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DEVELOPMENT

Developing an early alert system for metastatic spinal cord compression (MSCC): Red Flag credit cards

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Aim: To produce a user-friendly list of metastatic spinal cord compression (MSCC) Red Flags for non-specialist 'generalist' front-line clinicians working in primary-care settings. **Background:** The issue of identifying MSCC early to prevent serious long-term disability was a key theme identified by the Task and Finish Group at Greater Manchester and Cheshire Cancer Network (GMCCN) in 2009. It was this group who initially brokered and then coordinated the current development as part of their strategic approach to improving care for MSCC patients. **Methods:** A consensus-building approach that considered the essential minimum data requirements to raise the index of suspicion suggestive of MSCC was adopted. This followed a model of cross-boundary working to facilitate the mutual sharing of expertise across a variety of relevant clinical specialisms. **Result:** A guideline aimed at helping clinicians to identify the early signs and symptoms of MSCC was produced in the form of a credit card. This credit card includes key statements about MSCC, signposting to key sources of additional information and a user-friendly list of Red Flags which has been developed into an eight-item Red Flag mnemonic. To date, an excess of 120 000 cards have been printed by a variety of organisations and the distribution of the cards is ongoing across the United Kingdom and the Republic of Ireland.

Key words: clinical guide; early warning; metastatic spinal cord compression (MSCC); Red Flags

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Background

Cancer is the second most common cause of death in the United Kingdom; metastases to the spinal column occur in 3–5% of all patients with cancer, most commonly those with breast, prostate and lung cancer, in whom the incidence may be as high as 19%. In total, there are ~4000 cases of metastatic spinal cord compression (MSCC) in England and Wales per annum (NICE, 2008). MSCC is a well-recognised complication of cancer and is usually an oncological emergency. The condition occurs when there is pathological vertebral body collapse or direct tumour growth causing compression of the spinal cord, leading to irreversible neurological damage (Levack *et al.*, 2002). In addition to the agonising pain and spinal instability

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that the condition can cause, compression on the spinal cord can also lead to paraplegia or quadriplegia and double incontinence. At diagnosis, 82% of patients with MSCC are unable to walk or only able to do so with help. The development of paraplegia and loss of control of bladder and bowel function have a devastating effect on the quality of life that remains and considerably reduce life expectancy (Levack *et al.*, 2002; Patchell *et al.*, 2005). Those with established paraparesis and loss of bladder control by the time of treatment are unlikely to regain useful function (Christie Hospital NHS Foundation Trust, 2008). It is well documented that the best outcome for MSCC in terms of function and prognosis depends on a high index of suspicion, early diagnosis, onward referral for urgent investigation and prompt treatment in order to prevent or limit neurological damage. It is therefore important that all health-care professionals are aware of the early symptoms and signs of MSCC (Husband, 1998; Levack *et al.*, 2002; Loblaw *et al.*, 2003). However, early detection and diagnosis of MSCC, before the development of neurological symptoms, rely solely on the subjective history taking. This is extremely challenging when considering that on average patients present to a variety of non-specialist practitioners in a broad range of locations within three weeks of the onset of back pain (Levack *et al.*, 2002), and that 25% of patients present with MSCC as the first presentation of malignancy, with no signs of cancer or primary malignancy yet diagnosed. This 25% are a key group for clinicians to successfully identify in primary care (Christie Hospital NHS Foundation Trust, 2008; NICE, 2008). The difficulties associated with early identification of MSCC are compounded by the sheer number of people suffering from low back pain, the variety and vagueness of symptoms articulated by the patients, and the paucity of concise high-quality guidelines. For example, the guidelines for the physiotherapy management of low back pain (CSP, 2007) reported that there were 163 individual items that could be considered as Red Flags (Red Flags are possible indicators of serious spinal pathology). Clearly, this presents a major problem in terms of the practical and clinical utility of the current system of spinal Red Flags; in addition, none of the 163 items are actually specific to MSCC.

