Coping with an exulcerated breast carcinoma: an interpretive phenomenological study

Probst S., Arber A., Faithfull S

Abstract

Objective: Devising therapy strategies for the care of a malignant fungating wound (MFW) caused by cancer presents significant challenges to patients, their informal carers and health care professionals. The aim of this study is to explore how women living at home with a MFW can 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 was used. 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. Hiding and denying or going into isolation were the used coping strategies. Strategies that are integrated in a palliative, holistic, empathic approach is needed if taking care of a patient with a MFW.

Key words:

Malignant fungating wound, coping, experiences, palliative wound care
Introduction

Malignant fungating wounds (MFW) occur through locally advanced, metastatic or recurrent cancer that infiltrates the skin, disrupt it’s the skin’s integrity and causes a chronic wound that doesn’t heal. Closure of MFWs is usually impossible unless the malignant cells are treated by cancer therapy. Around 7% of patients with cancer develop such wounds\(^1\). However life expectancy is increasing for those with advanced cancer and there may be more people suffering from this distressing condition especially on the breast\(^2\). The frequently affected area to find a MFW is the breast\(^1\). The average life expectancy for people with a MFWs is short around six to twelve months, so this is a palliative situation\(^2\). Providing care for patients with a MFW is challenging as patients quality of life can be poor. Patients with MFW have many symptoms such as pain as well as the emotional aspects of dealing with an advanced cancer that is visible causing immense extreme physical and psychological distress\(^3,4\).

Background

Caring for a patient with a MFW is distressing and challenging due to the many physical and psychological demands from a cancer with a visible wound on the breast. Nurses have described caring for patients with MFW as an intense and unforgettable experience\(^5\). Patients with MFW who described delaying seeking medical help report a sense of shame and blame by putting the experience of a MFW to the side and ignoring the changes occurring to their breast until their situation became unmanageable\(^6\). MFWs create an immense challenge and burden for patients and their carers\(^7\). One of the worst aspects is the shame and embarrassment resulting from the unpleasant odour from the wound. Patients worry about leakage of exudate, experience of severe 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 participants to lose self-confidence and some kept the wound a secret from family members to avoid losing face. The many symptoms experienced by those with a MFW is linked to a poorer quality of life\(^9\). Among the issues frequently experienced were pain, malodour,
and psychological distress. It has to be mentioned that there is a lack of studies in MFWs and the existing studies have limits.

The study

Aim

The aim of the study is to explore the lived experience of women with a MFW of the breast and how they cope with the wound at home.

Method

The study is designed to explore women’s lived experience and how they make sense and cope with a major life experience associated with a visible cancer wound on the breast. The chosen methodology of phenomenology enabled the exploration of women’s lived experience with as faithful and close to that experience as possible. The researcher sought to avoid bringing in meanings which are not supported by the by the participants data. Phenomenology is interested in the taken-for-granted experiences and allows the researcher to explore the quality of that experience with participants. 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. 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.

Setting and sample

The study was conducted using a purposive sample of nine women recruited from three Cantons of Switzerland (Zurich, Bern and Baselland) from January until November 2009 (see Table 1). Initial contact was made in each Canton through a nurse or physician of either a cancer and/or beast care centre. Inclusion criteria for the study included living with a MFW of the breast for a least six months; aged over 40 years; fluent in German in written form and orally, to enable written informed consent and agreement to participate in an interview lasting about one-hour interview. The breast is the most common site for MFWs, with 49.3% of such wounds affecting the breast in Switzerland. The women interviewed were aged between 40 and 80 years. This age group is based on the survey of
Probst et al. (2009) in which 24% to 40% of the population 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: Firstly, 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 taken and was furnished with double quotes. Secondly, each transcript was read and re-read in an attempt to become immersed in the text, in order 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 that responded to the research question were marked. A process of phenomenological reduction was carried out where the phenomena are isolated and compared to phenomena that are already known. Thirdly, after re-reading the transcript, the marked thematic phenomena were isolated and abstracted. Finally each phenomenon was categorised. Categorisation has to make sense of the essential meanings of the phenomenon. In doing so, common phenomena 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.

Ethical considerations

Ethical permission for the study was gained through each Canton and the University of Surrey Ethics Committee and a favourable opinion was granted. Due to the highly vulnerable patient population all participants were granted enough time to consider whether they would participate in the study. The study information was given in written form in the participant information sheet as well as orally by the researcher enabling relatives to be involved in the decision-making process to be involved in the study. Written consent was completed before the interview started. Participants were advised
that they could withdraw from the study at any time without any implications for the care. One researcher (SP) carried out all the interviews. Eligible participants were contacted initially through either a nurse or a physician in each of the three cantons.

