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# Malignant fungating wounds – The meaning of living in an unbounded body

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A B S T R A C T

*Background:* Malignant fungating wounds may have significant physiological, psychological and emotional consequences on patients and their families. This study focuses on understanding the lived experiences of patients with a malignant fungating breast wound and their informal carers.
*Method:* The methodological framework of interpretative phenomenological approach according to Heidegger was used. Nine patients were interviewed from January until November 2009.
*Results:* The results demonstrate that most of the patients and their informal carers were on their own while struggling with the erosion of their physical boundaries. The women report a lack of information and advice about how to manage the wound as well as the physical and social limitations imposed on them because of copious wound exudate, odour and bleeding. The women used many different methods and approaches to maintain the boundedness of the body.
*Conclusion:* This study contributes to understanding that losing control over the body meant for the women losing control over themselves and their lives. The unboundedness was demonstrated through the symptom experiences. Therefore the care of women needs strategies that are integrated in a palliative, holistic, empathic approach. In particular skills for palliative wound care among medical and nursing staff need to be developed as the women and their carers report a lack of information and advice about how to manage the wound as well as the physical limitations and psychosocial consequences of struggling to maintain the boundedness of the body.


## Introduction

Current evidence at a European level (Eurocare 4, 2010) shows considerable improvement in survival following treatment for cancer. However for some, cancer is still an aggressive and chronic disease (Singletary and Cristofanilli, 2008) resulting in unpleasant symptoms, psychological distress and sometimes malignant fungating wounds. In 2006 in Europe, there were an estimated 3,191,600 cases of cancer diagnosed and 1,703,000 deaths from cancer. Women with breast cancer make up a sizeable proportion of people with cancer with 429,900 cases, which, accounts for 13.5% of all cancers, making breast cancer the most common cancer in Europe (Ferlay et al., 2007). Improvements in screening and treatment have reduced breast cancer mortality in Europe by 19% between 1989 and 2006 (Autier et al., 2010). In Switzerland the incidence in breast cancer is similar to that of Europe with 26,222 new cases diagnosed between 2003 and 2007, resulting in an average of 5244 cases per year which represents 32% of all cancer cases (Swiss Association of Cancer Registries, 2011). Breast cancer occurs in women who are in good health and mostly in those without any previous illness. After the diagnosis they are confronted with a life threatening illness, that changes their life and that of their families quickly and fundamentally (Schmid-Buchi et al., 2005). Those with advanced cancer can now live for long periods; with a good quality of life due to supportive care and symptom management into the end-of-life period. It is important that cancer services and palliative care are integrated to enable good symptom support and this requires national guidelines and accredited standards (Grocott, 2007). However there are a shortage of health professionals educated to use a palliative care approach in the context of the complex symptoms associated with a malignant fungating wound (Lo et al., 2008).

### *What is a malignant fungating wound*

A malignant fungating wound is an infiltration of a cancer or metastasis into the skin and the afferent blood and lymph vessels in the breast (Grocott and Cowley, 2001; Young, 2005). Unless the malignant cells are brought under control, through treatment with chemotherapy, radiotherapy or hormone-therapy, the fungation

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may spread outwards by local extension and as a consequence it causes damage through a combination of loss of vascularity, proliferative growth and ulceration (Grocott, 2000; Mortimer, 2003). Women still present at initial diagnosis with a malignant fungating wound. They may delay seeking help and try to hide the reality of the cancer, which highlights the huge impact and shame associated with such a wound on an intimate part of the body, which is deeply significant for sexuality and feminity (Boon et al., 2000). Those with malignant fungating wounds experience may problems such as excessive exudate and leakage, unpleasant odour from the wound, and the fear of being diagnosed with cancer, which may lead to delay in seeing medical help (Lund-Nielsen et al., 2011).

It is difficult to determine accurately the numbers of patients being treated for malignant fungating wounds as there are no exact statistics of the incidence of these wounds across Europe. Incidence rates are not recorded in population-based cancer registers (Grocott and Cowley, 2001). Most data are based on estimates made within a given population (Ivetic and Lyne, 1990). A survey of the prevalence of fungating wounds undertaken by Thomas (1992) in the UK is often cited in the literature. He used information collected retrospectively from radiotherapy and oncology units, and reports a projected annual figure of 2417 malignant wounds. This gives a monthly total of 295 patients presenting with metastatic skin involvement. The prevalence of fungating wounds in Thomas' study ranges from 5 to 10% with 5% referring to a primary tumour and 10% to metastasis (Thomas, 1992).

