

The Psychological Effects of Malignant Fungating Wounds



SUMMARY

Malignant fungating wounds (MFWs) are a result of cancerous cells invading the skin and nearby vessels¹. They are most common in patients with breast cancer but also have a high incidence in patients with head and neck cancers^{2, 3}. MFWs typically occur at the site of the primary cancer as well as in the surrounding lymph nodes³.

MFWs have a multitude of physical effects on patients including pain, bleeding, and exudate. It is important, however, to understand the psychological impacts that MFWs and the symptoms associated with MFWs have on the lives of patients. The aim of this article is to review the literature on the psychological impacts of MFWs.

A search of four databases identified 24 papers comprising four main themes: the physical symptoms of MFWs, the effects of MFWs on patients' sense of self, the effects of MFWs on patients' relationships, and support for patients with MFWs.

MFWs have a profound impact on the psychological well-being of patients and contribute to how patients view themselves and their illness. Feelings of isolation tend to predominate, but the impact of MFWs on the lives of patients and patients' families can be mitigated with specialist and supportive care.

INTRODUCTION

A malignant fungating wound (MFW) is the result of a tumour or metastasis penetrating the skin. MFWs can also affect lymph and blood vessels around the site of penetration (e.g. the breast)⁴. If a tumour is not treated sufficiently, it can spread to nearby local tissue and cause vascular damage or severe ulceration⁵. MFWs can occur anywhere on the body, but they are most commonly found on the breast (62%) and the head and neck (24%)⁶.

The prevalence of MFWs is unclear, due in part to insufficient documentation and identification of MFWs in cancer registers⁷. A survey in the United Kingdom in 1992 reported 2,417 new cases of MFW per year, with 5% of those cases caused by a primary tumour and 10% caused by

metastatic disease⁸. The pathology of the remaining 85% of the MFW cases in the survey was not identified. The prevalence has remained constant over the years since the 1992 survey, with reports that 5–10% of patients with cancer develop an MFW⁹⁻¹². However, Prevalence may be higher as some patients do not report MFWs due to embarrassment.

Although the prevalence of MFWs is unclear, there is a need to understand the impact that MFWs have on patients. The aim of this review is to gain a better understanding of the psychological effects that MFWs have on patients.

METHOD

The Cinahl, PsychINFO, Scopus, and CancerLit databases were searched between 31 August 2014 and 11 November 2014 using the following keywords either alone or in combination: 'fungating', 'wounds', 'patient', 'psychological', and 'palliative'. The searches were limited to articles published in English in peer-reviewed journals since 2000.

Twenty-four papers met the review criteria, including 8 original research articles, 14 literature reviews, and 2 case studies. Four major themes emerged from the literature: the physical symptoms of MFWs, the effects of MFWs have on patients sense of self, the effects MFWs on patients' relationships, and support for patients with MFWs. Although each of those themes is discussed here in detail, it should be noted that the number of papers related to each theme was very small.

PHYSICAL SYMPTOMS (THEME 1)

One of the most prevalent issues for patients with MFWs is how to cope with physical symptoms including pain, exudate, odour, itch, and bleeding^{11, 13-16}. Using an interpretative phenomenological analysis, Probst et al. interviewed nine patients with breast cancer¹⁷. All of the patients reported that pain had a major and serious impact on their



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life and described the pain as ‘stabbing’, ‘sharp’, or ‘acute’. The patients were all afraid to use prescribed pain relief on a regular basis for fear that they would become addicted. The patients who took over-the-counter pain medication all noted that those medications did not have an effect on the pain. Additionally, multiple studies reported that pain occurred as a consequence of the MFW, and multiple descriptors were used to describe the pain including ‘constant’, ‘stabbing’, ‘spontaneous’, ‘persistent’, and ‘inflammatory’^{15, 16}.

Bleeding was reported as both a fear and a reality for many patients with MFWs^{11, 15, 18, 19}. In one study, a patient described how her wound began to bleed during a work meeting and produced visible marks on her clothing [18]. Because of that, she always had to carry spare clothing and dressings with her, and she found the bleeding to be a major source of embarrassment. Another patient stated that she could no longer attend the sauna because of the ‘unpredictable nature of the wound’ related to bleeding. Because bodily fluids are usually confined within the body, patients felt that their bodies were letting them down and that bleeding was a major issue that affected their lives¹⁸.

One patient used complimentary alternative medicine in the form of compressions made of cured cheese in efforts to manage bleeding caused by an MFW [18]. She stated that she managed to keep the bleeding under control using that method, although she still found the process distressing. Another patient stated that a scab would eventually form at the site of her MFW but would come off after every shower, returning the wound to its initial stage. The duration of the bleeding episodes varied, and in a study by Lo et al., one patient stated that she always had bleeding from the wound following a dressing change or exercise, which rarely subsided until the following day¹¹.

