Living with a malignant wound can be an overwhelming experience for the patient and their family, yet the psychosocial effects are often overlooked at assessment. If care is to be holistic, then these issues must be addressed.

**Malodour; exudate; pain; bleeding; psychosocial issues**

This is the second in a series of articles summaising the literature on malignant wounds in a holistic format that practitioners can use to inform their practice decisions. The first article, focused on the epidemiology, aetiology, presentation and assessment of these wounds. This article examines the literature on the key symptoms and their psychosocial effects. Full details of the search methodology and use of terminology were provided in part one. The series will conclude with an article on the management of malignant wounds.

**Living with a malignant wound**

The most common physical symptoms of malignant fungating wounds cited in the literature were:

- Malodour
- Exudate
- Pain
- Bleeding

Other symptoms included: depression, embarrassment, shame, guilt, stigmatisation, loss of confidence, worthlessness, demoralisation, fatigue, interrupted sleep patterns, impaired mobility and activity levels, anorexia, nausea, dyspnoea, pruritus, lymphoedema and social isolation.

**Malodour**

Of all the symptoms associated with malignant wounds, the offensive smell is often described as the one causing most distress to patients, their carers and families. Likened to the smell of rotting flesh, malodour is frequently recognised by nurses as one of the most difficult symptoms to treat. Anaerobic bacteria, such as those in the *Bacteroides* and *Clostridium* species, are considered to create the malodour. The bacteria bury themselves in the oxygen-free dead tissue of the wound, where their metabolic processes produce volatile short-chain organic acids (n-butyric, n-valeric, n-caproic, n-heptanoic and n-caprylic). These agents combine with the amines and diamines (cadaverine and putrescine) produced by the metabolic processes of other proteolytic bacteria to produce the pungent odours that invoke the gag reflex.

**Exudate**

Malignant fungating wounds can produce large amounts of exudate, sometimes over a litre per day. Such high levels are notoriously difficult to manage, usually necessitating frequent dressing changes and increasing the risk of maceration. Difficulties in objectively measuring exudate have been acknowledged and there is as yet no user-friendly, validated tool for its assessment. The TELER tool, discussed in part one of this series, may be useful in assessing exudate in malignant wounds. Using the TELER tool, researchers measured exudate, based on the degree of exudate leakage from dressings, dressing fit and the number of dressing changes required in a 24-hour period. In recognition of the heterogeneity of malignant wounds, these assessments were individualised by subsequently assessing the impact for each individual patient.

S. Alexander, Bachelor of Health (Nursing) (Hons), RN, MRCNA, Researcher, CQ University, Bundaberg, Australia. Email: s.alexander@cqu.edu.au
Exudate closely resembles blood plasma. It comprises water, electrolytes, nutrients, inflammatory mediators, leucocytes, growth factors, enzymes and waste products. There are important differences between exudate from acute wounds and from chronic, non-healing wounds. The latter contains fewer growth factors and increased levels of proteolytic enzymes (matrix metalloproteinases [MMPs]) and other caustic substances that are capable of degrading the peri-wound tissue and enlarging the wound size.

To date, no studies have investigated malignant wound exudate, but it is reasonable to suggest that its composition is different to exudate from acute or other chronic wounds, if only because of the presence of tumour cells. If sinuses or fistulae are present, the wound fluid may also be contaminated with saliva, peritoneal fluid, faecal fluid or urine.

The importance of controlling malignant wound exudate was highlighted by Grocott, who discussed the impact of leakage, soiling, frequent dressing changes or reinforcement, peri-wound maceration and malodour on the patient’s already battered physical and psychosocial self-concepts. She found that exudate was the dominant issue for patients and described it as a pivotal link because other issues (malodour, bleeding, maceration, pain and psychosocial) all appeared to relate to the problem of heavy exudate.

Exudate often leaks onto clothing and bedding, which is not only embarrassing and distressing for the patient but also increases the burden for the carer. Patients have described their lives as being taken over by dressing changes, leakage of exudate, soiling and laundry. For example, one patient was so embarrassed by the leaking exudate that he remained motionless for long periods to avoid disturbing the dressing and thus allowing the exudate to escape. Not only did this reduce his quality of life, but it also increased his risk of pressure ulceration.

Similarly, Banks and Jones reported the case of a man whose exudate from a nasal carcinoma ran back into his mouth. His condition was exacerbated by anorexia and by the psychosocial impact of facial disfigurement.

Further problems associated with heavy exudation included anaemia and other metabolic imbalances resulting from ongoing fluid loss. It has also been suggested that large volumes of exudate may dilute topical wound medications, but there is, as yet, no robust evidence to support these suggestions.