Rationale

Managing the diversity and sometimes vagueness of clinical problems encountered demands that primary-care practitioners use a variety of clinical decision-making strategies (André *et al.*, 2012). These decision-making strategies culminate in a diagnostic conclusion, which is referred to as 'the conclusion of the greatest belief' (Straszecka, 2006). The conclusion of the greatest belief then informs clinical decision making in terms of the next stage of the patient journey. In complex clinical situations such as MSCC, it may be extremely difficult to interpret signs and symptoms; we are trying to assist clinicians in coming to a conclusion of the greatest belief that suggests further diagnostic testing or onward referral to a specialist is indicated. The issue of identifying MSCC early to prevent serious long-term disability was a key theme identified by the Task and Finish Group at Greater Manchester and Cheshire Cancer Network (GMCCN) in 2009, and it was this group that initially brokered and then coordinated the current development as part of their strategic approach to improve care for MSCC patients. This development aims to improve outcomes for MSCC patients by increasing awareness in health-care professionals who may be in clinical scenarios where identifying MSCC at earlier stages is possible. GMCCN recognised that there was a problem at both ends of the clinical pathway for MSCC, and that expert knowledge of MSCC was 'hidden' in professional silos. The GMCCN used the 'needle in a haystack' analogy to describe the problem of managing MSCC, whereas in primary care they needed help in finding the 'needle'. However, in Oncology, they needed help to manage the 'haystack'. Interestingly, at roughly the same time, two other MSCC projects were being conducted independently of each other in the North West: these were being led by clinicians from opposite ends of the MSCC pathway. The first was the development of The Christie guidelines (Christie Hospital NHS Foundation Trust, 2008) by the MSCC steering group. This group consisted of specialist oncology physiotherapists a consultant oncologist and other clinicians with an interest in MSCC. The Christie MSCC Guidelines were designed to assist all health-care clinicians identify MSCC earlier in the disease process. A previous

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supra-regional audit of three centres had highlighted that the management of MSCC was poor with delays in recognising the symptoms and the subsequent ordering of appropriate investigations, leading to late diagnosis, treatment and rehabilitation. The other project centred on a qualitative research project aimed at informing primary-care musculoskeletal physiotherapists about MSCC (Greenhalgh and Selfe, 2009). This project was developed in recognition that NHS reforms and new clinical pathways had resulted in physiotherapists moving 'upstream' in terms of the patient journey and that they were not always well equipped to identify a variety of serious spinal pathologies in their early stages. GMCCN had by this stage become very aware that to make any impact at all, the level of awareness of the Red Flags that potentially indicated the presence of MSCC had to be raised and raised across a wide variety of staff. The GMCCN therefore used their strategic position to bring together the oncology expertise from the Christie group and the primary-care musculoskeletal physiotherapy expertise to work on producing a user-friendly list of MSCC Red Flags for non-specialist 'generalist' front-line clinicians working in primary-care settings.

The development process began with an in-depth period of negotiation between experts in the field of oncology and musculoskeletal primary-care with close collaboration with an academic physiotherapy department at a local university. The negotiation considered the essential minimum data requirements to raise the index of suspicion suggestive of MSCC. Face-to-face discussion alongside wider peer review with oncologists, palliative care specialists, a GPSI and an orthopaedic surgeon took place over a three-month period. An overview of progress and a strategic perspective was given by the GMCCN. The approach followed a model of cross-boundary working to facilitate the mutual sharing of expertise where specialists in one health-care sector educate staff working in other sectors (Sibbald *et al.*, 2004). Bringing the expertise of this multidisciplinary group together in this way was extremely valuable as each individual saw the problem from a different perspective and was able to educate the others about the challenges they faced about MSCC. It was very challenging to meet the needs of the primary-care musculoskeletal therapists and the oncology specialists; a good example of this was around the discussion on whether to include age as a Red Flag. Age above 50 or 55 years is a very well-recognised Red Flag in the orthopaedic and musculoskeletal literature and it appears as a potential Red Flag on virtually all guidelines on low back pain; however, the oncologists were clear and also adamant that age could not be considered as a Red Flag for MSCC from their perspective. One of the other challenges was around ensuring the use of a common language so that both groups would recognise the importance of MSCC as a serious oncology problem. A key area of debate centred on the use of the word anguish. Anguish was considered essential from an oncology perspective. However, from a primary-care musculoskeletal (MSK) perspective, it was felt that this word could be misleading as many patients present with high levels of anguish associated with benign MSK problems. A compromise was reached by using the phrase 'agonising pain causing anguish and despair'. Despite these challenges, the period of negotiation of the minimum data set between experts concluded with consensus being achieved in a relatively short time frame.