Results

Participants in the study describe the enormous challenges they face in living with a MFW and coping with the changed body image presented by the wound both physically and psychologically. All the women describe managing the wound-related problems such as excessive exudate, wound odour, wound pain, bleeding and itching. However managing these problems was not easy because they aroused revulsion and had a significant impact on mental health and well-being. They experienced severe shame and embarrassment in case anyone identified 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 disguising the wound odour and exudate and a variety of strategies were used to manage symptoms. Two categories that emerged from the data are: “Living with a MFW; and “Feeling different”, which will be discussed next.

Living with a MFW

Living with a MFW changed the women’s life completely. When the cancer became visible the women experienced severe distress. The wound related problems were often uncontrollable and unpredictable as they could appear at any time during the day or night despite the strategies used 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 some sort of control.

i) Coping with odour

Wound-related symptom odour was an issue that caused much distress. The women describe how they could smell the wound and they tried everything possible to palliative the wound so it did not smell. It was very difficult to mask the wound odour as the field notes of the first author illustrated: “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.”

Linda was very well aware that others would be able to smell the wound odour if she could:

“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.”

Malodour is a very distressing problem for Linda compounded by the fact that she knows that if she can smell her wound then others will too. Her only solution to coping with the odour was to wash the wound before entering into social interaction to avoid the shame and anguish associated with anyone knowing that she had this discrediting and shameful wound.

Like Linda, 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 describes the intensity of the work to bring the wound odour under some kind of control and order and this meant intensive time with the wound treating it every hour at times and it caused limitations on her time and many constrictions 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 used 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 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.

ii) Managing exudate

Another wound-related 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.”

This statement by Carmen shows the labour intensive management of the exudate. Further, it demonstrates how much distress the symptoms caused in losing the control over the boundaries of her body. Being distressed about leaking from the wound and being concerned this might be obvious to others is confirmed in the literature\textsuperscript{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 big focus of time spent on the wound every day and it also gave rise to a financial burden for the women, such as sourcing effective dressings. Uncertainty around whether the dressing was applied correctly, due to the constant leaking, had a big impact on emotional well-being and worry that their situation would be uncovered. Uncertainty and unpredictability during illness experiences such as cancer may result in anxiety, fear and distress\textsuperscript{16, 17}.

iii) Bleeding

Bleeding was another serious problem, which affected the daily life of 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. Yes, 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.”

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.”

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.

iv) 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 either the physician prescribes something for the pain or they get an over the counter painkiller from the pharmacist. On the other hand they were afraid to take a lot of pain killers in case they became addicted to them. The analgesia that was 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:

“Yes sometimes I nearly burst because of this terrible pain. Yes 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 waiting until it had gone. If you go to the doctor you get some painkillers that make you addicted to. That is why I wait until it had gone.”

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. (2010) pain has traditionally been under-treated with the most significant reason being that that pain is considered as a symptom of the primary illness, and the medical focus has been on treating the illness without addressing the associated pain. 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 lay people.

v) Itching

Itching was a problem for some of the women and was more difficult to manage. Christine and Livia specifically mentioned itching as a symptom they suffered from. Tension in the breast was a prelude to the fact in a few days’ time they would have to deal with itching. 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.”

This statement demonstrates the way Livia understood and listened to her body. Lundgren and Bolund (2007) report in their phenomenological study with 10 women that there was a connection between body and mind. Further Lundgren and Bolund demonstrate that the participants were striving towards positive thinking to help the body combat the cancer. With listening to her own body Livia is interpreting her symptoms. Here it is about subtle changes of feelings and small signs that only the women can feel and her cold compress sometimes helped 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 also found a remedy that offered some relief eg Marigold ointment. Marigold is described in the literature as an anti-inflammatory substance and has a cooling effect and relieved the itching for Christine.

Livia and Christine show their problem solving skills related to the wound and how successful they were in a number of respects in managing wound symptoms, sometimes using unconventional remedies. In addition, it demonstrates 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 and isolation.

