Coping with an exulcerated breast carcinoma: an interpretative phenomenological study

- **Objective:** To explore how women living at home with a malignant fungating wound (MFW) cope with such wounds.
- **Method:** To explore coping through the lived experiences of patients a methodological framework, using Heideggerian hermeneutic phenomenology and semi-structured interviews. Nine patients were interviewed from January until November 2009.
- **Results:** The results are divided into two categories: 'living with a MFW' and 'feeling different'. These categories demonstrate how it is to live with the unpredictability, and uncontrollability of a MFW due to symptoms such as malodour, bleeding, exudate, pain and itching. The loss of control of the body boundary due to uncontrollable symptoms led to significant levels of distress and suffering for the patients. Different coping strategies were used to live with this wound.
- **Conclusion:** This study demonstrates how difficult it is to live and cope with a malignant fungating wound. Coping strategies, including going into isolation, or denying any issues, were used. When taking care of patients with MFWs, strategies need to integrate a palliative, holistic, empathic approach.

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malignant fungating wound; coping; experiences; palliative wound care

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Malignant fungating wounds (MFW) occur through locally-advanced, metastatic or recurrent cancer that infiltrates the skin and disrupts its integrity. Around 7% of patients with cancer develop such wounds, with the breast being the most frequently affected site;[1] however, with increasing life expectancy of patients with advanced cancer, there may be an increase of those suffering from this condition.[2]

The average life expectancy for people with a MFW is around 6–12 months,[2] so this is a palliative situation. Closure of MFWs requires the malignant cells to be treated by cancer therapy. Providing care for patients with a MFW is challenging, as coping with symptoms such as pain, and the emotional aspects of dealing with a visible cancer, can negatively impact on patient quality of life. Patients with a MFW can suffer extreme physical and psychological distress.[3,4]

Nurses have described caring for patients with MFWs as an intense and unforgettable experience.[5] The problems associated with a MFW create an immense challenge and burden for both patients and their carers.[6] Patients with advanced breast cancer, who developed a MFW and delayed seeking medical help, reported feeling a sense of shame and blame, which contributed to their avoidance strategy by putting the experience of a MFW to the side and ignoring the changes occurring to their breast until their situation became unmanageable.[7] Among the issues that create shame and embarrassment are the unpleasant odour from the wound, which is one of the worst aspects for patients, as well as concerns about leakage of exudate, pain and other fears related to being diagnosed with advanced cancer.[5,8]

Wound-related stigma was a significant finding in one study,[2] whereby patients felt socially isolated because of the wound exudate and odour, which led them to lose self-confidence; some kept the wound a secret from family members, to avoid losing face. The number and burden of symptoms experienced by those with a MFW is linked to a poorer quality of life.[9] Among the issues contributing to a poorer quality of life were the experience of pain, malodour, psychological issues and age.

The aim of the study is to explore how women with a MFW on the breast cope at home.

Method

The study is designed to explore women's lived experiences and how they make sense and cope with a visible cancer wound on the breast. The goal of phenomenology is to describe the phenomenon under review, being as faithful as possible to the participant's experience, without bringing in meanings that are not supported by the lived experiences as reported by participants.[10]

Phenomenology is concerned with the taken-for-granted experiences and allows the researcher to explore the quality of that experience with participants.[11] Phenomenology in nursing research deals with the participants understanding of the experience and takes their standpoint on illness, suffering and care as the focus of the research.[12,13] An interpretive approach was used to explore women's experiences of coping with a MFW on the breast. The study is influenced by Heidegger's hermeneutic version of phenomenology.[10]

Setting and sample

The study was conducted using a purposive sample recruited from three Cantons of Switzerland (Zurich, Bern and Baselland), from January to November 2009. Initial contact was made in each Canton through a nurse or physician of either a cancer and/or breast-care centre. Inclusion criteria for the study included:

- >40 years
- Living with a MFW of the breast for at least 6 months
- Fluent in German in written form and orally (to enable written informed consent and agreement to participate in a 1-hour interview).

