptoms • Healthcare professionals’ knowledge of MSCC • When to seek help • Who to contact [for example primary cancer team, community team, MSCC coordinator], end of treatment summary letters • Support with functional activities of daily living • Information about types of treatment (decision making) – what’s involved and when to start, where treatment is carried out • What happens next after treatment – for example brace management following discharge • What’s safe/not safe to do • New onset symptoms (pain, neurological) who to contact • Psychological support

Context	Services providing information and support to people with metastatic spinal disease, direct malignant infiltration of the spine or metastatic spinal cord compression within a health care setting.

MSCC: metastatic spinal cord compression.

For further details see the review protocol in appendix A.

Methods and process

This evidence review was developed using the methods and process described in [Developing NICE guidelines: the manual](). Methods specific to this review question are described in the review protocol in appendix A and the methods document (supplementary document 1).

Declarations of interest were recorded according to [NICE's conflicts of interest policy]().

Qualitative evidence

Included studies

Five qualitative studies were included for this review (Eva 2009, Lape 2020, Lee 2013, Manson 2017, Warnock 2014).

Four studies involved people with metastatic spinal cord compression (Eva 2009, Lee 2013, Manson 2017, Warnock 2014) 1 of which also involved families or carers (Lee 2013). One study included people receiving treatment for spinal metastasis (Lape 2020).

Four studies were from the UK (Eva 2009, Lee 2013, Manson 2017, Warnock 2014) and 1 was from the USA (Lape 2020).

All studies were done in a tertiary care setting.

The included studies are summarised in Table 2.

See the literature search strategy in appendix B and study selection flow chart in appendix C.

Excluded studies

Studies not included in this review are listed, and reasons for their exclusion are provided in appendix K.

Summary of included studies

Summaries of the studies that were included in this review are presented in Table 2.

Table 2: Summary of included studies.

Study	Population	Methods	Author main themes
Eva 2009 Qualitative UK	N = 9 people with MSCC **Age, mean (SD) years:** Mean and SD NR but range provided - 42 to 82 years **Sex:** 1 woman and 7 men **Ethnicity**: NR **Setting**: Radiotherapy unit in a regional cancer centre **Primary cancer**: breast, prostate, kidney, thymus and myeloma Survival post diagnosis of MSCC:	**Data Collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Acknowledging the problem • Not acknowledging the problem • Managing the tension

Study	Population	Methods	Author main themes
	ranged from 15 days to 2.5 years		
Lape 2020 Qualitative USA	N=23 people with spinal metastases **Age, mean (SD) years:** 62 (SD NR) **Sex:** 10 women and 13 men **Ethnicity:** White: 23 **Setting:** Three academic tertiary care centres in the departments of orthopaedic surgery, neurosurgery, or radiation oncology **Primary cancer:** Breast 1, Kidney 6, Lung 4, Prostate 2, Thyroid 1, Head and neck cancer 1, Multiple myeloma/ lymphoma 4, Testicular 1 Uterine 1, Paraganglioma 1, Pancreatic 1	**Data Collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Diagnostic context • Locus of decision-making • Treatment-related considerations
Lee 2013 Qualitative UK	N = 8 people with MSCC and 6 family/carers **Age, mean (SD) years:** NR **Sex:** NR **Ethnicity:** NR **Setting:** Hospital, Lothian NHS **Primary cancer:** NR	**Data Collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Facing uncertainty in MSCC • Finding a balance in uncertainty of MSCC
Manson 2017 Qualitative UK	N = 11 people with MSCC **Age, mean (SD) years**: Mean and SD NR but range provided - 63 to 85 years **Sex:** 2 women and 9 men **Ethnicity**: NR **Setting**: A regional cancer centre **Primary cancer:** Breast 2, Prostate 7, Thyroid 1, Lymphoma 1	**Data Collection:** Semi-structured interviews **Analysis:** Framework analysis	• Time • Past • Present • Near future • Bridging past, present and future
Warnock 2014 Qualitative UK	N = 10 people with MSCC **Age, mean (SD) years**: Mean and SD NR but range provided - 59 to 81 **Sex:** 3 women and 7 men **Ethnicity:** NR **Setting:** A regional cancer centre **Primary cancer:** Breast 2, Prostate 5, Lung 3	**Data Collection:** Semi-structured interviews **Analysis:** Framework analysis	• Thinking through the implications of MSCC • Meeting the challenges of MSCC

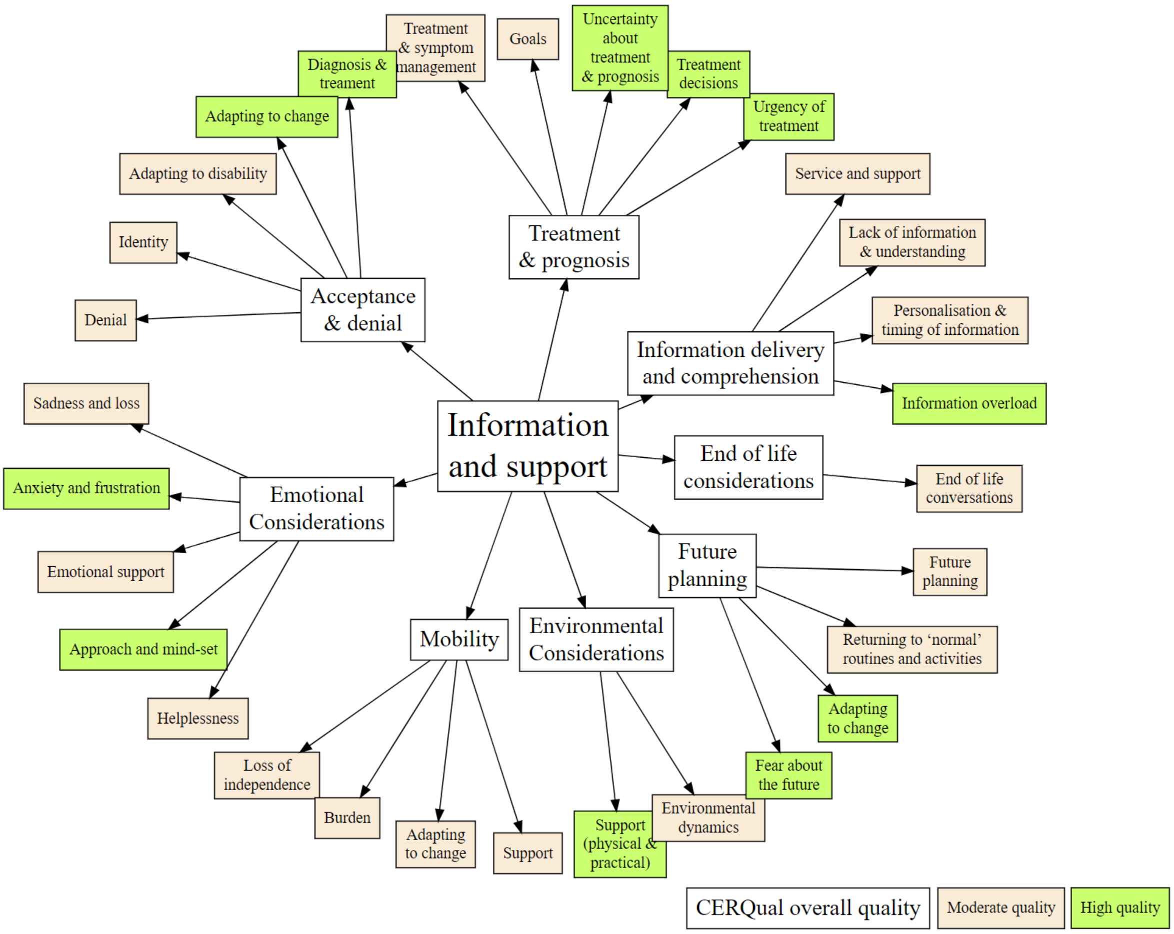
MSCC: metastatic spinal cord compression; NR: not reported; SD: standard deviation

See the full evidence tables in appendix D. No meta-analysis was conducted (and so there are no forest plots in appendix E).

Summary of the evidence

The valued information and support identified in the included studies fell under 8 main themes – information delivery and comprehension, treatment and prognosis, acceptance and denial, emotional considerations, mobility, environmental considerations, future planning and end of life considerations. A total of 30 subthemes were associated with the 8 main themes, and these are illustrated in Figure 1. The quality of the evidence for the 30 subthemes ranged from moderate to high.

Figure 1: Theme map



See appendix F for full GRADE-CERQual tables.

Economic evidence

Included studies

A systematic review of the economic literature was conducted but no economic studies were identified which were applicable to this review question.

A single economic search was undertaken for all topics included in the scope of this guideline. See supplement 2 for details.

Excluded studies

Economic studies not included in this review are listed, and reasons for their exclusion are provided in supplement 2.

Summary of included economic evidence

No economic studies were identified.

Economic model

No economic modelling was undertaken for this review because the committee agreed that other topics were higher priorities for economic evaluation.

The committee's discussion and interpretation of the evidence

The outcomes that matter most

The aim of this review question was to identify the information and support valued by adults with suspected or confirmed spinal metastases, direct malignant infiltration of the spine or associated spinal cord compression, and by their families, and carers. As a result, the views of this population were considered the most important for this question. The committee suggested potential themes which might emerge from the evidence such as information about symptoms and treatments but did not want to constrain the question; so any views and preferences about information and support expressed by the population were included.

The quality of the evidence

When assessed using GRADE CERQual methodology the evidence was moderate to high quality. In some cases, there were minor concerns due to relevance when themes were partly based on evidence from healthcare professionals. In most cases these concerns were not sufficient to downgrade the evidence overall and the evidence from healthcare professionals was consistent with that from patients and carers. For some themes there were also minor to moderate concerns about methodological limitations as per CASP qualitative checklist and minor to moderate to concerns about the adequacy of the data, which came from a small number of studies or participants. Theme extraction was not stopped at any point due to data saturation.

In most cases the recommendations were drafted based on high quality evidence, but moderate quality evidence from 4 subthemes was also used: subthemes 1.2 lack of information & understanding, 3.2 adapting to change, 5.1 mobility support and 8.1 end of life considerations. The phenomena described by these subthemes were consistent with the experience of the committee and so they agreed to use them as supporting evidence.

Benefits and harms

The evidence showed that people with MSCC report many information and support needs related to treatment, options, decisions and prognosis.

Providing a coordinated MSCC service

The committee made a strong recommendation that MSCC services should establish links and communication pathways with primary care and other relevant services so that information about the person's care and support needs is shared effectively to ensure safe discharge from hospital, continuity of care and appropriate follow-up. This was based on high quality evidence showing that people needed support to adapt to change and value the services that provide such support when they leave hospital, for example people talked about adaptations that they need at home (see sub-theme 3.2 adapting to change). The evidence also indicated that continuity of support is potentially at risk when people are discharged from hospital to home. People talked about variations in getting support particularly with symptom management, information and advice and co-ordinating community services, including additional equipment (see sub-theme 1.4). The committee agreed that access to support should be maintained after discharge home and that coordinated pathways between hospital, community and social services are a way to help ensure people have any help needed to maintain their independence at home.

Supporting decision making

The committee made a strong recommendation to ensure that people with suspected or confirmed spinal metastases or MSCC and their families and carers are given information and support so that they are fully informed and involved in all decisions about their care. This was supported by high quality evidence which showed that people needed support to make decisions, for example about treatment), and they valued support of family and healthcare professionals (see sub-theme 2.3 treatment decisions). The committee agreed that the NICE shared decision making guideline covers the involvement of family members and healthcare professionals in supporting the person and that the NICE guideline on patient experience in adult NHS services includes a lot of principles about giving information and communicating with people and they therefore cross referred to these so that people are properly informed and involved.