Description

A guideline aimed at helping clinicians to identify the early signs and symptoms of MSCC was produced in the form of a credit card. This guideline will help ensure that appropriate patients are referred for urgent investigation and prompt treatment in order to prevent or limit neurological damage.

Three key statements about MSCC were formulated along with signposting to key sources of additional information (www.nice.org.uk; www.gmccn.nhs.uk):

- Past medical history of cancer (but note 25% patients do not have diagnosed primary).
- Early diagnosis is essential (as the prognosis is severely impaired once paralysis occurs).
- A combination of Red Flags increases suspicion (the more red flags, the higher the risk and greater urgency).

In addition, a user-friendly list of Red Flags for MSCC was agreed upon, which was then developed into an eight-item Red Flag mnemonic (Figure 1).

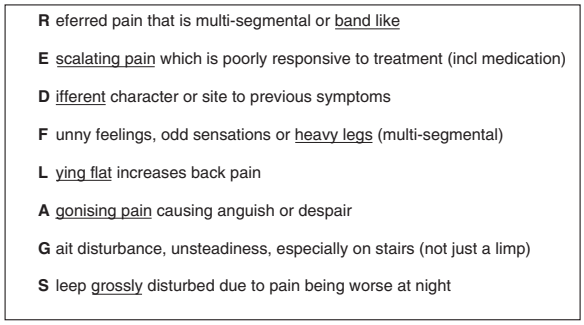

Figure 1 Red Flag mnemonic. Referred pain that is multi-segmental or band like. Escalating pain that is poorly responsive to treatment (including medication). Different character or site to previous symptoms. Funny feelings, odd sensations or heavy legs (multi-segmental). Lying flat increases back pain. Agonising pain causing anguish or despair. Gait disturbance, unsteadiness, especially on stairs (not just a limp). Sleep grossly disturbed because of pain being worse at night.

During the consensus-building process, the idea of a credit card-sized reminder of the red flags was proposed as the optimum design vehicle for conveying these important messages. During a large experienced-based design project carried out in Bolton in 2009 as part of a service improvement strategy, a variety of stakeholder groups that included primary-care musculoskeletal physiotherapists identified a credit card format as a quick, visually attractive way of helping to promote key clinical messages and to raise awareness of particular health issues across a broad range of professionals.

Examples of the card use

In October 2010, the GMCCN funded the production of 9000 cards and conducted a training workshop for Allied Health Professionals (AHPs), GPs and anybody with an interest in MSCC. A directory of local MSCC leads was developed at the same time, with the aim to improve the recognition of early symptoms and to provide a coordinated approach to timely rehabilitation for patients with MSCC following treatment. Following this, the cards were distributed more widely to organisations and departments throughout the North West of England. The cards were distributed to the named MSCC leads in each organisation for onward distribution to relevant departments such as A&E departments, rehabilitation staff, district nurses and clinical nurse specialists. The cards were also distributed to walk-in centres, GPs, GP out-of-hours services, and followed up with on-site training when requested to do so. Very quickly a national demand for the cards developed, and in 2011 NHS (24) Scotland funded the production of 100 000 cards. These will be distributed to physiotherapists and GPs across Scotland, and in 2012 NHS (24) Scotland also commissioned a more general video podcast about Red Flags for serious spinal pathology (http://www.youtube.com/user/MSKEducation). In 2011, news articles about the cards appeared in the national physiotherapy magazine Frontline and in the National Cancer Action News. Most recently, in 2012, the National Cancer Action Team funded the printing of 10 000 cards for distribution throughout England and Wales and the development team were finalists in the 2012 National Patient Safety Awards.

