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Nursing considerations for supporting cancer patients, with metastatic spinal cord compression: a literature review.

<u>Abstract</u>

Background: Metastatic Spinal Cord Compression (MSCC) is an oncology emergency. Prevalence is increasing. Treatment and care are complex and those diagnosed may be faced with life changing challenges.

Aims: To review the impact and management of MSCC in patients with cancer, in order to analyse nursing considerations for supporting patients.

Methods: A literature review and thematic analysis of 5 primary research papers, published between 2009 and 2014.

Findings: Two themes of prognosis/survival time and independence vs. dependence were discovered.

Conclusion: The onset of MSCC may result in paralysis and associated loss of independence, impacting upon a patient's quality of life. Understanding individuals' prognosis and treatment/care preferences is fundamental for the sensitive, individualised support of patients with MSCC. The findings reinforce the nurses' role in health education, in order to raise awareness of MSCC and promote early diagnosis so that patients maintain function and independence as along as possible. The findings support the need for nurses to be equipped with appropriate communication skills to initiate and engage in sensitive, difficult and pro-active conversations with patients and their families, supporting the delivery of humanised care.

Key words:

Metastatic spinal cord compression (MSCC); prognosis/survival time; independence versus dependence; health education; palliative care; humanising care framework.

Key phrases:

Metastatic spinal cord compression (MSCC) may be a life changing complication of advanced cancer and an oncology emergency.

Early diagnosis of MSCC can preserve neurological function but diagnosis is common after the onset of neurological symptoms.

Health education could help to facilitate early diagnosis of MSCC.

Understanding the impact of prognosis/survival time and independence versus dependence, enables nurses to engage with patients in a humanising way, using meaningful communication in order to empower them and support their choices.

Introduction

Metastatic spinal cord compression (MSCC) may be a life changing complication of advanced cancer and an oncology emergency (Al-Qurainy and Collis, 2016; Bowers, 2015). MSCC, is defined as compression of the spinal cord or cord equina by metastatic or direct spread of a malignancy to the vertebrae (National Institute for Health and Care Excellence, 2018; Farrell, 2013). It is an oncology emergency since it may cause neurological impairment, but prompt

treatment while the patient remains ambulant results in maintenance of the ability to walk in 80-100% of cases (London Cancer, 2012).

Whilst spinal cord compression may be non-malignant in origin and present in people with or without cancer, MSCC can be the first presentation of an undiagnosed primary cancer which has progressed, or may reflect secondary disease (Wanman et al., 2017). Any cancer has the potential to metastasise to the spine, but MSCC most commonly presents in breast, lung and prostate cancer, lymphoma and myeloma. Advances in cancer treatment have resulted in higher long-term survival rates after cancer, therefore the risk of developing MSCC is increasing (Bowers, 2015; Spratt et al., 2017). Signs of MSCC centre on spinal pain and neurological symptoms as summarised in figure 1.

Spinal pain in the middle (thoracic) or upper	Neurological symptoms
(cervical) spine	Radicular pain
Progressive lower (lumbar) spinal pain	Any limb weakness
Severe unremitting lower spinal pain	Difficulty walking
Spinal pain aggravated by straining	Sensory loss or bladder or bowel dysfunction
Localised spinal tenderness	Signs of spinal cord or cauda equina
Nocturnal spinal pain preventing sleep.	compression.

Figure 1. Signs and symptoms of MSCC, in patients with cancer (NICE, 2008)

Diagnosis of MSCC is by whole spine MRI, unless contraindicated. Definitive treatment should be initiated as soon as possible and within 24 hours where neurological symptoms or signs suggest MSCC (NICE, 2008). Definitive treatment of MSCC may include pain control, bisphosphonates, corticosteroids, kyphoplasty and vertebroplasty, radiotherapy, surgery, or supportive care including rehabilitation and community support, or palliative care (NICE, 2008).

Presentation of MSCC commonly follows the onset of neurological symptoms, with the potential for paraparesis (a partial paralysis of the lower limbs), or permanent paraplegia (an impairment in motor or sensory function of the lower extremities) and associated complications, such as bowel, bladder and sexual dysfunction and prognosis is poor. Loss of mobility and function due to MSCC commonly impacts on quality of life (Kaplow, 2016). This work explores the impact of MSCC, in order to analyse the role of the nurse in supporting individuals.