The recommendations about discussing why investigations and treatments are being offered by the MDT was supported by high quality evidence which indicated that people want to understand the clinical reasoning and rationale for treatment options and what they mean for the future (see sub-theme 2.3 treatment decisions).

The committee noted that people reported that they wanted information about their prognosis and treatment but that they also felt uncertain and that they had concerns about what the future held (see sub-theme 2.2 uncertainty). The evidence also showed that people felt overwhelmed by the amount and complexity of information they received (see sub-theme 1.1 information overload). The committee addressed this by recommending giving people opportunities to discuss concerns and ask questions. Giving information when the person wants and needs it will make them feel less overwhelmed. Providing information to people about how the condition may affect them in the future will also address the feelings of uncertainty and worry that people in the studies talked about (see sub-theme 1.2 lack of information & understanding).

The committee agreed that there can be progression of symptoms of spinal metastases, for example from back pain to neurological symptoms. In such cases, immediate treatment may be needed to avoid neurological impairment. In the evidence people described that there is a need to move forward quickly with treatment (see sub-theme 2.1 urgency of treatment). Based on this the committee decided that providing contact information helps minimise treatment delays which can help preserve neurological function.

Providing support

A strong recommendation was made to carry out a holistic needs assessment as soon as possible. Although no evidence was reviewed about holistic needs assessment as an intervention, the committee discussed the evidence that people and their families and carers valued support for physical, psychological, emotional and spiritual needs (see sub-themes 4.4 emotional support, sub-theme 5.2 support and sub-them 6.2 support (physical and practical)). The committee decided that identifying such needs could only be done via a holistic needs assessment which focuses on the person's physical and emotional needs. They agreed that holistic needs assessments have become an established part of cancer care.

The evidence also indicated that these needs can change from diagnosis to treatment and return home (see sub-theme 5.1 adapting to change). The committee agreed that specialist support would not be needed in all cases: for example routine specialist psychologist support may not be available or needed, however the committee noted that other healthcare professionals can or are able to give non-specialist psychological or emotional support (for example nursing staff) and help to identify people who may need extra support.

The committee drew on the evidence showing that people found it hard to deal with uncertainty and adapt to changes (see sub-theme 2.2 uncertainty) and noted that people in studies talked about wanting to stay autonomous and independent (see sub-theme 5.3 loss of independence). To address this they made a recommendation directly highlighting that people should be helped dealing with this where possible.

There was evidence that people with MSCC want information and support with end of life planning and conversations (see sub-theme 8.1 end of life conversations). The committee acknowledged that many people with MSCC have a life limiting condition and that advanced care planning is a way for them to express their preferences for how they should be cared for in the final months of their life.

Support from healthcare services including discharge from hospital

The evidence showed that people with MSCC often experience ongoing disability, such as reduced mobility, and have long term support needs (see sub-theme 3.3 adapting to disability). By providing access to support services for advice, assessment and rehabilitation people should be able to maintain independence for as long as possible.

The committee discussed the evidence that indicated that support is potentially not always provided for techniques and equipment that is needed both in hospital and after discharge (see sub-theme 6.1 support (physical and practical). They agreed that ongoing access to support and training is necessary to ensure that people and their families can cope with the changes that the person experiences in order to maintain independence, for example equipment to support mobility.

Cost effectiveness and resource use

No economic evidence was identified for this topic. The committee discussed the cost effectiveness of information and support based on their own knowledge and experiences in MSCC.

The recommendations based on this review were largely about the content and presentation of information. Any resource impact from changing that will be upfront and associated with staff time to update information. As information leaflets and websites are already in place and regularly updated and reprinted to keep them relevant to the latest clinical evidence and service arrangements there will be no or a very small resource impact from this. Improved information is likely to increase satisfaction with services, highlight signs to look out for and allow for care to be received early improving quality of life.

Recommendations about specialist support not being required in all situations should reduce the costs as non-specialist support is typically less expensive. It should also reduce the time needed to access such services improving quality of life.

Recommendations around a coordinated MSCC service may have some costs in the areas where this is not already established mostly around recruiting and employing coordinators of the service and developing pathways. Coordinated services should lead to better care and allow for people with MSCC to remain independent and in their own home. From other cost effectiveness evidence identified in this guideline, radiotherapy and surgery, reducing inpatient and community care costs, associated with reduced independence can lead to very large cost savings and increases in quality of life. The committee thought it was likely that these cost savings from improved care would outweigh any set-up costs within the first few years.

Other considerations

The details about how best to inform and involve people are covered by NICE guidelines on shared decision making (NG197) and patient experience (CG138).

The committee agreed that end of life care and bereavement support services should be offered as set out in NICE's guidelines on end of life care for adults and care of dying adults in the last days of life.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.1.14 and 1.2.1 to 1.2.13 (except 1.2.8) in the NICE guideline.

References – included studies

Qualitative

Eva 2009

Eva G, Paley J, Miller M, et al. Patients' constructions of disability in metastatic spinal cord compression. Palliative Medicine 23, 132-40, 2009

Lape 2020

Lape E, Katz J, Blucher J, et al. Patient experiences of decision-making in the treatment of spinal metastases: a qualitative study. Spine Journal, 20, 905-914, 2020

Lee 2013

Lee S. 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 (MSCC). (Thesis). Edinburgh Napier University. Retrieved from http://researchrepository.napier.ac.uk/id/eprint/6215, 2013

Manson 2017

Manson J, Warnock C, Crowther L. Patient's experiences of being discharged home from hospital following a diagnosis of malignant spinal cord compression. Supportive Care in Cancer 25, 1829-1836, 2017

Warnock 2014

Warnock C and Tod A. A descriptive exploration of the experiences of patients with significant functional impairment following a recent diagnosis of metastatic spinal cord compression. Journal of Advanced Nursing 70, 564-74, 2014

Appendices

Appendix A Review protocols

Review protocol for review question: What information and support is valued by adults with suspected or confirmed spinal metastases, direct malignant infiltration of the spine or associated spinal cord compression, and by their families, and carers?

Table 3: Review protocol

ID	Field	Content
0.	PROSPERO registration number	CRD42021288171
1.	Review title	Information and support for adults with suspected or confirmed spinal metastases, direct malignant infiltration of the spine or associated spinal cord compression, and their families and carers
2.	Review question	What information and support is valued by adults with suspected or confirmed spinal metastases, direct malignant infiltration of the spine or associated spinal cord compression, and by their families, and carers?
3.	Objective	To establish the information and support that is valued by adults with suspected or confirmed spinal metastases, direct malignant infiltration of the spine or associated spinal cord compression, and by their families and carers
4.	Searches	The following databases will be searched: • Cochrane Central Register of Controlled Trials (CENTRAL) • Cochrane Database of Systematic Reviews (CDSR) • Cumulative Index to Nursing and Allied Health Literature (CINAHL) • Database of Abstracts of Reviews of Effects (DARE) • Embase • Epistemonikos • International Health Technology Assessment (IHTA) database

ID	Field	Content
		• MEDLINE & MEDLINE In-Process Searches will be restricted by: • Date: 2005 onwards (see rationale under Section 10) • English language studies • Human studies • Qualitative studies filter Other searches: • Inclusion lists of systematic reviews With the agreement of the guideline committee the searches will be re-run between 6-8 weeks before final submission of the review and further studies retrieved for inclusion. The full search strategies for MEDLINE database will be published in the final review.
5.	Condition or domain being studied	Views, perceptions and/or lived experiences of adults and/or their families or carers with confirmed or suspected spinal metastases, direct malignant infiltration or associated spinal cord compression
6.	Population	Inclusion: • Adults with confirmed or suspected o metastatic spinal disease o direct malignant infiltration of the spine and their families & carers • Adults with suspected or confirmed spinal cord or nerve root compression because of o metastatic spinal disease o direct malignant infiltration of the spine and their families & carers Exclusion: • Adults with spinal cord compression because of primary tumours of the spinal cord and meninges • Adults with spinal cord compression because of non-malignant causes. • Adults with nerve root tumours compressing the spinal cord

ID	Field	Content
		• Children and young people under the age of 18
7.	Intervention/Exposure/Test	Not applicable (this is a qualitative review)
8.	Comparator/Reference standard/Confounding factors	Not applicable
9.	Types of study to be included	• Systematic reviews of qualitative studies • Studies using qualitative methods: semi-structured and structured interviews, focus groups, observations • Surveys conducted using open ended questions with qualitative analysis of responses
10.	Other exclusion criteria	Inclusion: • Full text papers Exclusion: • Conference abstracts • Articles published before 1990 – the date when MRI use became regular in this population. MRI had large impact on diagnosis and management and the views and experiences of patients before this time will be less relevant. • Papers that do not include methodological details will not be included as they do not provide sufficient information to evaluate risk of bias/ study quality • Surveys using mainly closed questions or which quantify open ended answers for analysis • Non-English language articles
11.	Context	Metastatic spinal cord compression in adults: risk assessment, diagnosis and management (2008) NICE guideline will be updated by this review question. Included studies will be relevant for developing and improving information and support provided to people with metastatic spinal disease, direct malignant infiltration of the spine or metastatic spinal cord compression within a health care setting.
12.	Phenomenon of interest	Themes will be identified from the literature. Themes considered potentially relevant by the committee include:

ID	Field	Content
		• Uncertainty about prognosis • Information about when to present (for example in high-risk patient groups) • Patients may struggle with identification of symptoms • Healthcare professionals’ knowledge of MSCC • When to seek help • Who to contact [for example: primary cancer team, community team, MSCC coordinator], end of treatment summary letters) • Support with functional activities of daily living • Information about types of treatment (decision making) – what’s involved and when to start, where treatment is carried out • What happens next after treatment – for example brace management following discharge • What’s safe/not safe to do • New onset symptoms (pain, neurological) who to contact • Psychological support
13.	Secondary outcomes (important outcomes)	Not applicable as this is a qualitative review
14.	Data extraction (selection and coding)	All references identified by the searches and from other sources will be uploaded into EPPI reviewer and de-duplicated. Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. Dual sifting will be performed on all records; 90% agreement is required. Disagreements will be resolved via discussion between the two reviewers, and consultation with senior staff if necessary. Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason for its exclusion. A standardised form will be used to extract data from studies. The following data will be extracted: study details (reference, country where study was carried out, type and dates), participant characteristics, inclusion and exclusion criteria, details of the interventions if relevant, setting and follow-up, relevant outcome data and source of funding. One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.