Pain
Pain is a complex phenomenon that affects different people in different ways. The physical sensation of pain in malignant wounds may be caused by a number of factors, including:

- Pressure from the tumour mass on other body structures
- Damage to nerves by the advancing tumour
- Exposure of dermal nerve endings
- Recurrent infections
- Swelling resulting from impaired capillary and lymphatic drainage
- Wound-care procedures

There are very few statistics on the incidence of pain in malignant wounds. One small study (n=13) found that 38% of the patients experienced wound pain. This study, which was piloting the development of a staging system for malignant wounds, stated that 3/13 patients reported pain scores less than 5 on a visual analogue scale (VAS) and 2/13 reported scores greater than 5.

It is important to note that the experience of pain is not just physical, as pain may be experienced in all of the domains (physical, psychological, social, spiritual). The founder of the hospice movement, Dame Cicely Saunders, recognised this multidimensional nature of pain when she described the concept of ‘total pain’. Total pain recognises psychological factors — such as anger, fear, anxiety and depression — that affect the pain experience. Naylor addressed this issue in his article on the assessment and management of pain in fungating wounds. He suggested that normal cognitive responses to physical pain may be affected by increased anxiety. Once again, the importance of individualised and comprehensive assessment is highlighted to determine all of the factors contributing to the pain experience.

The contribution of psychosocial-spiritual issues to the total pain experience was also recognised by a number of authors, who found that malodour was a major contributor to patients’ experiences of pain. One case study found that better pain control was achieved only when malodour had been successfully treated, while another reported that mean pain scores of participants receiving metronidazole reduced significantly as the malodour became less noticeable.

Once again, however, the lack of robust research into malignant wounds is highlighted as other factors may contribute to the reduction of pain following the administration of metronidazole. For example, the pain of an underlying infection may be relieved if the metronidazole is effective against the infection. More robust evidence is required to determine the relationship between malodour reduction and total pain experience.

Although not strictly categorised as painful, pruritus can cause such discomfort that it has been described as deserving the same attention as pain and is possibly one of the most bothersome symptoms of advanced cancer. The itch may be localised or widespread, and may be so severe the patient scratches their skin until it bleeds.
Although the causes of pruritus in advanced cancer are diverse, they commonly include dehydrated skin, cholestasis, uraemia, thrombocytosis and an overabundance of histamine, serotonin, cytokines or opioids. According to Zylcz et al., pruritus occurs when free nerve endings are subjected to irritation at the dermo-epidermal border. The irritation is most commonly caused by histamine released from mast cells and platelet-activating factor. Sites most likely to be affected by pruritus are rich in unmyelinated C- and A fibres, which are similar to those conducting pain impulses. Signals are conducted by these fibres to the thalamus and brain cortex.

**Bleeding**

Malignant wounds often manifest bleeding and clotting irregularities due to the abnormal vasculature in the advancing tumour. Altered peri-tumour angiogenesis and coagulopathy may result in an overabundance of tortuous, thin-walled vessels that bleed easily and resist haemostasis. Additionally, systemic coagulopathy resulting from existing comorbidities or pharmaceutical regimens may further exacerbate the friability of a malignant wound. Conversely, two reports suggested that higher concentrations of thromboplastin secreted by some neoplastic tumours may increase clotting, but neither provided any frequency statistics for this. Catastrophic bleeds are also possible if the advancing tumour erodes a major blood vessel. These bleeds signal imminent death. Practitioners should develop plans to ensure optimum management of these situations should they arise.

**Psychosocial issues**

A malignant wound affects all dimensions of a patient’s existence: physical, psychological, social and spiritual. Accordingly, for treatment plans to be effective, assessment must take account of the wound’s multidimensional nature. However, this is not emphasised in guidance documents on the assessment and management of malignant wounds. Although some tools have been developed to assess the psychosocial issues of patients with malignant wounds (see WOSSAC and TELER tools, discussed in part one of this series), there remains little formal guidance on managing them.

The NHS Clinical Knowledge Summaries (formerly PRODIGY) guidance on the management of malignant ulcers mentioned the need to include psychosocial aspects in assessment, but disappointingly the management section deals with physical issues only, with no guidance on how to address these psychosocial issues.

On a more promising note, the US Institute of Medicine report, *Cancer Care for the Whole Patient: meeting psychosocial health needs*, highlighted the importance of psychosocial issues in cancer patients, but acknowledged that, in oncology services, attending to psychosocial-health needs was the exception, rather than the rule.

Although not discussing malignant wounds specifically, some authors did highlight the psychosocial issues of patients with cancer or disfiguring conditions. Steele et al. conducted a cross-sectional, descriptive study of 103 Canadian women with gynaecological cancers. The patients completed self-report questionnaires identifying their care needs and whether these were being met. The researchers found that eight out of the 10 most frequently reported needs were psychosocial. If, as health professionals, we are to provide holistic care, it is clear that we must understand and be prepared to address psychosocial needs. Yet, they are often not viewed as a priority in clinical practice.