Members of the development team regularly get e-mails requesting the credit cards; the following is a typical example from an advanced orthopaedic physiotherapy practitioner;

> *Having recently had cause to further increase our awareness about the importance of spotting early indicators for cancer within our practice and subsequently reading about the Red Flag cards in Frontline, I was wondering how we could obtain some of the cards. There are 17 in our practice we would be very happy to pay the going rate and postage.*

We have also received e-mails confirming that individual clinical reasoning and subsequent clinical practice has changed in response to the cards; the following is an extract from a General Practitioner (GP) referral to an orthopaedic clinical assessment and triage team, where the Red Flag mnemonic on the credit card has been used in a quite literal way to structure the referral;

> *Referred pain affecting more than one myotome*
> *Escalating back and leg pain*
> *Different pain-at 83 yrs she has never had back pain or sciatica*
> *Funny odd feelings in right leg – she describes her leg as feeling like it does not belong to her*
> *L – She can lie down but can't sit on right buttock*
> *Agonising pain which is making her cry*

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Gait is very disturbed with frequent falls over the last 3 weeks
Sleep is grossly disturbed

Another area the cards appear to be affecting is in helping to shape clinical pathways where services are being reviewed; the following is an edited excerpt from an e-mail from an extended scope physiotherapist;

I was wondering whether you might be able to help us out. I read your comments in Frontline in relation to your Red Card alert system with some alarm in regards to the number of malignancies that are coming through your service. Although we are a small service averaging about 100-120 referrals a month we don't seem to be picking up similar percentages despite most likely having a similar population base. I was wondering whether you could possibly send me a PDF or word version of your Red Flag card system so we can compare this with our current protocols to make sure we are doing everything correctly.

Discussion

The development of the Red Flag credit cards has been a very rewarding process. Cross-boundary working has been the key feature of the success of this development. Cross-boundary working has helped the team members to understand each other's viewpoints, it has contributed significantly to individual learning and it has also raised the awareness of MSCC within the team itself. The development team did not anticipate that the cards would generate such a high level of interest nationally and have been somewhat surprised but very pleased by this. The main strength of the cards is that they are very cost-effective as highlighted by the recent Allied Health Professions QIPP Cancer care toolkit (2012: 21): 'The cost of circulating 9000 cards at £800 would be far outweighed by the cost saved if even one case of MSCC is diagnosed early or prevented'. Each paper card costs 9 pence to produce and the plastic version costs 13 pence to produce. As the cards are so cheap, they have been made available to a large number of practitioners nationally, and therefore we feel that we have been able to reach out and raise awareness of MSCC in a way that would not have been possible through traditional forms of dissemination, such as lectures and journal publications. It is important to recognise that the use of the cards needs to be embedded within a framework of training and the cards alone should not be seen as a cheap panacea to dealing with MSCC. However, the training in turn also needs to be supported by appropriate organisational structures. For example, NICE (2008: 9) guidance states 'Every cancer network should have a clear care pathway for the diagnosis, treatment, rehabilitation and on-going care of patients with metastatic spinal cord compression (MSCC)'. Unless the appropriate organisational and training structures are in place, the cards alone will be limited in their impact. The framework of training needs to ensure that appropriate support mechanisms are in place to help clinicians convert explicit knowledge about MSCC, derived from the cards, into the appropriate clinical action (Eraut, 2000). Initially, we would envisage that training will increase the awareness of and familiarity with the card and its contents. This awareness raising would be an important first step, as there is a tendency for clinicians to use familiar schemata for quick action (Eraut, 1994). In the case of MSCC, this would be timely onward referral for further diagnostic testing or referral to a specialist. Ideally, training would then use strategies such as clinical presentation mapping and critical incident analysis to facilitate routinisation of onward referral for MSCC. Eraut (2000) proposes that the process of routinisation can begin by following checklists such as that described on the cards and through repetition this explicit procedural knowledge can be converted to tacit knowledge followed by routinisation of action, which will lead to improved patient outcomes.