Method and search strategy

The search used keywords, precisely focused to the question (see figure 2). Contextually synonymous keywords were included to extend the breadth of available literature. Search results were returned in CINAHL Complete, MEDLINE Complete and PSYCH Info.

("MM Spinal Cord Compression") AND (management OR treatment OR intervention OR therap* OR diagnos*) AND (oncology OR cancer OR malignancy OR tumour OR tumor OR metasta*).

Figure 2. Search terms.

The search returned 311 records. After applying inclusion and exclusion criteria (see figure 3), the remaining 29 full-text papers were accessed, read in full and discarded if they did not directly answer the research question. Ultimately, 5 original papers, clearly focused on the

question, were systematically analysed and scored, using Critical Skills Appraisal Programme checklists, serving to strengthen the validity, reliability and transparency of the research process (CASP, 2018). Papers with a score of 9 or above were considered to be appropriate for inclusion in the literature review.

Inclusion criteria:	Exclusion criteria:
Research with adult patients	Papers published more than a decade ago
Peer-reviewed primary research papers	Papers with a wholly surgical or medical
Papers written in the English language	focus
International papers where	Papers focusing on an elderly population
transferable/generalisable to UK practice	

Figure 3. Inclusion and exclusion criteria.

Data from each paper were plotted to enable thematic analysis. The process involved becoming familiar with the data, searching for themes and writing up the results.

Author(s).	Date.	Sample characteristics	Design	Data Collection
Fattal, C. et al.	2009	26 adult patients with spinal	Quantitative	Retrospective chart
		metastases treated within 4 Physical		review
		Medicine and Rehabilitation (PM&R)		
		centres in France		
Warnock, C.	2014	10 inpatients, newly diagnosed with	Qualitative	Semi-structured
and Tod, A.		MSCC, with difficulty mobilising,		interviews

		admitted for radiotherapy treatment.		
Eva, G. et al.	2009	2 female and 7 male patients, aged	Qualitative	Semi-structured
		between 42-82, with MSCC, arising		interviews.
		from a range of primary cancers.		
Guo, Y. et al.	2010	87 adult patients, with MSCC, who	Quantitative	Retrospective chart
		required a physical medicine and		review
		rehabilitation consultation, in		
		America		
Warnock, Cal	2008	Randomised sample of 50 adult	Quantitative	Retrospective chart
		patients who received radiotherapy		review
		for MSCC in 2005 at a regional		
		cancer centre		
			Quantitative	Staff questionnaire
				about mobility
		Sample of 21 Consultants, 14		practices, bowel and
		Specialist Registrars and 107 nurses		bladder management,
		from the centre		and psychological
				concerns
			1	

Table 1: Study characteristics

<u>Findings</u>

Prognosis/survival time

At the time of a randomised audit of 50 charts (out of 150 admissions in one year), for patients who received radiotherapy for MSCC in a UK regional cancer centre, 90% (n=45) had died

(Warnock et al 2008). In 22% of cases (n=11) the diagnosis of cancer was made at the time of presentation with MSCC. In 14% of cases (n=7) the patient died before they could be discharged. The average length of stay was 13 days (range 6-48 days) with longer stays for patients who developed problems requiring further treatments. The mean time between admission with MSCC and death in the research sample was 58.6 days (range 2-319 days). This data reinforces the potential for MSCC to be a presenting symptom of undiagnosed cancer and the poor prognosis associated with it.

A retrospective chart review of 26 patients across 4 Specialist Physical Medicine and Rehabilitation (PMR) centres in France, over 5 years, explored impacts of rehabilitation care in patients with MSCC paraplegia, using measures including survival time. In 53% of cases (n=14), patients were deceased, with their mean survival rate post-paraplegia 12.7 months (range 3-38 months) (Fattal et al 2008). The majority (86%) of patients (n=12) who died had spent more than a third of their time in the centre after diagnosis. There was 1 patient lost to follow-up. The 42% patients (n=11) who were alive at the time of the study had a mean survival time of 21.1 months. Rehabilitation care plans and interventions were found to increase functional aptitudes in 65% of patients (n=18). Crucially however, the time spent in the rehabilitation centre (average 161 days) was deemed to be too long in comparison to the patient's prognosis with the drawbacks of reduced time with family and loved ones outweighing the benefits. This data reinforces the potential to improve function through rehabilitation interventions, however these need to be balanced against prognosis.