Exudate and its management had a considerable psychological effect on patients as the patients tried to cope not only with the visible signs but also with the constant dressing changes and reminders of the underlying disease^{11, 15, 18}. Feelings of stress and exacerbation were reported as patients struggled with excessive amounts of exudate, requiring multiple clothing changes and considerable time spent reapplying dressings (which is described as very labour intensive), causing distress, anxiety, worry, and also the financial burden of sourcing adequate dressings^{11, 15, 18}. The management of excessive exudate caused many patients to remain in their own homes for long periods just to be able to manage their wounds. Throughout the studies, the participants remarked on the embarrassment of the exudate, which could become visible at any time^{11, 18, 20}.

Patients consistently identified odour as the worst element of their MFW and stated that the wound odour significantly affected their quality of life and the quality of life of those who cared for them^{15, 19, 21-24}. In some

studies, patients described the odour as ‘mouldy’, ‘putrid’, or ‘similar to spoiled meat’ and reported feelings of living within a body that was ‘rotting’¹⁸. All of the patients found it difficult to mask the odour. One patient remarked that if she could smell the wound, she knew that others could too. That was borne out in many studies in which patients feared that others could smell their wound, which in turn led to the patients isolating themselves within the confines of their home from family and caregivers¹⁷⁻¹⁹. Many of the patients found that the only way to disguise the odour was to wash the wound many times per day, but they found that to be time consuming, which again caused them to stay indoors. One patient used tissue to pack the wound and perfume to disguise the smell, while others resorted to using baby talcum powder and essential oils. A recent international survey showed just how challenging wound odour management can be; clinicians and patients reported using a multitude of agents topically and within the wound environment to manage the odour, with no clear recommendations emerging on how best to manage the problem²⁴.

Although less common than odour and pain, itch (pruritus) was a significant source of distress for individuals with MFWs¹⁵. For some patients, itching occurred both inside the wound and in the area surrounding the wound. One patient identified ‘tensions’ in the breast; she knew that a few days later, the itch would commence^{15, 17}.

EFFECTS ON SENSE OF SELF (THEME 2)

In a study by Lund-Nielsen et al. of 12 women undergoing treatment in Denmark for progressive breast cancer, 42% of the women reported that their wounds had a negative effect on their femininity²⁵. The inability to wear a bra because of the dressing affected the ability to choose clothes of a feminine nature. The older women (>70 years of age) did not report a particular loss of femininity but stated that if they were younger, the wound might have had a significant impact on their sense of femininity. The effects of pain on femininity are documented throughout many studies^{17, 25}.

A new sense-of-being in the world was described in a very profound way by the participants in one study. Those patients reported that they had to find a new existence and reasoning within the world that they had become accustomed to since becoming ill²⁰. The patients described feeling that the MFW dictated their lives and that they had a very different existence compared with the existence they once knew. The patients described ‘mourning’ the life they once had and finding it very difficult to accept and adjust to a new life of acceptance, loss, and confusion. The patients described lives prior to having an MFW that included interactions with their family, friends, and wider community; a sure sense of self; and connections with the various elements of life to which they had be-

come accustomed. Living with an MFW greatly affected those interactions and connections. Patients described the wound as symbolising the end of their life, as many of the elements of their former daily life were replaced by loss of independence, embarrassment, anger, depression, and fear²⁰.

A sense of embarrassment emerged very strongly from the patient narratives¹⁷. Embarrassment due to the wound dressing became very difficult for some patients, impacting on the activities of daily living, causing further embarrassment with family members. Some patients described becoming isolated in their own homes due to the embarrassment caused by the symptoms of the wound. One patient described herself as 'falling apart' and feeling marginalised from society, safe only in her own surroundings and away from the eyes of others¹⁸.

Probst et al. reported patients feeling isolated and trying to disguise the problem¹⁸. The patients found it difficult to hide the problem, however, because of associated issues like lymphedema. Attempts to disguise the MFW often left the patients isolated, as they did not want anyone else to know about the problem.

Some of the patients who lived with family members avoided talking about the wound. They never showed it to family members, and some members of the family did not even know the wound existed²⁵. One participant could not bring herself to tell her husband but confided instead in close friends, which provided a way for her to voice her concerns and anxieties.

There were reports throughout the literature of patients feeling a stigma associated with the wound. Patients recounted how they would keep the wound a secret and how the wound affected them socially and greatly compromised their body image and confidence^{11, 17, 19, 25}. One patient had previously always travelled with his family but no longer did so because of his MFW. All the patients found their wound to be a constant reminder of their cancer. One patient stated: 'I don't want to die, but this wound looks as if death is more and more near me. I can't escape'.

Some patients viewed the MFW as a visible demonstration of what the tumour was doing to the inside of their body¹⁹. One patient was very distressed at the thought of what the tumour was doing inside her body when she could see what the MFW was doing on the outside. Lack of control over the body was another common issue among the study participants. A loss of self, meaning one is no longer the person he or she used to be, caused patients to lose faith in their body and to not trust in their body's capabilities. Loss of identity was a major factor for patients. Reconciling what patients expected of their body with the reality of the disease was a huge hurdle.