ID	Field	Content	
15.	Risk of bias (quality) assessment	Quality assessment of individual studies will be performed using the following checklists: • CASP checklist for qualitative studies • Risk of bias of systematic reviews of Qualitative studies will be assessed using the ROBIS Systematic Review check-list. The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.	
16.	Strategy for data synthesis	Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes. A theme map will be developed from the extracted study themes. The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research; Lewin 2018) approach will be used to summarise the confidence in qualitative evidence. The overall confidence in evidence about each theme or sub-theme will be rated on four dimensions: methodological limitations, applicability, coherence and adequacy of data. Methodological limitations refer to the extent to which there were problems in the design or conduct of the studies and will be assessed with the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies. Applicability/relevance of evidence will be assessed by determining the extent to which the body of evidence from the primary studies are applicable to the context of the review question. Coherence of findings will be assessed by examining the clarity of the data. Adequacy of data will be assessed by looking at the degree of richness and quantity of findings. The more complex the finding, the more detailed the supporting data need to be.	
17.	Analysis of sub-groups	As this is a qualitative review, formal sub group analysis is not appropriate.	
18.	Type and method of review	☐	Intervention
		☐	Diagnostic
		☐	Prognostic
		☒	Qualitative
		☐	Epidemiologic
		☐	Service Delivery
		☐	Other (please specify)

ID	Field	Content		
19.	Language	English		
20.	Country	UK		
21.	Anticipated or actual start date	01 December 2021		
22.	Anticipated completion date	29 September 2023		
23.	Stage of review at time of this submission	Review stage	Started	Completed
		Preliminary searches	☑	☑
		Piloting of the study selection process	☑	☑
		Formal screening of search results against eligibility criteria	☑	☑
		Data extraction	☑	☑
		Risk of bias (quality) assessment	☑	☑
		Data analysis	☑	☑
24.	Named contact	5a. Named contact National Guideline Alliance 5b Named contact e-mail metastaticspinal@nice.org.uk 5e Organisational affiliation of the review National Institute for Health and Care Excellence (NICE) and National Guideline Alliance		
25.	Review team members	National Guideline Alliance. Senior Systematic Reviewer National Guideline Alliance. Systematic Reviewer		
26.	Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance, which receives funding from NICE.		

ID	Field	Content	
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.	
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: [NICE guideline webpage].	
29.	Other registration details		
30.	Reference/URL for published protocol	https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=288171	
31.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: notifying registered stakeholders of publication publicising the guideline through NICE's newsletter and alerts issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.	
32.	Keywords	Adult; Biophysical Phenomena; Caregivers; Humans; Spinal Cord Compression; Spinal Cord Neoplasms; Spinal Neoplasms; Spine	
33.	Details of existing review of same topic by same authors	Not applicable	
34.	Current review status	☒	Ongoing
		☐	Completed but not published
		☐	Completed and published

ID	Field	Content	
		☐	Completed, published and being updated
		☐	Discontinued
35..	Additional information	None	
36.	Details of final publication	www.nice.org.uk	

CDSR: Cochrane Database of Systematic Reviews; CENTRAL: Cochrane Central Register of Controlled Trials; DARE: Database of Abstracts of Reviews of Effects; GRADE-CERQual: Grading of Recommendations Assessment, Development and Evaluation - Confidence in the Evidence from Reviews of Qualitative Research ; HTA: Health Technology Assessment; MSCC: metastatic spinal cord compression; NGA: National Guideline Alliance; NHS: National health service; NICE: National Institute for Health and Care Excellence.

Appendix B Search strategy (qualitative)

Literature search strategies for review question: What information and support is valued by adults with suspected or confirmed spinal metastases, direct malignant infiltration of the spine or associated spinal cord compression, and by their families, and carers?

Database: Medline – OVID interface

#	Searches
1	exp Spinal Cord Neoplasms/ or Spinal Neoplasms/
2	((spine or spinal or vertebr*) adj2 (adeno* or cancer* or carcinoma* or intraepithelial* or intra epithelial* or malignan* or neoplas* or tumo?r*)).tw.
3	((spine or spinal or vertebr*) and (metast* or oligometast*)).tw.
4	Spinal Cord Compression/
5	((cauda equina or cervical* or cervicothoracic or cord* or coccyx or duralsac* or dural sac* or intervertebr* or lumbar or lumbosac* or lumbo sac* or medulla* or orthothoracic or sacral or sacrum or spinal or spine* or thecal sac* or thoracic or vertebr* or epidural or extradural or extra dural or ((axon* or neuron* or nerve*) adj2 root)) and (collaps* or compress* or pinch* or press*) and (adeno* or cancer* or carcinoma* or chordoma* or intraepithelial* or intra epithelial* or malignan* or metast* or neoplas* or oligometast* or tumo?r*)).tw.
6	(myelopath* or myeloradiculopath* or radiculopath*).tw,hw. or (radicular adj2 (disorder* or syndrome*)).tw.
7	(mescc or mscc).tw.
8	((adeno* or cancer* or carcinoma* or intraepithelial* or intra epithelial* or malignan* or metast* or neoplas* or tumo?r*) adj3 (escap* or infiltrat* or invasiv* or metast* or spread*) adj5 (cauda equina or cervical* or cervicothoracic or cord* or coccyx or duralsac* or dural sac* or intervertebr* or lumbar or lumbosac* or lumbo sac* or medulla* or orthothoracic or sacral or sacrum or spinal or spine* or thecal sac* or thoracic or vertebr* or epidural or extradural or extra dural or ((axon* or neuron* or nerve*) adj2 root))).tw.
9	or/1-8
10	Access to Information/ or Activities of Daily Living/ or Attitude of Health Personnel/ or exp Audiovisual Aids/ or Braces/ or Communication/ or exp Communication Barriers/ or exp Communications Media/ or exp Community Health Services/ or exp Computers, Handheld/ or Consumer Advocacy/ or Consumer Health Information/ or exp Counseling/ or Decision Making/ or Decision Support Systems, Clinical/ or Electronic Mail/ or Empowerment/ or Government Publications as Topic/ or Health Communication/ or Health Education/ or exp Health Information Management/ or Health Knowledge, Attitudes, Practice/ or Health Literacy/ or Health Promotion/ or Help-Seeking Behavior/ or Hotlines/ or Information Centers/ or Information Dissemination/ or Information Seeking Behavior/ or Information Services/ or exp Internet/ or Internet-Based Intervention/ or Mass Media/ or Mobile Applications/ or exp Mobile Phone/ or exp Nurses/ or Pamphlets/ or exp Oncologists/ or Patient Advocacy/ or exp Patient Care Team/ or Patient Education as Topic/ or Patient Education Handout/ or Patient Medication Knowledge/ or Patient Participation/ or Patient Safety/ or Peer Group/ or exp Professional-Patient Relations/ or exp Psychotherapy/ or Radio/ or Self-Help Groups/ or Social Media/ or exp Social Networking/ or exp Social Support/ or Telemedicine/ or Telephone/ or Television/ or Text Messaging/ or Therapy, Computer-Assisted/mt or Uncertainty/ or exp Video-Audio Media/ or Web Browser/
11	((daily or decision or function* or group* or psycho*) adj2 support*).tw.
12	(app or apps or blog* or booklet* or brochure* or cellphone* or discussion* or download* or dvd* or elearn* or e-learn* or email* or e mail* or facebook or facetime or fora or forum* or google or handout* or hand out* or helpline* or help line* or hotline* or hot line* or ict or information* or internet* or ipad* or iphone* or leaflet* or letter* or magazine* or manual or manuals or media or messag* board or myspace or newsletter* or pamphlet* or phone* or podcast* or poster? or publication* or skype* or smartphone* or social media or social network* or sms or telephone* or text messag* or twitter or tweet* or video* or webpage* or web page* or web based or web search* or website* or web site* or wiki* or written or youtube* or zoom or helpseek* or help seek* or healthcareseek* or healthcare seek* or healthseek* or health seek* or care seek* or careseek*).tw.
13	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or sister* or spous* or mother* or parent* or wife* or wive* or consumer* or inpatient* or man or men or patient* or person or people or population or user* or women or woman or clinician* or counselor* or counsellor* or doctor* or gp? or health visitor* or coordinator* or co ordinator* or nurs* or officer* or personal assistant* or personnel or physician* or practitioner* or primary care or professional* or psychiatrist* or psychologist* or worker* or cancer team* or community team* or oncolog*) adj2 (advice or advise? or advising or communicat* or educat* or guid* or inform* or involv* or knowledge* or learn* or support* or understand*)).tw.
14	((information* or support* or advice or guidance) adj2 (access* or brace? or bracing or contact* or disseminat* or model* or need* or provid* or provision or program* or requir* or resource* or seek* or service* or shar*)).tw.
15	((communicat* or inform* or support*) adj2 (accura* or barrier* or benefi* or clear* or facilitat* or help* or hinder* or hindran* or practical* or support*)).tw.
16	((information* or support* or advice or guidance) adj2 (aid* or content* or format* or method* or quality or sheet* or symptom* or type*)).tw.
17	((added or additional or extra or further or prompt* or time* or timing or when) adj3 (advice or informat* or support* or guidance)).tw.
18	patient education handout.pt.
19	or/10-18
20	9 and 19
21	Anthropology, Cultural/ or Cluster Analysis/ or Focus Groups/ or Grounded Theory/ or Health Care Surveys/ or Interview.pt. or "Interviews As Topic"/ or Narration/ or Nursing Methodology Research/ or Observation/ or "Personal Narratives As Topic"/ or Personal Narrative/ or Qualitative Research/ or "Surveys And Questionnaires"/ or Sampling Studies/ or Tape Recording/ or Videodisc Recording/

#	Searches
22	(qualitative* or interview* or focus or questionnaire* or narrative* or narration* or survey* or experience* or themes).tw.
23	(ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic adj4 analys*) or theoretical sampl* or purposive sampl*).tw.
24	(hermeneutic* or heidegger* or husser* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).tw.
25	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*).tw.
26	(critical interpretive synthes* or (realist adj (review* or synthes*)) or (noblit and hare) or (meta adj (method or triangulation)) or (cerqual or conqual) or ((thematic or framework) adj synthes*)).tw.
27	or/21-26
28	Patient Preference/ or exp Patient Satisfaction/
29	(dissatisf* or expectation* or experienc* or opinion* or perceive* or perspective* or preferenc* or satisf* or view*).ti.
30	((adult* or people* or population* or consumer* or patient* or user* or parent* or famil* or relati* or carer* or caregiver* or care giver* or inpatient* or spous* or husband* or wife* or wive* or partner* or mother* or father* or sibling* or sister* or brother*) adj6 (attitude* or concern* or dissatisf* or expectation* or experienc* or opinion* or perception* or perceive* or perspective* or preferenc* or satisf* or view*)).tw.
31	or/28-30
32	27 or 31
33	20 and 32
34	limit 33 to english language
35	limit 34 to yr="2005-Current"