“Feeling different”

All women emphasised that they tried to live a normal life even though they felt different. “Feeling different” means 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 malignant fungating wound. Some of the women retreated into isolation and others appeared to be in denial and hoping that they will wake up one morning and go back to normal. Charmaz (1997:23) states that the “assumption of recovery make 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.

i) Hiding and disguising the problem

Irene discusses how difficult it is 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, eh 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 and 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 not only has the MFW to worry about but also the visibility of her swollen arm due to lymphoedema. The women often felt guilty about suffering side effects of the cancer treatment not only the wound but also lymphoedema of her arm. Irene was unable to hide her changed body particularly her swollen arm, and had to wear loose clothing to disguise her swollen arm and she also had limited mobility. Further, 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.

ii) 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:

“So I would like to get back to normal, well yes back to normal. 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.”

Unlike some of the other participants Linda is still managing to leave the home and go out. She appears 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 home.
Some of the women who lived with family did not discuss the wound with their loved one or even show it to them and some family members did not know of the existence of the MJFW. One reason for this is 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 is acting to protect her family and avoid worrying them. So she pretends that there is no problem so she can continue a ‘normal’ life with her husband. 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. Later in the interview Carmen confides:

“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.”

This shows clearly that some women were keen to integrate their malignant fungating wound 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 despite being different.

iii) Finding support

Helen was able to tell her family about the MFW and this was a very supportive experience 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.”
This statement again shows to an impressive degree 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. Chillingly Helen contrasts the immense support she gets from her family in contrast to those at the hospital. Helen is identifying a shortfall in care and attention from the hospital where she is being treated. Helen’s daughter is helping her manage the wound and she is only having to treat it twice a day which means she spends less time on the wound and has a better quality of life than Carmen for example who needs 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 like the Atkins diet as they believed it made them feel better. Preparing a special diet was very time consuming and Christine describes reaching the limit of her capacity and had to employ somebody to enable her to continue with her CAM diet.

Discussion

Living in a body with a MFW that leaks and smells is a tremendous challenge for these women and leads to significant emotional, physical and social distress. The women are using trial and error methods to cope with their unpredictable and unbounded body that cannot contain fluids and odours and leads 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. (2009) who found that uncontrollable symptoms challenged hope and that building hope is significantly related to a better health-related outcomes. The use of CAM in cancer patients has increased over the last few decades. Yildirim
(2010) 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. The most commonly used therapy was herbal medicine followed by nutritional supplements and prayer. Schernhammer et al. (2009) found that mostly women and older people favoured alternative medicine. On the other hand Schernhammer et al. (2009) highlight that people who are satisfied with conventional medicine were less inclined to use alternative medicine. The women interviewed were mainly in their 60’s and many were using CAM such as ointment of marigold or curd cheese to manage wound related symptoms. CAM are often used in Western societies when people feel dissatisfied with the care they currently 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. 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.

It is fairly predictable that as the symptom experience intensifies that the quality of life for these women will deteriorate over time. 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 be able to cope and its link with depression are explanatory factors for negative changes in quality of life. According to Lawton (2000) 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. 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. Active coping could be encouraged by healthcare 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 and 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. (2009) pain is the most common symptom of patients with a MFW. Physical pain caused by MFWs is a complex phenomenon and has a serious impact on quality of life. This pain can be caused through the growing tumour, the pressure of the tumour on body structures, swelling resulting from impaired capillary and lymphatic drainage, wound infection, exposure of dermal nerve endings or due to the change of the dressings. The results of the current study demonstrate that the women were afraid to go to the doctor as they were scared of becoming addicted to opioids. Paice et al. (1998) describe in their survey of 200 cancer patients that a majority of the patients (55.6%) reported that they were concerned of becoming addicted to pain medication.

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. These wounds may cause not only physical harm but also psychological, social, and existential suffering. 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 the coping strategies 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. There was little reference to the resources available from health care services and from this data there is evidence that health care services did not provide the women with the strategies needed to manage such a complex wound and to manage pain. 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’.

This study was conducted in Switzerland. 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. A transferability of the findings in other context must be reassessed. There is a need for further research in the field of MFW especially related to coping.

**Implications for practice**

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 or base themselves on 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 (2001) the problem of suffering is not how we know it but how we clinicians encounter it. One possible approach is with a broader holistic multidisciplinary assessment. With a holistic multidisciplinary assessment and management clinicians 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 on the patient’s 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. A possible tool would be a care pathway individualised to the patient to enable recovery in the hospital or in an outpatient clinic to a level of wellbeing that is achievable and appropriate for each woman in partnership with her family. Through that care pathway the patients will have the opportunity to reflect on their unbounded body, discuss fears and develop expectations for the future.
References