The women interviewed were aged 40–80 years. This age group is based on the survey of Probst et al.[1] in which 24–40% of the population with MFWs was within this age group. Semi-structured interviews were conducted on one occasion only. The length of the interviews varied between 55 and 95 minutes. The women decided on the location of the interviews, but most were conducted in the home.

Data analysis

The data analysis involved four steps. First, a verbatim transcription of the interview was made. This was done by the first author. The whole interview was transcribed from Swiss German into Standard German; if a word or an expression could not be translated because an equivalent word did not exist in Standard German, the Swiss German word was used in quotation marks.

Each transcript was read and re-read in an attempt to become immersed in the text, so as to identify and discover the essential qualities of the narrated experiences. This process was guided by the research question. During this phase of the analysis, all phenomena relating to the research question were marked. A process of phenomenological reduction was carried out whereby the findings were isolated and compared with phenomena that are already known.

After re-reading the transcript, the marked thematic phenomena were isolated and abstracted.[10] Finally each finding was categorised. Categorisation has to make sense of the essential meanings of the phenomenon. In doing so, common findings, such as the challenge of the wound management and the work performed on the wound, were identified and collated. The final step involves analysing how each phenomenon will be categorised. The qualitative computer analysis program MAXqda2 was used to format and organise the data.

Table 1. Participant demographics

Name	Age (years)	Employed?	Year of diagnosis of breast cancer	Year of exulceration
Anna	53	Yes	2002	2007
Berta	59	No	1992	2008
Carmen	76	No	2000	2005
Christine	58	Yes	2009	2008
Helen	67	No	1994	2006
Irene	69	No	2007	2007
Linda	61	Yes	1995	2001
Lisa	40	No	2008	2008
Livia	59	Yes	1995	2005

Ethical considerations

Ethical permission for the study was gained from each Canton and the University of Surrey, UK. Due to the highly vulnerable patient population, all participants were granted sufficient time to decide whether they would participate on the study or not. The study information was given both written and orally. Relatives could have been involved during the decision-making process. Written consent was completed before the interview. Participants were advised that they could withdraw from the study at any time. One researcher (SP) carried out all the interviews.

Results

In total, nine women were recruited and interviewed in the study (Table 1). Participants in the study described the enormous challenges they face in living with a MFW and coping with the changed body image, both physically and psychologically. All the women described managing wound-related problems, such as excessive exudate, wound odour, wound pain, bleeding and itching; however, managing these problems was not easy, as they aroused revulsion and had a significant impact on their mental health and wellbeing.

They experienced severe shame and embarrassment, fearing that someone would identify the problems they were having, in particular the unpleasant smell of the wound. Each woman developed her own strategies to cope with the wound and how they disguised the wound odour and exudate and coped with the many wound-related symptoms. Two categories that emerged from the data were 'living with a MFW' and 'feeling different'.

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Living with a MFW

The women reported that living with a MFW changed their life completely. When the cancer became visible, they experienced severe distress. Wound-related problems were often uncontrollable and unpredictable, as they could appear at any time during the day or night, despite strategies to control the problems. It slowly became more and more of a challenge for the women to contain and disguise odour and exudate. Many different types of dressings and applications were used to bring the wound under control.

- **Coping with odour** Wound-related odour caused much distress. The women described how they could smell the wound and they tried everything possible to control the odour. It was difficult to mask the wound odour, as the lead researcher noted:

> *'Opening the front door I smelt a putrescent odour. This odour became more intense in the living room and every time the patient made a move the malodour was amplified. I don't know if the patient noticed that.'* (SP)

Linda was aware that if she could smell the wound odour, then so too could others:

> *'Well I had a very large hole, and then it festered. Well you know there was this yellow fluid and in time it started to smell. That was very unpleasant. And I always thought everyone else could smell it. I have a very sensitive nose, and I always smelt it. Well it came from down there up to my nose. And so I asked myself: "If I smell it, will others smell it too?" And they did, I am sure. So I washed it with cold water before I met anyone.'* (Linda)

This made malodour a very distressing problem for Linda. Her only solution to coping with the odour was to wash the wound before any social interaction, to avoid the shame and anguish associated with anyone knowing about the wound.