Health economics search

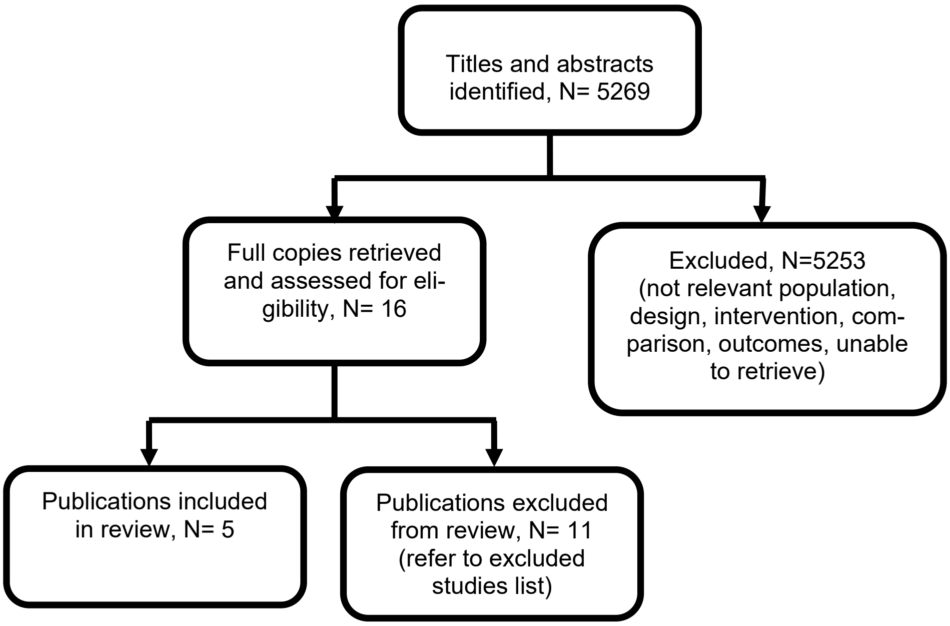
Database: Medline – OVID interface

#	Searches
1	exp Spinal Cord Neoplasms/ or Spinal Neoplasms/
2	((spine or spinal or vertebr*) adj2 (adeno* or cancer* or carcinoma* or intraepithelial* or intra epithelial* or malignan* or neoplas* or tumo?r*)).tw.
3	((spine or spinal or vertebr*) and (metast* or oligometast*)).tw.
4	or/1-3
5	Spinal Cord Compression/
6	((cauda equina or cervical* or cervicothoracic or cord* or coccyx or duralsac* or dural sac* or intervertebr* or lumbar or lumbosac* or lumbo sac* or medulla* or orthothoracic or sacral or sacrum or spinal or spine* or thecal sac* or thoracic or vertebr* or epidural or extradural or extra dural or ((axon* or neuron* or nerve*) adj2 root)) and (collaps* or compress* or pinch* or press*) and (adeno* or cancer* or carcinoma* or chordoma* or intraepithelial* or intra epithelial* or malignan* or metast* or neoplas* or oligometast* or tumo?r*)).tw.
7	(myelopath* or myeloradiculopath* or radiculopath*).tw,hw. or (radicular adj2 (disorder* or syndrome*)).tw.
8	(mescc or mscc).tw.
9	or/5-8
10	((adeno* or cancer* or carcinoma* or intraepithelial* or intra epithelial* or malignan* or metast* or neoplas* or tumo?r*) adj3 (escap* or infiltrat* or invasiv* or metast* or spread*) adj5 (cauda equina or cervical* or cervicothoracic or cord* or coccyx or duralsac* or dural sac* or intervertebr* or lumbar or lumbosac* or lumbo sac* or medulla* or orthothoracic or sacral or sacrum or spinal or spine* or thecal sac* or thoracic or vertebr* or epidural or extradural or extra dural or ((axon* or neuron* or nerve*) adj2 root))).tw.
11	or/4,9-10
12	Economics/ or Value of life/ or exp "Costs and Cost Analysis"/ or exp Economics, Hospital/ or exp Economics, Medical/ or Economics, Nursing/ or Economics, Pharmaceutical/ or exp "Fees and Charges"/ or exp Budgets/
13	(cost* or economic* or pharmacoeconomic*).ti.
14	(budget* or financ* or fee or fees or price* or pricing* or (value adj2 (money or monetary))).ti,ab.
15	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
16	or/12-15
17	11 and 16
18	limit 17 to english language
19	limit 18 to yr="2005 -Current"

Appendix C Qualitative evidence study selection

Study selection for: What information and support is valued by adults with suspected or confirmed spinal metastases, direct malignant infiltration of the spine or associated spinal cord compression, and by their families, and carers?

Figure 2: Study selection flow chart



Appendix D Evidence tables

Evidence tables for review question: What information and support is valued by adults with suspected or confirmed spinal metastases, direct malignant infiltration of the spine or associated spinal cord compression, and by their families, and carers?

Table 4: Evidence tables

Eva, 2009

Eva G, Paley, J, Miller, M, et al. Patients' constructions of disability in metastatic spinal cord compression; Palliative Medicine, vol. 23 (no. 2); 132-40, 2009

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK, England
Setting	Oxford Radcliffe Hospitals NHS Trust
Data collection and analysis	**Data Collection:** Semi-structured interviews ranging from 30-105 minutes. Pawson and Tilley's Context-Mechanism-Outcome (CMO) configuration was used as the conceptual basis for data collection. A guide was drawn up for each interview; subsequent interview questions were formulated on the basis of earlier data collection with the aim to construct a plausible CMO hypothesis for each case. Interviews were tape-recorded and transcribed verbatim. NVivo was used to manage, develop and revise the coding structure, confirm categories and explore connections between categories. **Analysis:** Within-case and between-case analysis was conducted.
Recruitment strategy	Not clearly stated. Nine patients were recruited, using maximum variety sampling within the constraints of research with a vulnerable population. Where possible, interviews were conducted at various points during the course of the patient's illness; intervals varied according to the patients' circumstances but were sufficiently spaced to capture significant changes in the patients' conditions.
Study dates	Not stated.

Sources of funding	Oxfordshire Health Services Research Committee
Inclusion criteria	Not reported.
Exclusion criteria	Not reported.
Sample size	N = 9
Participant characteristics	**Age, mean (SD) years**: Mean and SD NR but range provided - 42 to 82 years **Sex:** 1 women and 7 men **Ethnicity:** Not reported **Setting:** Radiotherapy unit in a regional cancer centre **Primary Cancer:** breast, prostate, kidney, thymus and myeloma **Survival post diagnosis of MSCC range:** from 15 days to 2 years and 6 months
Results	**Author's main themes** • Acknowledging the problem • Not acknowledging the problem • Managing the tension **Subtheme: Exploring the boundaries** " I'm realising that there are limits now. I walked up to the doctors and I had to keep stopping, and I realised I just, I couldn't do that any more. I'm just kind of working out boundaries, seeing what I can and can't do. And I think I'm quite disappointed at what I can't do. (Pt B, I1) p. 134 " **Subtheme: Concern about dependence on others** " [The furniture for the new flat comes] flat-packed [and my son] is going to assemble them because I haven't got the strength to do it anymore. You want to know the most frustrating thing since my health's gone? Is having to get people to do things for me. (Pt A, I2) p. 134 " " No possibility of me going home, at this moment. I'd have to go to my daughter's. Young family. They all love granddad, I mean, you know, we all get on very well, good laugh together. But, I can't see myself—my daughter's not going to—it won't be fair, it won't be fair to them. So, going home, no. (Pt D, I2) p. 134 " " [My wife] had a very full life, I mean, she was a school governor and things like that. And for me she's more or

less had to forgo most of it, you know. I feel sorry for [her] because of, you know, it's changed her life completely. (Pt F, I2) p. 134 ”

Subtheme: Reordering and restructuring

” Walking is my main hobby other than writing. At the moment I'm just preoccupied with making my home somewhere where I can cope, achieve as many of the normal things which will, in my case, involve using a car to get out, both to see friends and perhaps to get to the flat places where I can walk or be pushed in a wheelchair to scenic country. (Pt H, I1) p.134-135 ”

” My life is ruled by where the next toilet is really, you know. This has happened about three times actually. I went with [my wife] down to the bank and I was perfectly all right. I climbed out of the car and without any warning whatsoever I pooed myself. It was absolutely everywhere. On the floor, on the pavement, in the car, have you any idea. (Pt A, I2) p.135 ”

” It would have been helpful to have simple things explained, like the balance between rest and activity. I've made up my own little exercises and I try to do at least a half mile walk everyday [but] I really don't know whether that's sensible or not. Maybe it's partly my fault that I didn't find that out before I left [hospital] but you know, you don't know the right questions. [Now] I don't really feel I can just phone up and ask. Who would I ask, I don't know. (Pt B, I1) p. 135 ”

Subtheme: Having information on SCC

” Patient D: You just don't know [what the future will hold]. Nobody can tell me. Interviewer: Have you asked? Patient D: No not really. What [the doctor has] told me, he is very straightforward. But I haven't sort of cornered him, if you know what I mean. I mean, will he just wag his finger at me and say, ‘Well you are never getting out of here, D!’ (Pt D, I1) p. 135 ”

Subtheme: Asserting normality

” It has changed the perception of me, undoubtedly. It's not something you really notice, it's just everyone's very supportive and kind and stuff. But obviously implicit in that, there's no one treats you like just a mate any more. Everybody knows about the cancer and there is a stigma attached to it. And that's what I wanted to avoid for as long as possible. I think what I wanted to preserve was the absolute preciousness of normality. (Pt B, I2) p.135 ”

Subtheme: Finding possibilities

” I want to walk before the year is out. (Pt F, I1) ”

” My mum and dad are coming up tomorrow. I've said to them that I need to get a few things from the shop, and

	probably we'll get the ramps out for the front door and my mum will take me over to town. (Pt G, I3) p. 137 " Total words quoted from Eva 2009 =716. Maximum individual quote length =102 words.

Critical appraisal

Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Can't tell *(Lack of justification for research design)*
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Can't tell *(No explanation of recruitment approach.)*
Data collection	Was the data collected in a way that addressed the research issue?	Yes
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell (*A lack of researcher reflexivity*)
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns (*Lack of justification for research design. No explanation of recruitment approach. A lack of researcher reflexivity)*
Overall risk of bias and relevance	Relevance	Relevant

Lape, 2020

Lape E, Katz J, Blucher J, et al. Patient experiences of decision-making in the treatment of spinal metastases: a qualitative study. Spine Journal, 20, 905-914, 2020

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	USA
Setting	Three academic tertiary care centres in the departments of orthopaedic surgery, neurosurgery, or radiation oncology.
Data collection and analysis	**Data Collection:** Semi-structured interviews were conducted via phone or at Brigham and Women's Hospital. An interview guide was drawn up that probed: participants' goals for treatment, the people and sources of information they consulted, their valuation of different health states, and their understanding of the trade-offs involved in choosing operative or nonoperative management. The study team regularly met during enrolment to assess if thematic saturation had been met. All participants consented, demographic and clinical information was obtained before, or at the time of, the interview. **Analysis:** Interviews were audio-recorded with permission, transcribed verbatim and all transcripts were deidentified. Data were analysed using a thematic analysis.
Recruitment strategy	Patients presenting for evaluation and treatment of spinal metastatic disease at three academic tertiary care centres were recruited. Potentially eligible participants were invited to participate and given 10 days to opt out of study participation. Those who had not opted out within 10 days were contacted by a research assistant confirmed eligibility and obtained verbal consent. Participants were compensated $25 for their time.
Study dates	Not stated.
Sources of funding	National Institutes of Health (NIH-NIAMS) grants
Inclusion criteria	• patients presenting for evaluation and treatment of spinal metastatic disease • age >18 • ability to speak English
Exclusion criteria	Not reported
Sample size	N = 23 patients with spinal metastases
Participant characteristics	**Age, mean (SD) years:** 62 (NR) **Sex:** 10 women and 13 men **Ethnicity:** White: 23 **Setting:** Three academic tertiary care centres in the departments of orthopaedic surgery, neurosurgery, or radiation oncolo-

	gy **Primary tumour:** Breast 1 Kidney 6 Lung 4 Prostate 2 Thyroid 1 Head and neck cancer 1 Multiple myeloma/lymphoma 4 Testicular 1 Uterine 1 Paraganglioma 1 Pancreatic 1
Results	**Author’s main themes** • Diagnostic context • Locus of decision-making • Treatment-related considerations **Subtheme: Enormity of condition** ” You don’t know the questions to ask, because I had no idea I was gonna have tumors on my spine. If I had known that, I would have come in and said … are we gonna do surgery, or are we gonna do radiation… p.5 ” ” I didn’t think there were any options other than [receiving the treatment offered], because it seemed like if this wasn’t dealt with then I could definitely end up with some deficit including paralysis. p.5 ” **Subtheme: Urgency** ” Whenever you have something in you that’s growing—it’s a growth—you probably want it—outta there as soon as possible. [Surgery] was scheduled pretty quickly p.5 ” **Subtheme: Anxiety** ” Any surgery can go bad and I knew that. But I was just … anxious to get it over and done with… p.6 ” ” If I go down that rabbit hole it just leads to an uncomfortable place. p.6 ”

	Subtheme: Ideas of the appropriate role for a patient ” They know a lot more than me, so you go with—it’s like goin’ to an auto mechanic. p. 6 ” **Subtheme: Family role** ” You’re in a bit of a fog. I just wanted to get done—whatever needs to be done get done. The other person who’s not feeling that is saying, ‘Well, hold on a second.’ They had more questions than I had. P. 6 ” ” That’s a pretty hefty decision-making thing to do. My wife and I … work it out, but in the end I relieve her or the doctors or anybody else of [the decision] ” **Subtheme: Choice of provider** ” I trust my doctors, so if my surgeon … or my radiation oncologist said … see if you think this might be helpful to you, I would do it. P. 7 ” **Subtheme: Goals** ” … I just wanted to stop the progression. And avoid being paralyzed. P. 8 ” ” My son is getting married in October and I’m part of his wedding party, and I don’t wanna do wheelchairs. I’d rather walk him down the aisle. P. 8 ” **Subtheme: Beliefs about surgery** ” I just wanted to give the other options an opportunity to work first. If they don’t, it’s nice to have the surgery option as a backup plan. P. 8 ” **Subtheme: Acceptance of treatment risks** ” I’m comfortable enough at this point with dying, that if I make a mistake, it’s just my mistake. I did it, so nobody will feel like, ‘… I made the wrong decision for him.’ p. 8 ” **Subtheme: Seeking and understanding information** ” You get home, and then you start researching, and then all the questions come. They’ve been really good about doing follow-up answers to my questions, but I’d rather be prepared. P. 9 ” ” They just don’t have the time. [You can’t] take up half of their … day so that you and everybody in your family can

	understand what [is] going on. P. 9 ” Total words quoted from Lape 2020 =460. Maximum individual quote length =46 words.