Some authors have discussed reasons for the lack of attention to psychosocial issues when treating patients. In some instances, it may be the case that practitioners are unsure of how best to address difficult issues. The malignant wound literature suggested that when psychosocial issues were assessed, they were usually described in general terms, without asking the patient what the experience was actually like for them. It was also noted that management plans tended to focus on physical aspects of care to the detriment of psychosocial issues.

What is known is that living with a malignant wound is often overwhelming. These wounds have been described as ‘the ultimate insult to body image’ and ‘a visible marker of underlying malignant disease’. The following quote illustrates the distressing nature of living with such a wound:

*‘Can we begin to imagine what it must feel like for a patient to see part of his body rotting and to have to live with the offensive smell from it, see the reaction of his visitors (including doctors and nurses) and know that it signifies lingering death?’*

The literature that did mention psychosocial issues associated with malignant wounds suggested that they included:

- Social isolation
- Altered body image
- Stigma
- Existential issues associated with approaching death and the search for meaning in life
- Altered relationships and loss of personhood

These issues are likely to be compounded in instances where fungating wounds are located in highly visible (head and neck) or intimate (breast or perineum) locations.

Despite the acknowledgement of the importance of psychosocial issues in complex cases such as malignant wounds, there has been little research...
into the experience from the perspective of patients, and much of the literature was based on the assumptions of practitioners. As a result, little is known about the lived experience of malignant wounds. This gap in existing knowledge is particularly worrying because, for many patients with chronic wounds, it is not the wound that causes the most concern but the psychosocial issues associated with it and the ensuing impact on their quality of life. 61,67,68 The fact that more research on the lived experience of malignant wounds would be a valuable addition to the literature has been recognised by a number of authors. 9,26,61,69,70

A study by Lund-Nielsen et al. was one of the first to investigate psychosocial issues associated with malignant wounds. In conjunction with the trial of an intervention programme, they used semi-structured interviews to learn how malignant wounds affected femininity, sexuality and daily life in 12 women with malignant breast wounds. Patients described how malodour and exudate triggered anxiety about leakage and prevented them from wearing feminine clothing. The odour led some women to feel as if their body was rotting away. As a result, their self-esteem diminished, the need for physical closeness and intimacy was suppressed and they experienced increasing social isolation. 6

The authors stated that the wound-care component of the programme helped the women to reduce their social isolation and wear a greater selection of clothes. They also stated that the intervention had improved the participants’ psychosocial wellbeing because they had more choices and were not being constantly reminded of the presence of the malignant wound. 9

Piggin and Jones also investigated the lived experience of patients with malignant wounds, but recognised the need for further research to increase understanding of the experience. They also suggested that the perspectives of lay caregivers or family members would be a useful addition to the existing literature. 64

The few authors who have investigated the impact on nurses of caring for patients with malignant wounds reported that these cases were difficult to manage and often personally distressing. On the whole, nurses strove to maintain the patient’s dignity and not lose sight of the person they were treating. Nurses identified patient isolation and altered body image as significant challenges to their provision of care and often felt personally guilty when they were unable to successfully manage a wound. 19,69,71,72

**Conclusion**

This part of the series has focused on the major symptoms and psychosocial issues associated with malignant wounds. The major physical symptoms were malodour, exudate, pain and bleeding, while a number of psychosocial issues were identified. Within the literature, malodour was often recognised as the symptom causing the greatest distress to patients, as well as being the most difficult one to treat. Heavy exudate was also often a problem for patients, frequently leaking through dressings and soiling clothing and bedding, and increasing the risk of maceration of peri-wound skin.

The literature also recognised the importance of assessing and managing the total pain experience, necessitating the assessment of pain in all domains of the patient’s existence. As the wound progresses, bleeding frequently becomes a problem as the disorganised, and at times overabundant, vasculature results in thin-walled vessels that bleed at the slightest trauma. Clinicians should be aware of, and prepared for, the possibility of a catastrophic haemorrhage should the advancing tumour erode an artery.

Although a range of psychosocial issues were identified in the literature, there was little discussion on how to address them. There has also been little investigation into the experience from the perspectives of patients, caregivers or nurses and much of the existing knowledge was based on health-care practitioners’ assumptions about what the experience was like for those enduring it. As a result, a number of authors have identified the need for further research into the lived experience of malignant wounds from the perspectives of those experiencing it. Such research would add to the existing knowledge base and help ensure that the care provided is truly holistic.

The next part of this series will review the literature on the management of patients with malignant wounds, including suggestions for managing psychosocial issues.

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