Similarly, Berta used water to try to keep the wound odour under control by keeping the wound clean:

> *'Well I rinsed it more often with lukewarm water, so it got clean again. And then I put on a new band aid. And it went OK for a little while, until the smell came through again. Yes sometimes it took longer, but sometimes I had to do it every hour. That was very unpleasant. I was very limited by this.'* (Berta)

Berta described the intensity of the work to bring the wound odour under some kind of control. This meant intensive time with the wound, treating it every hour at times, which caused limitations on her time and constriction to her life.

Many different types of dressings and materials were used to contain the wound exudate, such as gauze and tissues. Anna used a lot of tissues to completely seal the wound and perfume to disguise the odour of her wound:

> *'I usually took a lot of tissues and closed the wound. If I thought anyone could smell it, I used lots of perfume. That way I had no problem being in contact with other people.'* (Anna)

Anna felt pleased that she had been able to disguise the smell of the wound with perfume and this enabled her to continue to work in her business.

- **Managing exudate** Another problem was described as festering due to excessive exudate:

> *'Well, if it was festering, I dried it with kitchen paper. I always carried kitchen paper. Well I have to say sometimes it was very productive. Then I used a lot of kitchen paper. And I had to change it over and over again. Yes, sometimes five to six times a day.'* (Carmen)

This statement by Carmen shows the labour intensive management of the exudate. Furthermore, it demonstrates how much distress the symptoms caused in losing control over the boundaries of her body. Being distressed about leakage from the wound and being concerned this might be obvious to others is supported by the literature.[14,15] These wounds tend to have a large amount of exudate and a lot of dressing material was needed to contain exudate. This meant a lot of time spent on the wound every day; it also gave rise to a financial burden for the women, such as sourcing effective dressings.

Uncertainty as to whether the dressing was applied correctly, due to the constant leakage, had a big impact on emotional wellbeing and worry that their situation would be uncovered. Uncertainty during illness experiences, such as cancer, may result in anxiety, fear and distress.[16,17]

- **Bleeding** Bleeding was considered a serious problem, which affected the daily life of all the women in the study. Helen described how bleeding caused her distress, as it became unpredictable and uncontrollable:

> *'Yes, from time to time it bled very strongly. Sometimes immediately after I showered. Then I usually had a crust, which was macerated, and I rubbed it off and then it bled again. So I had to hold a towel against it until it stopped. This happened so often. I had so much laundry. It was so stressful. Even during the day you never knew if it would ooze or not.'* (Helen)

Not only did Helen have to cope with copious exudate, but also the wound was bleeding, particularly after a shower, when the scab was rubbed off.

Various methods were adopted by the women to get bleeding under control. Some used complementary and alternative medicines (CAM), such as Berta who consulted a variety of alternative medicine books:

> *'It bled from time to time. So, as I read in my books, I used cold water for the haemostasis. Sometimes I used curd cheese. Well, I made a compress with some curd cheese. Using these methods I had nearly everything under control.'* (Berta)

Using CAM enabled Berta to get things under control and she was able to achieve haemostasis. Berta had researched the best method from her CAM book to get her symptoms under control and this was working for her. This gave Bertha confidence that she could do something positive to control her symptoms. CAM use was a positive strategy used by a number of the women to get the wound and their life under control.

- **Pain** The women reported that the wound-related pain had a serious impact on their quality of life. On one side they were hoping that the physician would prescribe something for the pain, or they would get an over-the-counter painkiller from the pharmacist. However, they were afraid to take a lot of pain killers, in case they became addicted to them. The analgesia prescribed was either taken irregularly or the prescription was never converted. Livia, for example, did not go to a physician and bought over-the-counter pain medication:

> *'Sometimes I nearly burst because of this terrible pain. It was really terrible. I would cry. I would take every sort of over-the-counter pill, but they did not relieve the pain. The only thing you could do was wait until it had gone. If you go to the doctor, you get some painkillers that make you addicted too. That is why I waited until it had gone.'* (Livia)