The cards are very simple, but they have a very significant and well-thought out message, and in our opinion the Red Flag mnemonic is easy to remember. However, not everyone agrees that the mnemonic is easy to remember, as mnemonics tend to be memorable if they have five or fewer components such as CAGE (felt need to Cut down Annoyed other people, Guilty about drinking need morning Eye opener) for problem drinking or the current FAST (Facial drooping, Arm weakness, Speech difficulties, Time) heuristic for stroke. However, within the

physiotherapy community, the concept of Red Flags is firmly established and to use that as the basis for the mnemonic presents a logical step in raising awareness of MSCC. The cards are easy to carry and easy to use in the clinical workplace so that health-care staff can have at hand an invaluable reference tool, available in a clinical format, that can make a big difference to patient care and outcomes. The artwork is free to use for local groups to add their own logos, numbers and contact details; groups such as the Manipulative Association of the Chartered Society of Physiotherapy (MACP) are now distributing the cards to their members with the MACP logo as part of their continuing professional development training days.

The main limitation associated with this project is the lack of formal evaluation. The project was never conceived as a research activity, and the development team has been surprised by the rapid organic growth in interest and utilisation of the cards. In terms of understanding the effect of the cards, there are a number of significant confounding variables that challenge any formal evaluation. The key confounding variable is that other organisations such as Christie Hospital NHS Foundation Trust (2008) and NICE (2008) have also recently published MSCC guidelines, and therefore to attribute any raising of awareness solely on the cards would be very difficult. One of the other limitations is not necessarily about the cards themselves, but it revolves around ensuring that when clinician's awareness of MSCC has been raised appropriate MSCC coordinators are in place, and that there are suitable referral pathways locally for patients with suspected MSCC. Therefore, an important element of any training programme associated with the cards should include raising awareness of the role of MSCC coordinators and identifying local-care pathways for MSCC. This process requires significant primary-care involvement and, in particular, a high level of engagement from the GPs. Another limitation is that when mass produced by differing organisations it becomes very difficult to update the cards in response to any new evidence. The cards have been criticised as no information regarding sensitivity or specificity has been included. However, this seems to miss the point as the cards are intended as an educational tool to help raise awareness of MSCC and inform 'the conclusion of the greatest belief' so that clinicians will send patients that they are concerned about for early investigation. The cards themselves are not diagnostic tools, and therefore it would probably be inappropriate to subject them to a formal schedule of testing aimed at determining sensitivity and specificity.

Planned evaluation

Currently, two formal evaluations of the effect of the cards are planned for 2013. The first evaluation will use a survey methodology using a questionnaire instrument designed to assess knowledge of MSCC before and after participation in a bespoke training programme for a mixed group of Allied Health Professionals in a community NHS Trust. The second evaluation will utilise a similar survey methodology and the same questionnaire instrument as part of a competence-based assessment of physiotherapists taking part in a NIHR-funded research project investigating a self-referral scheme for low back pain. Both of these evaluations will help to inform us about changes in clinical knowledge, which is a critical first step. However, it is also important that changes in practice are evaluated. One approach to this would be significant event analyses of new cases of MSCC to see whether earlier recognition is occurring, as early recognition will have the most impact on patient outcomes. Owing to the publication of the Christie Hospital NHS Foundation Trust (2008) and NICE (2008) guidelines, it would be very difficult to isolate the effect on clinical behaviour of a single source of knowledge. As previously stated, a supra-regional audit of three centres in the north-west highlighted that the management of MSCC was poor with delays in recognising the symptoms and the subsequent ordering of appropriate investigations, leading to late diagnosis, treatment and rehabilitation. If funding were available, it would be possible to repeat the audit; however, as highlighted above, this would inevitably be a multifaceted audit from which it would not be possible to identify the specific contributions of any particular source of information. The recently appointed MSCC coordinators and AHP rehabilitation leads have roles that include dissemination and evaluation. These individuals should be well placed to carry out

localised evaluation of individual practitioner knowledge and they should also have a strategic overview, which will allow the evaluation of referral patterns within their localities.

Conclusion

Use of the Red Flag credit cards in combination with specific training programmes will alongside the guidelines also published by Christie Hospital NHS Foundation Trust (2008) and NICE (2008) help to raise awareness among health professionals about combinations of signs and symptoms that raise the suspicion about MSCC. MSCC coordinators, in particular, will have a role in the cards for further use and dissemination.

Ethics statement

Owing to the nature of this work, no ethics submissions were required. However, the appropriate ethics and governance permissions will be sought before the two planned evaluations.

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