The most frequent location of the fungating wound was the breast (62%), followed by the head and face (24%), the genitals, groin and the back (3%) and other areas (8%) (Thomas, 1992). A survey in Switzerland, reported a prevalence of 6.6% (Probst et al., 2009). Findings in the latter study concerning location, were similar to that of Thomas (1992) in which the most frequent location of the wound was, the breast (49.3%) followed by the neck (20.9%), chest (17.6%), extremities (16.6%), genitalia (16.6%), head (13.5%) and other (1.7%). It can be predicted that about five per cent of patients with cancer will develop a malignant fungating wound. The life expectancy for a person living with such a wound is very short with an average of six to twelve months survival (Lo et al., 2008). It is evident from a number of studies that malignant fungating wounds cause immense distress and significant morbidity and they are a neglected aspect of cancer nursing practice in some settings (Lo et al., 2008; in press; Wilkes et al., 2003).

### *Review of the literature*

One of the biggest problems identified in clinical reviews on malignant fungating wounds is symptom management. It is stated that this is as challenging area for patients, informal carers as well as for health care professionals (Grocott, 2007; Lo et al., 2008; Probst et al., 2009). The most common symptoms of malignant fungating wounds are that of malodour, excessive exudate, pain, bleeding and itching (Grocott, 2007; Probst, 2010). Maida et al. (2009) conducted a prospective sequential case series ($n = 67$) of palliative medicine consultations with the aim of quantifying the prevalence of malignant fungating wounds and wound symptoms at the point of referral. Further they were looking at the relationship between wounds, age, gender, the Palliative Performance Scale, and the anatomic site. 67.7% of the patients experienced one or more wound-related symptoms. Pain was the most common symptom reported (31.2%), followed by exudate (14.6%), odour (10.4%), itching (5.2%), bleeding (4.2%) and other symptoms like crusting. It was noted that 28.4% of the wounds were symptom free (Maida et al., 2009).

A study of 14 nurses, four patients and one carer, conducted in Australia, report that malignant fungating wounds are an intense and unforgettable experience with most of the distress caused by malodour (Alexander, 2010). Another UK study provides insight in to the meaning of living with a malignant fungating wound from the perspective of 5 women. The women who felt that there was an overwhelming sense of vulnerability in living within a body that was continually changing and could not be trusted (Piggin and Jones, 2007). Furthermore the visibility of the cancer wound caused immense distress, represented a huge new challenge and changed relationships with family and friends.

The impact of a malignant fungating wound upon day-to-day life and psychological health is illustrated in Lo et al.'s research. Lo et al. (2008) provides a grounded theory study of the lived experiences of 10 patients (six women and four men) with malignant fungating wounds in Taiwan. The researchers provide a detailed description of the trajectory that patients experience from the first stages of wound development through to the end stage of their illness (Lo et al., 2008). Five themes emerged from the data which were: 'declining physical wellbeing', 'wound-related stigma', 'need for expert help', 'strategies in wound management' and 'living positively with the wound'. The findings demonstrate how patients experienced distress related to the wound-related symptoms as well as embarrassment due to symptoms like malodour and leakage of exudate. The wound symptoms affected participants' social behaviour and interaction and resulted in a degree of social isolation. Lo et al. (2008) describe the benefits described by those patients who were seen by a wound care specialist, which enabled them to live more positively with the wound in terms of coping with dressing changes, access to modern dressings and reduction in the distressing experience of odour and pain. Care from the wound care specialist enabled patients to be more comfortable, less distressed and reduced the experience of stigma and social isolation because the wound-related symptoms were managed. Low levels of information and practical help from health professionals led some patients to use management strategies that could harm their wound and exacerbate problems such as bleeding (Lo et al., 2008). Only 15% of patients with a fungating wound, in one multi-centre study, ($n = 70$) are reported to have a specialist nurse involved in the care of their wound (Lo et al., in press).

Malignant wounds do not heal and are generally managed with palliative methods to control both wound-related symptoms and to manage pain, which is one of the most common symptoms identified by patients and by caregivers (Maida et al., 2009; Schulz et al., 2002). In relation to uncontrolled symptoms and wounds that leaked Lawton (1998) observed how patients who experienced the break down in the surface of their bodies from wounds and other problems, exhibited a loss of self and social identity when their bodies became irreversibly unbounded. Although palliative care seeks to palliate the unbounded body and where possible enable the bounding of the wound there is evidence from a number of studies that this group of patients with malignant wounds receive inadequate specialised professional help in relation to palliation of the fungating wound (Lo et al., 2008; Probst, 2010).

The aim of the research reported in this article is to explore the experiences of women with a malignant fungating breast wound living in the community in Switzerland.

## Methodology and method

The perspective taken in this study is that of interpretative phenomenological analysis (IPA). IPA is a qualitative approach influenced by the hermeneutic version of phenomenology. IPA is designed to explore how human beings make sense of a major life experience in its own terms (Smith et al., 2009). Various inductive methods have been developed by supporters of hermeneutic phenomenological research. Although there is no single method,