Critical appraisal

Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Yes
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell *(A lack of researcher reflexivity)*
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(A lack of researcher reflexivity)*
Overall risk of bias and relevance	Relevance	Relevant

Lee, 2013

Lee S. 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 (MSCC). (Thesis). Edinburgh Napier University. Retrieved from http://researchrepository.napier.ac.uk/id/eprint/6215, 2013

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK, Scotland
Setting	Hospital, Lothian NHS
Data collection and analysis	**Data Collection:** *Healthcare professionals* - the author held 3 focus groups lasting an hour each and interviewed healthcare professionals ranging from 30-60 minutes in a cancer center and health boards in East Scotland. A topic guide was used for focus groups and individual interviews, and the sessions were audio recorded. *Patients, carers and family* - the author conducted semi-structured interviews ranging from 40-80 minutes with patients at two timepoints; initial interviews were conducted after the first 5 fractions of radiotherapy and the second interview between 4-8 weeks later. The author also conducted semi-structured interviews ranging from 40-80 minutes with carers/family at 2 timepoints. *Key healthcare professionals* - the author conducted semi-structured interviews ranging from 40-80 minutes. **Analysis:** All audio tapes of the interviews were transcribed verbatim. Data were thematic analysed.
Recruitment strategy	**Phase one:** the author recruited healthcare professions through the oncology consultant, Head of Cancer and Palliative Services and Heads of Departments. **Phase two:** Patient were initially contacted by the treating oncologist, if the patient was agreeable the author explained the study to them and asked if their carer/family would be interested in participating in the study. The author allowed for 24-48 hours for the patients and their carers/family to consider participating, if agreeable informed consented sought by the author.
Study dates	**Phase one:** July - August 2009 **Phase two:** September 2009 to March 2010
Sources of funding	Not stated
Inclusion criteria	**Healthcare professionals:** Not stated **Patients:** • patients with a confirmed diagnosis of metastatic spinal cord compression

	• undergoing treatment • willing to reflect on their experience and willing to participate **Carers:** • patients' permission to approach their carers • supporting the patient with a radiological diagnosis of MSCC • 18+ years of age • able to give consent
Exclusion criteria	Not stated
Sample size	N = 25 healthcare professionals N = 8 patients N = 6 carers
Participant characteristics	**Not reported:** age, gender, ethnicity and primary tumor **Setting:** Hospital, Lothian NHS
Results	**Author's main themes** • Facing uncertainty in MSCC • Finding a balance in uncertainty of MSCC **Subtheme: Trying to make sense of it all** " I spoke to my daughter-in-law and I explained to her. I said 'well, I don't know what to do – whether to phone NHS24 or what to do? (Jane, wife (CS4), p12/6) p. 145 " " …like the lady next to me that's got it in her spine and she is saying she's dying. I'm listening to her day in, day out, and I don't want… The thought of being like that is really anxiety for me…umm…just being immobile… (Sandra, patient (CS2), Interview 1, p15/24) p. 143 " **Subtheme: Help us put the jigsaw together** " …one doesn't get time often to speak to people about what's going on in your body, what the disease actually is and what it's going to do to you and things like that. So, I do think being able to speak to people individually with the time, for me is quite a big factor, you know, even just being able to speak to your doctor for an extended length of time rather than just, you know, the few minutes that you often get with a GP; you need to have extended period of time (Richard, patient (CS5), Interview 1, p28/18) p.165 " **Subtheme: When to have a conversation about the future?**

” I know my left leg isn’t moving as it should be but because of my determination I will get that moving [laughs] so, err…and with the steroids it does make me confident to be able to get that (Emma, patient (CS6), p11/1) p.173 ”

” You don’t really want to know what someone’s opinion is of your life expectancy, you know, because I’m not very much in favour of that because I think that is a horrible burden to have. I think I’d rather not know something like that (Linda, wife (CS5), interview 1, p12/17) p.175 ”

Subtheme: Battle-plan – what is the next step?

” And, as I said, they couldn’t do anything more for me, but I said ‘we’ll take it from there’ I just take one day at a time and make the most of what I’ve got there in my family and… I’m quite…I’m not even stressing myself out about it because I know that this is another part of a journey I’m going on (Betty, patient (CS1), p21/13) p.191 ”

Subtheme: “They say there is support out there but…”

” I felt quite bad and what is the point of going on and looking back now, I felt as though I could end it now and it was the steroids that were doing it and I felt really down. I also felt really drunk all the time when I came home as though I had about 6 bottles of wine (Sandra, patient (Case Study 2), Interview 2, p9/1) p.206 ”

” You get lots and lots of support at the beginning or when you got problems and you spoke to the doctor. And I had the psychologist to talk to, she has moved away now. Erm…I got no one…and you know, my husband, I feel guilty because I feel as I talk something to do with me every day and it must wear him down (Sandra, patient (CS2), Interview 2, p14/24) p.207-8 ”

” And he’s got a Zimmer frame which I didn’t like him using it at all. Erm…we put it in the garden…erm…I didn’t like it in the house. I think it’s an old person’s …I just didn’t like seeing him using it (Gail, wife (CS7), Interview 1, p23/8) p.209 ”

” It’s hard for me because I feel as though I’m not doing my bit, I’m not doing my share, I’m not helping out and I’m not…eh…well…held my children as much. This is frustrating and a bit err…hard, a bit hard for me, you know what I mean (Tony, patient (CS7), Interview 2, p26/5) p.210 ”

Subtheme: Determining the final moments

” So, when Richard came back from that appointment, he was feeling very optimistic. I think just the fact that [name of consultant] had given him an appointment after Christmas had made him feel ’oh, gosh! so, I’ll make it past Christmas then! (Palliative Care Doctor (CS5), p17/9) p.213 ”

” He didn’t know how long, but I got that from [name of oncologist], but then I couldn’t keep that from Tony because we…we always shared things; we never kept anything from each other. So I went up, once the girls were in their

	bed that night, and I did tell him that 'I can't keep it from you: [name of oncologist] said you've got about two to three weeks,' and he said 'well, I kind of like knew that' (Gail, wife (CS7), Interview 2, p6/22) p.216-7 " Total words quoted from Lee 2013 =798. Maximum individual quote length =106 words.

Critical appraisal

Section	**Question**	**Answer**
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Yes
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Yes *(The author was not involved in the care of patients and described how they remained impartiality.)*
Ethical Issues	Have ethical issues been taken into consideration?	Yes

Section	Question	Answer
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
Overall risk of bias and relevance	Relevance	Relevant

Manson, 2017

Manson J, Warnock C, Crowther L. Patient's experiences of being discharged home from hospital following a diagnosis of malignant spinal cord compression. Supportive Care in Cancer 25, 1829-1836, 2017

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK, England
Setting	A regional cancer centre
Data collection and analysis	**Data Collection:** Semi-structured interviews lasting between 20-45 minutes, done by one researcher not involved in the patient's care. Interviews about their experiences at 1 and 3–4 weeks post-discharge home following a diagnosis of MSCC were audio-recorded and then transcribed verbatim. **Analysis:** Transcripts were analysed using a framework approach. Analysis was carried out independently by two investigators who met after each step to discuss the analysis to reach agreement. A third investigator verified the themes during mapping and interpretation. Themes were identified and this formed the initial framework matrix. Data was then extracted from the transcripts and transferred to the matrix; content was placed under all themes where appropriate. Data analysis and interpretation was refined using discussion and mapping by all three investigators. An iterative deductive approach was taken by referring to initial transcripts to ensure internal validity. Data saturation was reached by interview nine. The remaining

	two interviews were used to confirm and clarify the analysis.
Recruitment strategy	Recruitment was carried out in a regional cancer centre. Therapy services staff on in-patient wards identified potential participants, informed them of the study, gave them a copy of the written information sheet and obtained permission to be approached by the researcher. The research explained the project, answered any question and then obtained written informed consent if the patient was willing to participate. Participants were contacted by telephone at two time points after discharge, between 4 - 7 days and 14 - 21 days after returning home.
Study dates	August 2015 and March 2016
Sources of funding	Macmillan Cancer Support UK
Inclusion criteria	• admitted with newly diagnosed MSCC for radiotherapy treatment • being discharged home from the cancer centre • able to communicate in English over the telephone
Exclusion criteria	Not reported
Sample size	N = 11 MSCC patients
Participant characteristics	**Age, mean (SD) years**: Mean and SD NR but range provided - 63 to 85 **Sex:** 2 women and 9 men **Ethnicity:** Not reported **Setting:** A regional cancer centre **Primary Cancer:** Breast 2 Prostate 7 Thyroid 1 Lymphoma 1
Results	**Author main themes** • Time • Past • Present • Near future • Bridging past, present and future **Subtheme: Past** ” And I just want to get up and do things I used to do, but obviously I’m not going to be able to and I find that frus-

trating. - 003 interview 2 p 1831 ”

Subtheme: Present: Challenges encountered at home

” Some nights she gets a bit stressed out, doesn’t sleep very well, but when she sees me in tremendous pain she says she doesn’t know what to do. - 009 interview 1 p 1831 ”

” The only thing I have trouble with is washing. I can’t get a proper wash. I’m washing off a bowl, well they wash me every morning, give me a bath and that, but getting a shave and doing my teeth, it’s a real pain…. (wife) gets me the stuff but it’s not easy. – 001 interview 1 p.1832 ”

” I’ve no confidence in walking, I just felt as though I were going to fall over all the time…….it’s taking a little bit of effort even to just get out of the house to try walking about. – 010 interview 2 p.1832 ”

” you know you can lower the bed and higher the bed (in hospital) and it was easier. I’ve got quite a big mattress on my bed and probably it’s a bit higher than normal – 003 interview 1 p 1832 ”

” I do bits of jobs, but it’s just to be able to get in and out of bed and to get in and out of the shower, you know, so (carer) can go home a bit really and not be tied down with me in a way. -003 interview 2 p.1832 ”

Subtheme: Present: Support from community services

” Well as far as the GPs are concerned, I mean it’s a complete non-event. I mean they don’t, there’s no contact whatsoever, even a phone call from the surgery, from the GP or even one of the nurses or something who could ring up – 006 interview 1 p.1832 ”

” Yeah I think they (OT) were going to try and get round, but nobody’s been as yet. That were two or three weeks back as regards like such as when I’m getting in bath or shower, I felt very insecure thinking… I were going to fall down and one thing and another. -023 interview 2 p.1832 ”

” Well, I had the Macmillan nurse come to see me yesterday… She sorted three or four things out…. She’s going to get me one of these lift-up chairs because my ankles are swelling… She’s sorting, possibly, acupuncture, and she’s going to sort physios and OT as well, so she’s on the ball. -003 interview 1 p.1833 ”

Subtheme: Near future: “Getting back to normal”

” If I could go out in the streets, feel confident that I can go for a walk round without owt (anything) happening to me, I should feel smashing. -010 interview 1 p. 1833 ”

Subtheme: Distant future

	” at the end of the day I’ve got cancer that’s spreading ain’t I?… obviously it’s a big concern, because they never know what it’s going to attack next. But I’m trying to put that at the back of me mind and just carry on with life. -010 interview 1 p.1833 ” ” he’s concerned about whether or not he’s going to manage to get on his legs again, more than anything. You know, Dr (oncologist) said he could, or he may not. But nobody can answer these questions…it’s something that’s just got to be, we’ll take it as it comes, you know. -004 interview 2 p.1833 ” Total words quoted from Manson 2017 =595. Maximum individual quote length =62 words.