EFFECTS ON RELATIONSHIPS (THEME 3)

The odour and the appearance of the wound were two ele-

ments that caused patients to feel self-conscious regarding their sexual being^{25, 26}. They were a constant reminder to both patients and the patients' spouses of living with a rapidly progressing terminal illness.

The pain, irritation, reduced mobility, and discomfort caused by the wound made it difficult for patients to relax during sexual intimacy, and spouses feared causing even more pain or discomfort during intimacy²⁶. In the study by Probst et al., one patient was concerned about her partner's acceptance of her wound, and another reported that her spouse did all he could not to touch the breast during sexual activity¹⁸. All the patients reported a significant loss of intimacy and an impact on the quality of relationships. Some partners were afraid that they would hurt their spouse, while others would not discuss or touch the breast, as it was a constant reminder of the condition²⁶.

Patients spoke about the effect of the wound on their partners¹⁹. They stated that they no longer felt attractive or feminine. Many asked the question: 'How can he still love me when I'm not the girl he fell in love with?' One participant stated that she would not sleep beside her partner naked.

Guilt and blame were major factors for some patients, especially in regard to their children. One patient talked about feelings of loss due to not being able to see her children grow into adulthood. All of the patients reported guilt in relation to not being able to fulfil their role within certain relationships.

SUPPORT (THEME 4)

One patient found that although she could not confide in her husband, she was able to talk to the community nurses and also to her close friends¹⁷. Another patient was able to talk to her family and found that to be a great support. Patients identified the need for help with wound care, pain relief, and financial support from specialists in the early stages of their illness¹¹. Many patients reported very positive results following expert help and advice on dressings, wound care strategies, and what to expect from the wound, noting, for example, improved appetite, emotional stability, decreased malodour, reduced levels of pain, feeling more relaxed, sleeping better, generally improved quality of life and ability to live more positively with the wound¹¹.

Advice, appropriate dressings, and the ability to self-care for the wounds in an appropriate manner were all important elements in giving patients autonomy of care going forward¹¹, which in turn led to a more realistic care plan, making the experience less daunting for the patient. Some patients noted that since being able to appropriately manage the wound, they were able to go out more and to feel more comfortable doing so. One patient noted that the specialist nurse was excellent, especially in educating and supporting the patient's daughter regarding

the MFW. One patient said of the wound-care specialist nurse: 'I think that the wound specialist nurse is my angel, because she drives out my malodour and exudate. I was very pleased to have met her'¹¹.

DISCUSSION

There is a dearth of research on the impact that MFWs have on individuals, but the studies identified here reveal a very strong sense of isolation, loss of sexual identity, fear, anxiety, and distress. Those feelings were inextricably linked to the symptoms and the daily challenges of managing the wound and a body that could not be trusted. Physical symptoms such as pain, odour, bleeding, and exudate all negatively impact on patients and patients' relationships. The visual deterioration of the wound leads to physical, emotional, psychological, and spiritual distress, which is linked to the loss of many elements of the patient's life as he or she knew it, such as the patient's sense of identity, body in which he or she trusts, dignity, and sense of control^{13, 19}. Of particular relevance is the isolation that patients either feel or self-impose due mainly to the physical symptoms of the wound.

The reality is that all patients with MFWs will die. The prevalence of MFWs points to a great need for further research in that area. Although a substantial percentage of patients with cancer have an MFW, it is important to understand that the prevalence of MFWs is more than likely underestimated because of patients' reluctance to identify or disclose important information. Such reluctance is commonly related to embarrassment, denial, or

fear. The problem could be addressed in part through more education for clinicians surrounding MFWs and more psychological support for patients and families at the stage when an MFW is diagnosed. When patients' psychological needs are met early on, patients are able to better cope with and manage their disease¹¹ and to sustain a positive sense of identity.

Recently, some studies have sought strategies to improve MFW management, but there is still an urgent need for more research in that area^{24, 27, 28}. Research should focus on the relief of the physical symptoms, which will in turn help to alleviate the psychological distress.

CONCLUSION

The literature on the impacts of MFWs has predominantly focused on the physical symptoms. This review gives voice to the profound and distressing psychological impact that MFWs have on patients and families. MFWs are difficult to endure and often represent a terminal stage of an illness. What is notable is the constant reference to isolation due to the wound, which comes at a time when family and other support structures are very important. It is incumbent upon healthcare professionals to understand the psychological impacts of MFWs in order to help and support patients and patients' families. Healthcare professionals also must face the challenge of finding methods to effectively manage distressing symptoms of MFWs such as odour and itch, because more effective management of the symptoms will improve quality of life for patients and patients' families. ■

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