Livia suffered terrible pain and whatever analgesia she took didn't seem to relieve the pain. Furthermore, she was worried about becoming addicted to pain killers. According to Walwyn et al.[18] pain has traditionally been under-treated with the most significant reason being that pain is considered a symptom of the primary illness, and the medical focus has been on treating the illness, without addressing the associated pain.[18] Even though Livia was suffering, she was afraid to go to the doctor, as she was scared of becoming addicted to opioids. This is not an uncommon worry among patients.[18]

- **Itching** Itching was a problem for some of the women and was difficult to manage. Christine and Livia specifically mentioned itching as a symptom they suffered from. Tension in the breast was a precursor to the onset of itching, after a few days.[3,19] Livia reported:

> *'In the beginning, I got these tensions in the breast, so I knew that a few days later I would have a problem with itching. So I usually listened to my body and put something cold on it to prevent the itching. Sometimes it worked, sometimes it did not.'* (Livia)

This statement demonstrates the way Livia understood and listened to her body. Lundgren and Bolund[20] reported in their phenomenological study with 10 women that there was a connection between body and mind. They demonstrated that the participants were striving towards positive thinking, to help the body combat the cancer.[20] By listening to her own body, Livia was interpreting her symptoms. Here it is about subtle changes of feelings and small signs that only the women could feel, with her cold compress sometimes helping the situation.

For Christine, itching was a big problem:

> *'Well this itching was a big problem. I found out that applying tissues or ointment of marigold could relieve it a bit. But I can tell you I would scratch day and night.'* (Christine)

She also found a remedy that offered some relief in Marigold ointment. Marigold is described in the literature as an anti-inflammatory substance and has a cooling effect.[21] It relieved the itching for Christine.

Livia and Christine demonstrated problem solving related to the wound, and how they were successful in a number of respects in managing wound symptoms, sometimes using unconventional remedies. In addition, it demonstrated that they had to figure out different kind of solutions to take charge of their wound-related symptoms.

Most of the women found a way to treat their wound so as to be able to get back to a sort of 'normal life', although this wasn't always successful. Getting back to a normal sort of life involved strategies of trial and error in relation to treating the wound, disguising the wound and reducing feelings of shame.

Feeling different

All women emphasised that they tried to live a normal life, even though they felt different. 'Feeling different' represents their changed perception of themselves and their vulnerability, be it physically and/or emotionally. All the women wished that no one should be aware that they suffered from a MFW. Some retreated into isolation, while others appeared to be in denial, hoping that they would wake up one morning and be back to normal. Charmaz[22] stated that the 'assumption of recovery makes illness simply a way station between prior and future states of health'. Accepting the chronic nature of the MFW and the advancing nature of the disease was very difficult for the women.

Hiding and disguising the problem Irene discussed how difficult it was to hide her condition, due to a number of factors, including her lymphoedema:

> *'It is so difficult for me to hide it because I am someone who doesn't want anyone to know about it. I try to look as I did before the disease. But sometimes it is not possible because I try to do what other people do. But at the moment it is not possible. I am constricted. I have to wear loose clothes, so I can hide it. The problem is my swollen arm as well as the wound. I just want my free mobility back. I think I'd feel more normal then.'* (Irene)

Irene not only had the MFW to worry about, but also the visibility of her swollen arm. The women often felt guilty about suffering side effects of the cancer treatment, such as lymphoedema of the arm. Irene was unable to hide her changed body and had to wear loose clothing; she also had a lack of mobility. Furthermore, Irene's social network knew little of the existence of the wound. A consequence of this was that social support decreased and isolation became the norm.