Critical appraisal

Section	**Question**	**Answer**
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Yes
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Yes *(Interviewer was not involved in patient care.)*
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes

Section	Question	Answer
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
Overall risk of bias and relevance	Relevance	Relevant

Warnock, 2014

Warnock C and Tod A. A descriptive exploration of the experiences of patients with significant functional impairment following a recent diagnosis of metastatic spinal cord compression. Journal of Advanced Nursing 70, 564-74, 2014

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK, England
Setting	A regional cancer centre in the North of England, UK.
Data collection and analysis	**Data Collection:** Semi-structured interviews were done using open ended questions. These explored the patient's descriptions of their experiences leading up to diagnosis and during their admission to the cancer centre along with their thoughts and feelings about their future with MSCC. Interviews were done by the primary investigator, and ranged from 30 minutes to an hour and took place after completion of radiotherapy but prior discharge home. Interviews were taped and transcribed verbatim. **Analysis:** Data was analysed using Framework analysis. Rigour of analysis was achieved through verification of data analysis by both authors and internal validity was supported by use of constant comparison analysis.
Recruitment strategy	Ward nurses approached eligible patients and asked if they would participate in a research study. For those who agreed, the research explained the study and provided written information about the study. Interviews were done the following day if consent was granted.
Study dates	April 2009 – March 2010.
Sources of funding	Weston Park Hospital cancer care appeal
Inclusion criteria	• inpatients who had been admitted with MSCC for radiotherapy treatment

	• participants who had completed radiotherapy • patients with mobility problems due to MSCC • those who were still able to mobilize independently • able to speak and understand English.
Exclusion criteria	• patients who required assistance for mobilization, for example, wheelchair or bed-bound patients
Sample size	N = 10
Participant characteristics	**Age, mean (SD) years:** Mean and SD NR but range provided - range 59 to 81 **Sex:** 3 women and 7 men **Ethnicity:** Not reported **Setting:** A regional cancer centre **Primary Cancer:** Breast 2 Prostate 5 Lung 3
Results	**Author main themes** • Thinking through the implications of MSCC • Meeting the challenges of MSCC **Subtheme: Losing mobility and independence** ” The first doctor I saw said a little bit of degeneration in the spine which I can quite see that degeneration, arthritis, cancer in the spine can be muddled…the only sort of question mark I have had in mind over that and I don’t like to criticize but with a history of breast cancer and knowing now that it is a known secondary why did it take 5 months to raise a flag then. (INT 8) p.568 ” **Subtheme: Improving mobility and independence** ” They (nurses) are very positive and they allow me to try things….If I want to try something I can try. I have been succeeding in most things I have tried which makes me feel good. The first day I could hardly stand, the next time I stood up and down three times, not brilliantly I admit but I did. (INT 3) p.569 ” **Subtheme: Taking the right approach** ” I worry about it but I try to block it off, I just start thinking about other things, it is mainly in the morning when I am on my own I think about it so I watch documentaries on telly and it like stops you thinking, otherwise I am happy if

	they can contain it. (INT 5) p.570 ” ” I am not going to cry because it is a treatment I have got to have, if it does good then that is a bonus, if it doesn’t then I can’t do nothing about it…..which in my eyes is the way you have to look at the treatment. But I will take every day as it comes and I know deep in my heart I am still the same as when I came in. (INT 6) p.570 ” Total words quoted from Warnock 2014 =284. Maximum individual quote length =81 words.

Critical appraisal

Section	**Question**	**Answer**
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Yes
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can’t tell *(A lack of researcher reflexivity)*
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(A lack of researcher reflexivity)*

Section	Question	Answer
Overall risk of bias and relevance	Relevance	Relevant

Appendix E Forest plots

Forest plots for review question: What information and support is valued by adults with suspected or confirmed spinal metastases, direct malignant infiltration of the spine or associated spinal cord compression, and by their families, and carers?

No meta-analysis was conducted for this review question and so there are no forest plots.

Appendix F GRADE-CERQual tables

GRADE tables for review question: What information and support is valued by adults with suspected or confirmed spinal metastases, direct malignant infiltration of the spine or associated spinal cord compression, and by their families, and carers?

Table 5: Evidence profile: Theme 1. Information delivery and comprehension

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 1.1: Information overload					
2 (Lape 2020, Lee 2013)	2 qualitative studies using interviews, 1 qualitative study using focus groups	Participants were adjusting to the reality that they had spinal metastatic involvement. Emotional reactions to the gravity of their diagnoses, combined with illness uncertainty, made it difficult for participants to fully engage in the conversation and formulate questions. *"You don't know the questions to ask, because I had no idea I was gonna have tumors on my spine. If I had known that, I would have come in and said … are we gonna do surgery, or are we gonna do radiation…" (Lape 2020)* Patients reported feeling overwhelmed with the amount of information that was available and at times this could be confusing. There was a sense that the amount of information provided was a matter of personal preference. *"You get home, and then you start researching, and then all the questions come. They've been really good about doing follow-up answers to my questions, but I'd rather be prepared." (Lape 2020)* Some patients and their families/carers felt they may be imposing too much on the doctor's time if they asked too many questions, particularly due to the duration of the allocated appointment. *"They just don't have the time. [You can't] take up half of their … day so that you and everybody in your family can understand what [is] going on." (Lape 2020)*	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Evidence comes from a small number of studies or participants.	
Sub-theme 1.2: Lack of information & understanding					

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
2 (Eva 2009, Lee 2013)	2 qualitative studies using interviews, 1 qualitative study using focus groups	Due to the varied symptoms of MSCC, not all patients were able to recognise and associate their symptoms with the recurrence of cancer and these were attributed to other causes or pre-existing conditions. Patients also reported feeling confused and distressed in trying to make sense of the changes in their body and the impact it was having on them as a person. Not knowing what was going to happen next and what the immediate future held. *"You just don't know [what the future will hold]. Nobody can tell me." (Eva 2009)* In addition, healthcare professionals voiced their concerns that some symptoms of MSCC can be vague and that obtaining history is important but may not be easy, especially from elderly patients who may be confused or may have co-morbidities. Patients perceived follow-up appointments as an indicator to their life expectancy. *"So, when Richard came back from that appointment, he was feeling very optimistic. I think just the fact that [name of consultant] had given him an appointment after Christmas had made him feel 'oh, gosh! so, I'll make it past Christmas then!" - Palliative Care Doctor (Lee 2013)*	Methodological limitations	Moderate concerns about methodological limitations as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns some evidence comes from healthcare professionals	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Evidence comes from a small number of studies or participants	
Sub-theme 1.3: Personalisation & timing of information					
2 (Eva 2009, Lee 2013)	2 qualitative studies using interviews, 1 qualitative study using focus groups	Patients reported a lot of information being available from doctors, leaflets, books and the internet. However, they found it challenging to relate this back to their own experience and wanted more information and support relevant to their circumstances and needs at appropriate times during their journey. *"...one doesn't get time often to speak to people about what's going on in your body, what the disease actually is and what it's going to do to you and things like that. So, I do think being able to speak to people individually with the time, for me is quite a big factor, you know, even just being able to speak to your doctor for an extended length of time rather than just, you know, the few minutes that you often get with a GP; you need to have extended period of time" (Lee 2013)* On the other hand, healthcare professionals found it challenging when they should give more information related to the patient's future. Some took cues	Methodological limitations	Moderate concerns about methodological limitations as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns some evidence comes from healthcare professionals	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Evidence comes from a small number of studies or partici-	

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
		from their patients, while others felt they should have these conversations earlier to allow patients and their families to be prepared. *“Well, I think it’s best discussed after they’ve had their radiotherapy and you see the effect of the radiotherapy. Some people, it takes longer for them to get an effect, and if you start talking about all sorts of different things it can be quite distressing” – Registrar (Lee 2013)*		pants	
Sub-theme 1.4: Service and support					
3 (Eva 2009, Lee 2013, Manson 2017)	3 qualitative studies using interviews, 1 qualitative study using focus groups	There seemed to be variations in getting support particularly with symptom management, information and advice and co-ordinating community services, including additional equipment. Often times, the community palliative care nurses appeared to provide these roles. *“Well, I had the Macmillan nurse come to see me yesterday… She sorted three or four things out…. She’s going to get me one of these lift-up chairs because my ankles are swelling… She’s sorting, possibly, acupuncture, and she’s going to sort physios and OT as well, so she’s on the ball.” (Manson 2017)* Fatigue also presented problems, and patients noted a lack of help and advice in this respect. *“It would have been helpful to have simple things explained, like the balance between rest and activity. I’ve made up my own little exercises and I try to do at least a half mile walk everyday [but] I really don’t know whether that’s sensible or not. Maybe it’s partly my fault that I didn’t find that out before I left [hospital] but you know, you don’t know the right questions. [Now] I don’t really feel I can just phone up and ask. Who would I ask, I don’t know.” (Eva 2009)* There seemed to be variations in getting support from different geographical areas. In some regions, support was arranged and put in place at short notice, whereas in other areas, support services were not readily available.	Methodological limitations	Moderate concerns about methodological limitations as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns some evidence comes from healthcare professionals	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

Table 6: Evidence profile: Theme 2. Treatment & prognosis

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 2.1: Urgency of treatment					
2 (Lape 2020, Lee 2013)	2 qualitative studies using interviews, 1 qualitative study using focus groups	Participants described a perceived need to move forward quickly with treatment. *"Whenever you have something in you that's growing—it's a growth—you probably want it—outta there as soon as possible. [Surgery] was scheduled pretty quickly"* They also acknowledged that the process of receiving information on diagnosis and the planning of urgent treatment simultaneously can be challenging and shocking.	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Evidence comes from a small number of studies or participants, but data is sufficiently rich to support this finding.	
Sub-theme 2.2: Uncertainty about treatment & prognosis					
2 (Lee 2013, Manson 2017, Warnock 2014)	3 qualitative studies using interviews, 1 qualitative study using focus groups	Patients and carers experienced uncertainty in not knowing what the future held and wanted answers for some of their concerns. *"It's not possible to say how it's going to affect me, if it's going to affect me. So if I could get an answer for that I'd be happy, but if in three months, six months time we're still managing to enjoy ourselves going out, shopping, visiting places that we'd like to go to. Then we'll be reasonably happy with that." (Manson 2017)* Accounts from patients and family/carers also highlighted their strategies for coping with uncertainty when there were limited treatment options based on personal desired outcomes related to quality of life.	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 2.3: Treatment decisions					
2 (Lape 2020, Lee 2013)	2 qualitative studies using	Treatment decision making was an important factor for both patients and family/carers. Who serves as the decision maker(s) was largely dependent	Methodological limitations	Minor concerns about methodologi-	High