A retrospective chart review of 87 patients with MSCC, attending a rehabilitation consultation at an American cancer centre revealed that 100% of patients had impaired function, with 83% (n=72) requiring assistance with walking (Guo et al. 2010). At the time of the study 68% (n=59) of patients had died, with a median survival time of 4.3 months. Of these patients, 15% (n=13) had a 'do not resuscitate' order in place prior to their consultation and 44% (n=26) had DNR orders issued by their consultant at the centre. The median time from the DNR issue by their consultant, where in place, to death, was 16.5 days (range 6.5-38.3 days). The data supports that a sharp decline in function associated with MSCC is clearly linked to poor prognosis and should support practitioners to engage in communication about end-of-life choices.

Focusing on the experiences, concerns and priorities of patients, Warnock and Tod (2014) interviewed 10 patients with a recent diagnosis of MSCC (range 9-24 days since diagnosis), who had received palliative radiotherapy. Mobility was compromised in all cases with 90% (n=9) of patients immobile and 10% (n=1) with limited mobility. A theme of 'thinking through the implications of MSCC' included the concern of 'how will my cancer progress?'. Participants expressed understanding the extent of their cancer and 'relatively poor prognosis' (Warnock and Tod 2014). Whilst concerns predominantly focused on the physical impact of MSCC, some patients expressed frustration at apparent delays in diagnosing MSCC, having sought medical advice in the previous 1-6 months. In some cases this provoked anger and in others concern. Patients expressed uncertainty about their prognosis and about how much their mobility would improve, linked to how they (and their family) would cope functionally. The data support that late diagnosis is associated with poor prognosis, with some concern about the skills of physicians to diagnose early signs of MSCC, that might slow the onset of neurological symptoms.

The data in this theme reinforces the poor prognosis of a diagnosis of MSCC, particularly once neurological symptoms are present. Medical and nursing support and rehabilitation care may help to enhance functional capability, however the time required to achieve this can be to the detriment of time spent with family and loved ones. Patients understand the poor prognosis associated with MSCC, therefore referring them to palliative care services and engaging in discussions about end of life care as functional ability decreases can help them to maintain some control and to express choices for their care.

Independence vs Dependence

Independence is predominantly focused on mobility, however it can also be impacted by bowel and bladder dysfunction. Within the studies reviewed, a significant number of patients had lost their mobility at the time of diagnosis; 92% (n=24) were paraplegic or had paraparesis in Fattal et al's (2009) study, 90% (n=9) in Warnock and Tod's (2014) study were immobile and in Guo et al's (2010) study 83% (n=72) of patients were immobile. The reduction or loss of mobility caused patients sadness and made them concerned about their ability to manage at home and to get out the house when they wanted to (Warnock and Tod, 2014). They also expressed frustration that their attempts to raise concerns had not resulted in an earlier diagnosis of MSCC, that might have preserved mobility.

Warnock et al (2008) explored mobility and bowel/bladder related nursing care practices of patients diagnosed with MSCC in their audit, triangulated with retrospective chart data of the patients. They discovered that 69% (n=74) of nurses routinely nursed patients on flat bed rest throughout their radiotherapy treatment, however only 10% (n=5) had documented spinal instability and 16% (n=8) had a documented reason for bedrest. In relation to bowel and

bladder care, 81% (n=87) nurses felt care was insufficient. There was a reported failure to routinely initiate trial without urinary catheter following radiotherapy treatment and only 34% (n=36) nurses felt competent to teach patients intermittent self-catheterisation. Additionally, only 44% of nurses felt competent carrying out digital rectal evaluation of faeces. The data suggests that nursing care practices impact upon independence/dependence experienced by patients with MSCC. In 36% (n=18) patients, this resulted in documented psychosocial concerns, linked to loss of independence.

In a qualitative study, exploring the constructions of disability of patients' with MSCC, patients discussed their dependence and stated their need to restructure their activities of daily living (ADLs) and consider physical adaptations to their home, with a view to increasing their independence. Patients reported that morbidities of MSCC (bowel and bladder dysfunction, pain, mobility and fatigue), had been 'managed well' by nurses. However, they felt that nurses were not supporting them to develop self-management skills and were therefore failing to help them be independent (Eva et al 2009).