Getting back to normal and 'acting normal' For the women, striving to be normal also meant having the cancer therapy and wound-related symptoms under control. Some highlighted that, even though they had cancer treatment, they had not experienced side effects. As Linda mentioned:

> *'I am lucky that the chemotherapy did not do anything to me. I never had any nausea, nothing. If I could handle it like this, that would be of course ideal. And I always wash it with cold water and natural resources to try to keep it under control. Well for a long time it did not bleed. But sometimes it bled heavily. Yes and then I still manage to go out.'* (Linda)

Unlike some of the other participants, Linda was still managing to leave the house and go out. She appeared to be keeping the wound under some control, despite having to cope with bleeding. According to her narrative, she had perhaps a more 'normal' life than others, in that she did not feel tied to the house.

Some of the women who lived with family did not discuss the wound with their loved ones, or even show it to them, and some family members did not know of the existence of the MFW. One reason for this was that they did not want to trouble their family or upset their social environment. As Carmen describes:

> *'Yes, I must say only the community care nurses know about it; yes I will not say anything to my husband, because I do not want to trouble him. I try to act as normal as possible. But it gets bigger and bigger and I cannot wear a bra anymore.'* (Carmen)

Carmen pretended there was no problem so she could continue a 'normal' life with her husband. However, later in the interview she confided:

> *'I could not bear it always being alone. I had to tell my closest friends about it, I felt so lonely. This thing consumed me. Now I feel better. Since I told them about it, they come to visit me again like the old days.'* (Carmen)

This showed that some women were keen to integrate their MFW in their lives. For some, being able to tell friends allowed them to feel less isolated and lonely, and so recapture a part of normality.

Finding support Although Carmen was unable to talk to her husband about her situation, she was able to talk to the community nurses and eventually to her close friends. Helen was able to tell her family about the MFW and this was very supportive for her:

> *'I feel much better since I told my family about it. They support me in a nice way, unlike those at the hospital. I feel healthier than before. I also treat it by myself. I do it in the morning and in the evening. I was even able to go with my daughter and the kids to the sea. She helped me manage it. That was great. I loved it. I felt very normal.'* (Helen)

This statement again showed that if the women knew how to manage the wound and had explained their situation to their families, they retrieved the lost normality of their life. Helen contrasted the immense support she got from her family compared with those at the hospital. She identified a shortfall in care and attention from the hospital where she was being treated.

Helen's daughter helped her manage the wound and she was only having to treat it twice a day, which means she spent less time on the wound and had a better quality of life than those who needed to treat the wound more often.

To achieve normality, some of the women followed self-care methods, such as a special diet. Some (Livia and Christine) followed a diet recommended in CAM books, such as drinking freshly-squeezed grass juice. Others (Carmen and Linda) tried to follow a low carbohydrate diet, such as the Atkins diet, as they believed it made them feel better. Preparing a special diet was very time consuming and Christine described reaching the limit of her capacity and had to employ somebody to enable her to continue.

Discussion

Living in a body with a MFW that leaks and smells was a tremendous challenge for these women and led to significant emotional, physical and social distress. The women were using trial-and-error methods to cope with their unpredictable and unbounded body, which could not contain fluids and odours, and led to feelings of shame and frustration.

In this study, the women did their best to cope with a complex wound and tried to move on with their illness by building hope through strong relationships within the family. Some, like Berta, maintained hope by using CAM. Her belief that a special diet could help her to overcome her illness and regain a normal life enabled her to cope. This has been found in other studies; for example Wu et al., who found that uncontrollable symptoms challenged hope and that building hope was significantly related to a better health-related outcome.[23]

The use of CAM in cancer patients has increased over the last few decades.[24,25] Yildirim demonstrated in her cross-sectional study, with 68 women with metastatic stage IV breast cancer, that the most common reason for using alternative medicine was to treat cancer followed by improving health.[26] The most commonly used therapy was herbal medicine, followed by nutritional supplements and prayer.[26] Schernhammer et al. found that mostly women and older people favoured alternative medicine;[27] however, they highlight that people who are satisfied with conventional medicine were less inclined to use alternative medicine.