Study information		Description of theme or finding	CERQual assessment of the evidence		
	interviews, 1 qualitative study using focus groups	upon their level of understanding, the magnitude of the treatment decision, personal preference and circumstances, and personal beliefs and values that varied among individuals. *“That’s a pretty hefty decision-making thing to do. My wife and I … work it out, but in the end I relieve her or the doctors or anybody else of [the decision]” (Lape 2020)* Some patients entrusted the decision making responsibility to the healthcare professionals. *“She said that…the oncologists, the radiologists, the surgeons … meet and they actually look at the spine … working together to make the decision … when you hear things like that it’s very reassuring.” (Lape 2020)* Some patients relied on family/carers to seek clarification on the treatment options on their behalf as they are less emotionally involved. *“You’re in a bit of a fog. I just wanted to get done—whatever needs to be done get done. The other person who’s not feeling that is saying, ‘Well, hold on a second.’ They had more questions than I had.” (Lape 2020)* Patients and their family/carers reported feeling protective of their family/carers in the treatment decision process as they didn’t want to burden them with that responsibility. While others felt supported by sharing in the decision making process. On the other hand, their family and carers felt they were not involved in the decision making process and felt out of control., *“I spoke to my daughter-in-law and I explained to her. I said ‘well, I don’t know what to do – whether to phone NHS24 or what to do?” (Lee 2013)*		cal limitations as per CASP qualitative checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Evidence comes from a small number of studies or participants, but data is sufficiently rich to support this finding	
Sub-theme 2.4: Treatment & symptom management					
1 (Lee 2013)	1 qualitative study using interviews and focus groups	Accounts from patients and carers highlighted the disruption and difficulty in coping with side-effects from their treatments. *“I felt quite bad and what is the point of going on and looking back now, I felt as though I could end it now and it was the steroids that were doing it and I felt really down. I also felt really drunk all the time when I came home as though I had about 6 bottles of wine” (Lee 2013)*	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns: Findings were based	

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
				on one study with a small sample size and understanding of the theme would benefit from richer data	
Sub-theme 2.5: Goals					
1 (Lape 2020)	1 qualitative study using interviews	When considering a treatment plan/option, a key component in the decision making was centred around the patient's desired outcome and level of risk they were willing to accept. *"My son is getting married in October and I'm part of his wedding party, and I don't wanna do wheelchairs. I'd rather walk him down the aisle." (Lape 2020)* It was common for patients to prefer putting off surgery as long as possible as they believed that surgery was a 'last resort.' Occasionally, participants explicitly stated that surgery was the last resort because it was unpleasant, painful, and carried risks of complications. *"I just wanted to give the other options an opportunity to work first. If they don't, it's nice to have the surgery option as a backup plan." (Lape 2020)*	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns Evidence comes from a small number of studies or participants, and understanding of the theme would benefit from richer data	

Table 7: Evidence profile: Theme 3. Acceptance & denial

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 3.1: Diagnosis & treatment					
1 (Warnock 2014)	1 qualitative study using interviews	Acceptance was an important characteristic in coping with the diagnosis and treatment. *"I am not going to cry because it is a treatment I have got to have, if it does good then that is a bonus, if it doesn't then I can't do nothing about it…..which in my eyes is the way you have to look at the treatment. But I will take every day as it comes and I know deep in my heart I am still the same as when I came in." (Warnock 2014)* Some patients wondered about the impact of having an earlier diagnosis on their prognosis.	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Evidence comes	

Study information		Description of theme or finding	CERQual assessment of the evidence		
		“The first doctor I saw said a little bit of degeneration in the spine which I can quite see that degeneration, arthritis, cancer in the spine can be muddled…the only sort of question mark I have had in mind over that and I don’t like to criticize but with a history of breast cancer and knowing now that it is a known secondary why did it take 5 months to raise a flag then.”(Warnock 2014) Many patients talked about how they had accepted their diagnosis and prognosis and recognised that their life expectancy had been shortened. *"Well I’m not doing bad. I have my up days and I have my down days but, you know, you just have to get on with it don’t you really?" (Manson 2017)*		from a small number of studies or participants, but data is sufficiently rich to support this finding	
Sub-theme 3.2: Adapting to change					
2 (Lee 2013, Manson 2017, Warnock 2014)	2 qualitative studies using interviews, 1 qualitative study using focus groups	There was evidence that patients and their family/carers developed strategies for managing their new circumstances. *“I won’t go walking all the way around Morrison’s or anything like that. So what we do is we would go together and then I’ll do a little bit and then I’ll have a sit down while *** does the rest of the shopping and then, you know, we’ll – I’ll do as much as I think and then I’ll stop.” (Manson 2017)*	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 3.3: Adapting to disability					
2 (Eva 2009, Lee 2013)	2 qualitative studies using interviews, 1 qualitative study using focus groups	Patients acknowledged the need to reorder daily life and restructure their activities, and they took practical steps toward achieving this. *“Walking is my main hobby other than writing. At the moment I’m just preoccupied with making my home somewhere where I can cope, achieve as many of the normal things which will, in my case, involve using a car to get out, both to see friends and perhaps to get to the flat places where I can walk or be pushed in a wheelchair to scenic country.” (Eva 2009)* While some patients expressed difficulties in adjusting to their disability. *“I think it was just the realisation that I was in the chair and I had lost the use*	Methodological limitations	Moderate concerns about methodological limitations as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Evidence comes	

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
		of my legs and...erm... I was having to depend on everybody and I think that's basically what it was" (Lee 2013)		from a small number of studies or participants, but data is sufficiently rich to support this finding	
Sub-theme 3.4: Identity					
2 (Eva 2009, Lee 2013)	2 qualitative studies using interviews, 1 qualitative study using focus groups	Patients described the importance of being able to maintain an image of themselves as normal. They feared that common perceptions of cancer and disability would have an effect on the way they were treated by others. *"It has changed the perception of me, undoubtedly. It's not something you really notice, it's just everyone's very supportive and kind and stuff. But obviously implicit in that, there's no one treats you like just a mate any more. Everybody knows about the cancer and there is a stigma attached to it. And that's what I wanted to avoid for as long as possible. I think what I wanted to preserve was the absolute preciousness of normality." (Eva 2009)* While some family/carers whose loved ones were approaching the end of their life reported wanting to honour the image of their loved ones. Some patients and their family/carers reported that the family dynamics and roles had changed. *"It's hard for me because I feel as though I'm not doing my bit, I'm not doing my share, I'm not helping out and I'm not...eh...well...held my children as much. This is frustrating and a bit err...hard, a bit hard for me, you know what I mean" (Lee 2013)*	Methodological limitations	Moderate concerns about methodological limitations as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Evidence comes from a small number of studies or participants, but data is sufficiently rich to support this finding	
Sub-theme 3.5: Denial					
2 (Eva 2009, Lee 2013)	2 qualitative studies using interviews, 1 qualitative study using focus groups	Patients acknowledged that their lives had changed radically but in other respects, they chose not to acknowledge that fact. For instance, some patients and their family/carers didn't want to know their prognosis. *"You don't really want to know what someone's opinion is of your life expectancy, you know, because I'm not very much in favour of that because I think that is a horrible burden to have. I think I'd rather not know something like that" – Wife (Lee 2013)*	Methodological limitations	Moderate concerns about methodological limitations as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
			Adequacy	Minor concerns Evidence comes from a small number of studies or participants, but data is sufficiently rich to support this finding	

Table 8: Evidence profile: Theme 4. Emotional Considerations

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 4.1: Approach and mind-set					
2 (Lee 2013, Warnock 2014)	2 qualitative studies using interviews, 1 qualitative study using focus groups	The right approach had multiple elements including being positive and believing in your own strengths and ability to cope, with emphasis on taking it one day at a time. *"I know my left leg isn't moving as it should be but because of my determination I will get that moving [laughs] so, err...and with the steroids it does make me confident to be able to get that" (Lee 2013)* However, maintaining a positive mind-set wasn't always easy. *"I worry about it but I try to block it off, I just start thinking about other things, it is mainly in the morning when I am on my own I think about it so I watch documentaries on telly and it like stops you thinking, otherwise I am happy if they can contain it." (Warnock 2014)*	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Evidence comes from a small number of studies or participants, but data is sufficiently rich to support this finding	
Sub-theme 4.2: Anxiety and frustration					
3 (Lape 2020, Lee 2013, Manson 2017)	3 qualitative studies using interviews, 1 qualitative study using focus groups	Patients and their family/cares experienced anxiety around what the diagnosis of MSCC meant for their future, potential for functional decline and need for treatments with substantial complication profiles such as surgery or radiation therapy. Many patients were concerned about the burden on their family/carer and cited anxiety as a factor driving them to accept more aggressive treatments.	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	High
			Relevance	None or very minor	

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
		"Some nights she gets a bit stressed out, doesn't sleep very well, but when she sees me in tremendous pain she says she doesn't know what to do." (Manson 2017) Patients reported feeling confused and distressed in trying to make sense of the changes in their body and the impact it was having on them as a person.		concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 4.3: Sadness and loss					
2 (Eva 2009, Lee 2013)	2 qualitative studies using interviews, 1 qualitative study using focus groups	Patients were concerned for the well-being of family carers and were aware of the impact of caring on others' lives, which brought about a sense of sadness. *"[My wife] had a very full life, I mean, she was a school governor and things like that. And for me she's more or less had to forgo most of it, you know. I feel sorry for [her] because of, you know, it's changed her life completely." (Eva 2009)* Some of the patients expressed a need to know the prognosis so that they can mentally be prepared for the future.	Methodological limitations	Moderate concerns about methodological limitations as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Evidence comes from a small number of studies or participants, but data is sufficiently rich to support this finding	
Sub-theme 4.4: Emotional Support					
1 (Lee 2013)	1 qualitative study using interviews and focus groups	Patients need emotional support when receiving bad news as their family may not be there to provide this support. *"You get lots and lots of support at the beginning or when you got problems and you spoke to the doctor. And I had the psychologist to talk to, she has moved away now. Erm...I got no one...and you know, my husband, I feel guilty because I feel as I talk something to do with me every day and it must wear him down" (Lee 2013)* Some carers turned to spirituality for comfort. Others preferred a personal contact or a phone call from a healthcare professional.	Methodological limitations	None or very minor concerns	Moderate
			Relevance	Minor concerns some evidence comes from healthcare professionals	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns: Findings were based	

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
				on one study with a small sample size and understanding of the theme would benefit from richer data	
Sub-theme 4.5: Helplessness					
1 (Lee 2013)	1 qualitative study using interviews and focus groups	There was a sense of helplessness at the same time trying to have positive thinking by focusing on "here and now" instead of worrying about the future. *"And, as I said, they couldn't do anything more for me, but I said 'we'll take it from there' I just take one day at a time and make the most of what I've got there in my family and... I'm quite...I'm not even stressing myself out about it because I know that this is another part of a journey I'm going on" (Lee 2013)* Carers reported worrying about their loved ones suffering, not knowing how to recognise and cope with the deterioration in their condition particularly towards the end of life. *"Umm...I'd have liked to talk to somebody about the disease and the umm...progression of the disease and you know, what is...I mean I know everybody is a unique individual and everyone would be slightly different and how the disease progresses. I would just like some general information and you know progression and halting that progression and generally what kind of things helped" – Wife (Lee 2013)* While some family/carers reported that would prefer to shield their loved ones when receiving bad news so that they could better support them.	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns: Findings were based on one study with a small sample size and understanding of the theme would benefit from richer data	