In contrast, healthcare professionals have been viewed as key in supporting patients to develop new skills and test their limits to improve function and independence (Warnock and Tod 2014). Rehabilitation care plans have proven to be helpful in identifying patient goals and supporting independence with the activities of daily living and the ability to manage transfers (Fattal et al. 2009) where 66% (n=17) of patients experienced a significant increase in their overall functional aptitudes as a result of rehabilitation care plans. However, the time spent as an inpatient to increase function and independence was to the detriment of time spent with family and loved ones. In view of the poor prognosis associated with MSCC an alternative is the use of care packages, including palliative care services, enabling patients to be discharged home, or to other care settings, including hospice care (Warnock et al. 2008).

The theme of independence versus dependence is significant for patients presenting with MSCC. Most of the patients in the research reviewed had some degree of dependence, most receiving a diagnosis of MSCC on admission to hospital. This may not always be the case since prompt/early diagnosis and treatment of MSCC can help to preserve function and independence for as long as possible. Nurses have a moral and professional responsibility to support and educate patients to develop self-management skills that will facilitate their independence. The provision of care packages can support patients to return home in some cases or can support them to remain as independent as possible, for as long as possible.

Discussion

The themes of prognosis/survival time and independence vs dependence have emerged in this literature review. Diagnosis of MSCC is often after the onset of neurological symptoms, with many patients presenting with loss of mobility and neurological symptoms, when prognosis is poor. A possible causal factor of this is a lack of prophylactic information given to patients regarding the signs and symptoms of MSCC (Hutchison et al., 2012), even though early intervention with surgical or medical intervention can reduce morbidity, particularly when combined with rehabilitation interventions (Guo et al., 2003; Fattal et al., 2011). Since early diagnosis is crucial to maintaining as much function and independence as possible, the imperative appears to be health education, for those at risk (National Institute for Health and Care Excellence, 2018).

Hutchison et al. (2012) reinforce the importance of patient education, at every step of the cancer journey. This is a moral and professional imperative (NMC, 2018). Personal experience of one author as a patient reveals significant information sharing at diagnosis and during active treatment. Discussions about potential secondary disease are a sensitive issue and there is evidence that there is an absence of specific education about potential symptoms of secondary cancer, including MSCC (Hutchison et al, 2012). Cancer Research UK (2018) reinforce the urgency of reporting signs of MSCC, but this information is hidden within publications about secondary bone cancer. Information is available to the public through specific NICE guidelines (NICE, 2008) but without knowing the potential risk and symptoms of MSCC, patients cannot access information at the relevant time, that would enable them to seek appropriate treatment. Hutchison et al. (2012) highlight that patients (who are most likely to notice the early signs of MSCC) would like prophylactic information about MSCC. The question is when to deliver such information. The earliest point is at time of diagnosis with bone secondaries, but the point of discharge from services (usually around 10 years) would be an appropriate opportunity to educate patients about spinal pain, linked to MSCC. After discharge, the onus is on patients to notice and report symptoms. Understanding the signs of MSCC, may facilitate prompt GP referral, if the patient should experience them.

The key prognostic indicator for functional outcome in MSCC is mobility status at presentation (Drudge-Coates and Rajbabul, 2008). A secondary factor is the presence of neurological symptoms. Spinal pain is the first indicator of MSCC. Hutchison et al (2012) propose that educating cancer patients about the importance of highlighting spinal pain to their GP, especially in the presence of other neurological symptoms such as pins and needles or poor bladder control, will promote earlier diagnosis, that may enable treatment to take place before the onset of paralysis. The question is when to provide education about MSCC. Certainly, it is

advocated that specific health education about MSCC is undertaken if a patient with breast, lung, or prostate cancer, presents with bone metastases (Hutchison et al 2012). Health education is a fundamental nursing role, which has the potential to positively influence the patient experience of MSCC.

Management of MSCC in the United Kingdom is guided by NICE (2018) algorithms. These frameworks offer a clear pathway of support and care for MSCC, but may encourage health care professionals to overlook the individual as they promote a 'tick box' and 'one size fits all' approach. Treating patients as individuals and respecting their choices is a central tenet of effective nursing practice. The humanising framework enables nurses to consider individuals, rather than assigning them to a diagnostic group. Humanising care focuses on the individual behind the 'patient', putting them at the heart of care and seeking what to understand their personal story and what it means to them to be human (Todres et al., 2009). This framework encourages open communication and care planning, respecting individual choice. Nurses are ethically and professionally bound to respect every patient and to support their autonomy (NMC, 28). In the context of MSCC diagnosis, this can include rehabilitation interventions to promote independence, supportive care and/or palliative care, depending on the level of function on presentation and diagnosis, and/or the patient's prognosis, whilst respecting their choices.