The women interviewed in Schernhammer's study were mainly in their sixties and many were using CAM, such as ointment of marigold[21] or curd cheese, to manage wound related symptoms.[27] CAM are often used in Western societies when people feel dissatisfied with the care they receive or want more involvement in helping their recovery. For nurses, the use of CAMs is rarely seen as part of their skill set and is discouraged in many conventional medicine approaches.[21] This means that CAM may need greater recognition in the care of patients with a MFW, as patients are using a variety of CAM methods to bring their wound under some control. Furthermore, clinicians need to develop strategies to ask about CAMs and be more open to women's experience of using such methods.

As the symptom experience intensifies, the quality of life for these women will deteriorate over time.[22,28–30] Eventually, the resources at the women's disposal will be insufficient to the challenge of the wound and the other problems they face. The capacity to cope and its link with depression are explanatory factors for negative changes in quality of life.[31] According to Lawton, it is through the body and the ways the body is presented in public, as to whether the women felt they were socially acceptable and able to go out in public.[32] Being able to be socially active and to present a normal social front was important for the women. In addition, the literature demonstrates that active coping strategies used by patients with cancer are generally associated with positive outcomes.[23,33]

Active coping could be encouraged by health professionals by helping women to develop effective strategies to manage and disguise the wound. However, due to the unpredictability and uncontrollability of the symptoms, the women were unsure if they were doing the right thing when they were treating the wound. Every woman had a strategy to bring the symptoms under control; therefore, various methods were adopted, some fairly successfully and others less so.

Pain was a major problem for many of the women and this was generally poorly managed. According to Maida et al. pain is the most common symptom of patients with a MFW.[34] Physical pain caused by MFWs is a complex phenomenon and has a serious impact on patient quality of life. This pain can be caused through the growing tumour, the pressure of the tumour on other body structures, swelling resulting from impaired capillary and lymphatic drainage, wound infection, exposure of dermal nerve endings, or due to dressing change.[34,35] The results of the current study demonstrated that the women were afraid to go to the doctor, as they were scared of becoming addicted to opioids. In their survey of 200 cancer patients, Paice et al. described that a majority of the patients (55.6%) reported that they were concerned of becoming addicted to pain medication.[36]

Implication for clinical practice

This study was conducted in Switzerland, so it must be taken in consideration that the interviews were conducted in the German part of Switzerland and reflect the coping strategies of nine Caucasian Swiss German-speaking women.

To support patients with a MFW a broader holistic and empathic approach to palliative wound care is needed. A holistic approach could include both traditional medicine and also the use of CAM, which was used by a number of the women. Little is said in the literature in relation to complementary medicine and how it is utilised by patients with MFWs. Clinicians may incorporate both, traditional medicine and complementary approaches to managing MFWs, but should also ask about these practices when assessing patients.

Use of CAM is an approach that helps patients to cope with their situation and may contribute to minimising suffering, as patients feel they are doing something positive to help themselves. According to Frank,[37] the problem of suffering is not how we know it, but how, as clinicians, we encounter it. One possible approach is with a broader holistic multidisciplinary assessment. This could overcome the variances in care, while allowing individual patient assessment and care planned around choices and needs of patients and their families.

A comprehensive care plan focusing on control of physical symptoms, such as pain, as well as psychological, social and spiritual issues, needs to be developed with patients and including their families. This means that clinicians not only require skills to assess a palliative wound in its physical state, but also need to understand, and have the communication skills to discuss, sensitive issues, such as the psychological impact and shame associated with the wound, as well as the implications for the family. Furthermore, management of such wounds is taking place within a context of uncertainty as the condition of the patient and the wound can change frequently. This means that good symptom control may be seen as a requirement for acknowledging hope that the patients and families could live normally.

Conclusion

The results demonstrate how difficult it was to live and cope with a MFW. Most of the women lost control over their body, due to the unpredictable and uncontrollable wound-related symptoms. Most of the women gave time and thought to coping with their condition, and to move on with their illness by building hope through developing close relationships and use of CAM. However, hiding and denying, such as going into isolation were also used to cope with the shame of having a malodorous wound that leaks excessively. Every woman had different strategies to cope and bring the symptoms under control. Women had to find their own resources and turned to CAM to find a way to bring the wound and their life under some sort of control and to live 'normally'. ■

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