Table 9: Evidence profile: Theme 5. Mobility

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 5.1: Adapting to change					

Study information		Description of theme or finding	CERQual assessment of the evidence		
1 (Lee 2013)	1 qualitative study using interviews and focus groups	A drastic change in mobility meant that patients and their family/carers were faced with adapting to a change in their routines and abilities. Patients expressed sadness about the things they could no longer do. *"And I just want to get up and do things I used to do, but obviously I'm not going to be able to and I find that frustrating." (Lee 2013)* While family/carers expressed frustration in their attempts to resume normal family life. *"And he's got a Zimmer frame which I didn't like him using it at all. Erm...we put it in the garden...erm...I didn't like it in the house. I think it's an old person's ...I just didn't like seeing him using it" - Wife (Lee 2013*)	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns: Findings were based on one study with a small sample size and understanding of the theme would benefit from richer data	
Sub-theme 5.2: Support					
1 (Manson 2017, Warnock 2014)	1 qualitative studies using interviews	Improving functional ability emerged as an important goal and patients described the steps had been taken to increase their chances of achieving this. *"They (nurses) are very positive and they allow me to try things….If I want to try something I can try. I have been succeeding in most things I have tried which makes me feel good. The first day I could hardly stand, the next time I stood up and down three times, not brilliantly I admit but I did." (Warnock 2014)*	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns Evidence comes from a small number of studies or participants and understanding of the theme would benefit from richer data	
Sub-theme 5.3: Loss of independence					
3 (Eva 2009, Manson 2017, Warnock 2014)	3 qualitative studies using interviews	Reduced mobility was often reported as the root cause of the challenges that lead to losing their independence and not being able to do things they used to do. There was often a sense of loss expressed when these changes were described.	Methodological limitations	Moderate concerns about methodological limitations as per CASP qualitative checklist	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
		"[The furniture for the new flat comes] flat-packed [and my son] is going to assemble them because I haven't got the strength to do it anymore. You want to know the most frustrating thing since my health's gone? Is having to get people to do things for me." (Eva 2009)	Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 5.4: Burden					
4 (Eva 2009, Manson 2017, Lee 2013, Warnock 2014)	4 qualitative studies using interviews, 1 qualitative study using focus groups	Patients raised concerns about the burden placed on their family to provide care due to their reduced mobility and the impact this had on their role in the family and family activities. *No possibility of me going home, at this moment. I'd have to go to my daughter's. Young family. They all love granddad, I mean, you know, we all get on very well, good laugh together. But, I can't see myself—my daughter's not going to—it won't be fair, it won't be fair to them. So, going home, no. (Eva 2009)*	Methodological limitations	Moderate concerns about methodological limitations as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

Table 10: Evidence profile: Theme 6. Environmental Considerations

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 6.1: Support (physical & practical)					
2 (Manson 2017, Warnock 2014)	2 qualitative studies using interviews	Patients revealed their main concerns there were related to physical consequences of MSCC and its implications for themselves and their family. Two factors were important influences on getting home: physical characteristics of their house and the support available from their family and community services. Talking about getting home was often brought about sadness when reality of the situation came to light. *"Yeah I think they (OT) were going to try and get round, but nobody's been as yet. That were two or three weeks back as regards like such as when I'm getting in bath or shower, I felt very insecure thinking… I were going to fall down and one thing and another." (Manson 2017)*	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Evidence comes	

Study information		Description of theme or finding	CERQual assessment of the evidence		
				from a small number of studies or participants, but data is sufficiently rich to support this finding	
Sub-theme 6.2: Environmental dynamics					
1 (Lee 2013)	1 qualitative study using interviews, 1 qualitative study using focus groups	Ward environment and dynamics can negatively impact on patient experiences. *"...like the lady next to me that's got it in her spine and she is saying she's dying. I'm listening to her day in, day out, and I don't want... The thought of being like that is really anxiety for me...umm...just being immobile..." (Lee 2013)*	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns: Findings were based on one study with a small sample size and understanding of the theme would benefit from richer data	

Table 11: Evidence profile: Theme 7. Future planning

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 7.1: Adapting to change					
3 (Lee 2013, Manson 2017, Warnock 2014)	3 qualitative studies using interviews, 1 qualitative study using focus groups	Patients speculated future implications to their ability to manage at home and the changes it might bring to their family, social life, work and leisure activities. The coping strategies used by patients supported adjustment to their current situation, allowing them to maintain hopes and managing goals. *No supporting quotes reported.*	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 7.2: Fear about the future					

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
2 (Lee 2013, Manson 2017)	2 qualitative studies using interviews, 1 qualitative study using focus groups	Patients reported feeling anxious about an uncertain future. *"at the end of the day I've got cancer that's spreading ain't I?... obviously it's a big concern, because they never know what it's going to attack next. But I'm trying to put that at the back of me mind and just carry on with life." (Manson 2017)*	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Evidence comes from a small number of studies or participants, but data is sufficiently rich to support this finding	
Sub-theme 7.3: Future planning					
1 (Lee 2013)	1 qualitative studies using interviews, 1 qualitative study using focus groups	Some patients and carers expressed frustration in their attempts to return back to their normal family life. *No supporting quote.*	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns: Findings were based on one study with a small sample size and understanding of the theme would benefit from richer data	
Sub-theme 7.4: Returning to 'normal' routines and activities					
2 (Eva 2009, Manson 2017)	2 qualitative studies using interviews	Patients frequently spoke about their hopes of getting back to "normal" which included establishing routines, carrying out household tasks and being able to perform previously valued activities. *"If I could go out in the streets, feel confident that I can go for a walk round without owt (anything) happening to me, I should feel smashing." (Manson*	Methodological limitations	Moderate concerns about methodological limitations as per CASP qualitative checklist	Moderate
			Relevance	None or very minor	

Study information		Description of theme or finding	CERQual assessment of the evidence		
		2017) Some even reported looking forward to these activities. *“My mum and dad are coming up tomorrow. I’ve said to them that I need to get a few things from the shop, and probably we’ll get the ramps out for the front door and my mum will take me over to town.” (Eva 2009)*		concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns Evidence comes from a small number of studies or participants, but data is sufficiently rich to support this finding	

Table 12: Evidence profile: Theme 8. End of life considerations

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Sub-theme 8.1: End of life conversations					
1 (Lee 2013)	1 qualitative studies using interviews, 1 qualitative study using focus groups	Discussing end of life issues was sensitive. There was a sense of patients and carers protecting each other from receiving bad news and maintaining their dignity to the end. *“He didn’t know how long, but I got that from [name of oncologist], but then I couldn’t keep that from Tony because we...we always shared things; we never kept anything from each other. So I went up, once the girls were in their bed that night, and I did tell him that ‘I can’t keep it from you: [name of oncologist] said you’ve got about two to three weeks,’ and he said ‘well, I kind of like knew that’” – wife (Lee 2013)* Patients and carers also discussed anticipating a loss of income whilst others did not seem to have financial worries.	Methodological limitations	None or very minor concerns	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns: Findings were based on one study with a small sample size and understanding of the theme would benefit from richer data	

Appendix G Economic evidence study selection

Study selection for: What information and support is valued by adults with suspected or confirmed spinal metastases, direct malignant infiltration of the spine or associated spinal cord compression, and by their families, and carers?

No economic evidence was identified which was applicable to this review question.

Appendix H Economic evidence tables

Economic evidence tables for review question: What information and support is valued by adults with suspected or confirmed spinal metastases, direct malignant infiltration of the spine or associated spinal cord compression, and by their families, and carers?

No evidence was identified which was applicable to this review question.

Appendix I Economic model

Economic model for review question: What information and support is valued by adults with suspected or confirmed spinal metastases, direct malignant infiltration of the spine or associated spinal cord compression, and by their families, and carers?

No economic analysis was conducted for this review question.

Appendix J Excluded studies

Excluded studies for review question: What information and support is valued by adults with suspected or confirmed spinal metastases, direct malignant infiltration of the spine or associated spinal cord compression, and by their families, and carers?

Excluded qualitative studies

Table 6: Excluded studies and reasons for their exclusion

Study	Reason for exclusion
Abrahm, J. L.; Banffy, M. B.; Harris, M. B. (2008) Spinal cord compression in patients with advanced metastatic cancer: "all I care about is walking and living my life". JAMA 299(8): 937-46	Study design does not match protocol
Barton, L. B., Arant, K. R., Blucher, J. A. et al. (2021) Clinician Experiences in Treatment Decision-Making for Patients with Spinal Metastases: A Qualitative Study. Journal of Bone & Joint Surgery - American Volume 103(1): e1	Other protocol criteria - duplicate publication
Barton, L. B., Arant, K. R., Blucher, J. A. et al. (2021) Clinician Experiences in Treatment Decision-Making for Patients with Spinal Metastases: A Qualitative Study. The Journal of bone and joint surgery American volume. 103(1): e1	Population does not match review protocol – focuses on clinician's experiences
Conway, R., Graham, J., Kidd, J. et al. (2007) What happens to people after malignant cord compression? Survival, function, quality of life, emotional well-being and place of care 1 month after diagnosis. Clinical Oncology (Royal College of Radiologists) 19(1): 56-62	Study design does not match protocol
Csaszar, N., Ganju, A., Mirnics, Z. S. et al. (2009) Psychosocial issues in the cancer patient. Spine 34(22 Suppl): S26-30	Study design - systematic review without synthesised results, checked for relevant studies
Gal, R., Oostinga, D., Wessels, H. et al. (2020) Pre-treatment expectations of patients with spinal metastases: what do we know and what can we learn from other disciplines? A systematic review of qualitative studies. BMC Cancer 20(1): 1-16	Study design - systematic review without synthesised results, checked for relevant studies
Gal, R., Oostinga, D., Wessels, H. et al. (2020) Pre-treatment expectations of patients with spinal metastases: what do we know and what can we learn from other disciplines? A systematic review of qualitative studies. BMC Cancer 20(1): 1212	Other protocol criteria - duplicate publication
Harris, M. (2016) Quality of life in patients with malignant spinal cord compression: a review of evidence-based literature. International Journal	Study design - systematic review without synthesised results, checked for relevant studies

Study	Reason for exclusion
of Palliative Nursing 22(1): 37-43	
Hutchison, C., Morrison, A., Rice, A. M. et al. (2012) Provision of information about malignant spinal cord compression: perceptions of patients and staff. International Journal of Palliative Nursing 18(2): 61-8	Study design does not match protocol
Mahaligam, P., Ng, K., McLaren, A. et al. (2017) Improved provision of written information on metastatic spinal cord compression to at-risk cancer patients at a tertiary referral centre. Annals of Oncology 28(Supplement 5): v515-v516	Other protocol criteria – conference abstract
Troke, R. and Andrewes, T. (2019) Nursing considerations for supporting cancer patients with metastatic spinal cord compression: a literature review. British Journal of Nursing 28(17): S24-S29	Study design - systematic review without synthesised results, checked for relevant studies

Excluded economic studies

No economic evidence was identified for this review.

Appendix K Research recommendations – full details

Research recommendations for review question: What information and support is valued by adults with suspected or confirmed spinal metastases, direct malignant infiltration of the spine or associated spinal cord compression, and by their families, and carers?

No research recommendations were made for this review question.