NICE (2018) algorithms for management of MSCC highlight areas of patient dependency such as bowel and bladder management. Eva et al.'s (2009) study reported that patients' functional problems were managed well by nurses, but there was a failure to teach them self-care. Health education is proposed as essential at the diagnosis of MSCC, based on the requirements of individual patients (Hutchison et al 2012). The 'Making Every Contact Count' (MECC), brief intervention framework serves to promote health and reduce poor health through goal setting, based on meaningful brief conversations with patients and their families (Health Education England, 2018; Nelson et al., 2013). MECC supports the development of a therapeutic relationship and in the context of MSCC can help to identify goals for maintaining and increasing independence where possible (including practical skills such as transferring/mobility, and intermittent self-catheterisation for bladder problems) and for end-of-life care as appropriate.

Patients' quality of life is clearly affected by symptoms of MSCC (Harris 2016; Warnock et al 2008). Patients became frustrated when a diagnosis of MSCC followed neurological deficits, including loss of mobility. They reported frustration at not knowing what to look out for, therefore missing opportunities to seek medical help (Warnock and Tod 2014). Where patients had sought help, they understood their 'poor prognosis' but felt frustrated at the length of time it had taken for MSCC to be diagnosed. Some patients prefer not to think about the future, taking each day as it comes, which enables them to build 'hope' for the future (Harris 2016). The use of care planning enables them to work towards independence, which helps to build hope for the future.

Nursing should seek to support individuals' choice through empowerment (NMC 2018). Where MSCC results in a terminal diagnosis, referral to palliative care services is indicated. Discussions about choices at this time may include advance care planning, where patients are empowered to articulate their preferences and priorities for future care. Nurses in oncology and palliative care usually get to know patients and their families, their values, concerns and thoughts, over a period of time, so should feel able and confident to hold advance care planning conversations (Anderson Head et al., 2018). When patients present with MSCC as the first

indication of an underlying malignancy however, a therapeutic relationship needs to be built from scratch. This sensitive area of advance care planning requires advanced communication skills and appropriate experience as nurses need to understand when these conversations are, or are not, appropriate (Mullick et al., 2013). Ultimately, nurses should respect how much individuals want to know about their future and how much they want to be involved in decisions about their care (Nursing and Midwifery Council 2015; Peereboom and Coyle 2012). Overall, if nurses are able to relate to every patient as an individual and understand the relevance of diagnosis and prognosis for them, in relation to MSCC, they are best placed to offer the optimum standard of sensitive and individualised care.

Conclusion

MSCC, with associated neurological deficit, is an oncological emergency that signals development of secondary cancer. Early diagnosis (before the loss of mobility), enables prompt treatment and is therefore associated with the maintenance of physical function for a period of time. There is a higher risk of MSCC development in people with primary breast, lung and prostate cancer. Health education for these patients, about the significance of the onset of spinal pain, especially in the presence of neurological symptoms such as pins and needles or bladder dysfunction, at the time of discharge from follow-up care, or at least from the time of diagnosis of bone metastases, will enable prompt self-referral for medical advice.

Quality of life is significantly impacted by MSCC. Although frustrated at delays in diagnosis that impact on mobility and neurological function, patients with MSCC, in this literature review, describe a positive attitude to overcoming challenges, enabling hope. The use of care planning and interventions to promote function help to maintain independence and build hope. The

prognosis of those with MSCC is poor and palliative care support is key to enhancing the experience of patients and facilitating choices for end-of-life care. Individualised and humanising nursing care is central to empowering patients and nurses are ideally placed to engage in brief and meaningful communication interventions to develop a therapeutic relationship and deliver humanising care. Since communications extend to advance care planning decisions, effective communication skills are essential.

This literature review has explored the impact and management of MSCC. Thematic analysis resulted in two themes of prognosis/survival time and independence vs dependence. Understanding the themes enables nurses to plan health education with those at risk to promote early diagnosis. Following diagnosis, a humanising approach to care, combined with meaningful communication within a therapeutic relationship, can support patient choice in maintaining independence and in end-of-life care decisions.

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