

Caring for a loved one with a malignant fungating wound

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Abstract

Purpose Caring for a loved one with a malignant fungating wound is very challenging and causes extreme physical and psychological distress. The aim of this study was to explore the experiences of carers who care for a loved one with a fungating breast wound.

Method To explore the lived experiences of carers, a methodological framework using Heideggerian hermeneutic phenomenology and semi-structured interviews was used. Seven carers were interviewed from January until November 2009.

Results Having to deal with a situation of a loved one with a visible cancer was hard for all the carers. The visibility of the cancer was one of the most shocking aspects to deal with from the perspective of the patient and the carer. The presence of the visible wound and a cancer at an advanced stage contributed to a change in the relationship and extreme suffering for both the patient and the carer. Despite many problems such as wound odour and copious discharge from the wound, which was difficult to control, carers did their best to help their loved one with the wound. Gradually, the wound became the centre of the patient and carer's life, and a great deal of time was spent trying to control the wound symptoms. All carers managed the wound on their own

without help and advice from health care practitioners. For all of them, it was a major burden and they felt isolated.

Conclusion This study contributes to an understanding that the care of women and their carers needs strategies that are integrated in palliative wound care that takes a holistic and empathic approach that responds to patients' and carers' psychosocial and emotional needs and a practical need for information to help carers assist in managing the wound-related symptoms.

Keywords Malignant fungating wound · Palliative wound care · Carer · Caregiver · Family · Spouse

Background and context

In the context of patients with a malignant fungating wound, carers are often the ones who support their loved one and help them manage a very complex and distressing wound. There is a recognition that families of patients with a malignant fungating wound are likely to experience extreme physical and psychological distress [1]. A malignant fungating wound originates as an infiltration of a tumour or a metastasis into the skin [2]. The fungation spreads out, and as a consequence, it evokes damage at the wound site through a combination of the loss of vascularity, proliferative growth and ulceration [3, 4]. Malignant fungating wounds have physiological and psychological consequences for the patient. The physiological consequences are intense pain, repugnant odour, bleeding, leaking exudate, itching and wound infections [5]. These physical changes result in changes in body image, depression and social isolation [5]. It is difficult to determine accurately the number of patients being treated for malignant fungating wounds. However, it is thought that over 5 % of patients with cancer develop a

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malignant fungating wound [6]. In Switzerland, the prevalence reported by nurses was 6.6 % [7]. The life expectancy for a person living with such a wound is very short with an average of 6–12 months survival [1].

In a phenomenological study, Alexander (2010) investigated the experiences of patients, nurses and one female carer [8]. She demonstrated that patients experienced a new way of being-in-the-world as a result of the malignant fungating wound, which changed the carer's life, and the wound became a full-time job for the carer due to the many demands of the wound. All those involved in the wound found the experience of malodour one of the most difficult things to deal with, and the distress associated with malodour affected the quality of life of the patient and the carer. In a review of the effect of malodour, caused by a malignant fungating wound, on patients' body image and quality of life, it is reported that the appearance and smell of a malignant fungating wound are more distressing for carers than for patients, and nurses also report feeling tainted by the smell after caring for patients with a malignant wound [8–10]. Furthermore, Piggan and Jones (2007) suggested in their study that the experiences of lay carers and families could facilitate the support for patients with a malignant fungating wound. However, Spichiger (2008) explored end-of-life care of ten terminally ill patients and ten carers in Switzerland and found that the burden of caring can cause serious disruption to carers' lives [11]. These changes do not happen immediately after their loved one gets diagnosed but occurs when the person becomes seriously ill or receives aggressive medical treatment [12]. In the context of malignant fungating wounds, there is a lack of knowledge about the experiences of carers who take care of a loved one who suffers from a malignant fungating wound. The aim of this study is to explore the experiences of carers who care for their loved one with a fungating breast wound.

Methodology and method

To explore the lived experiences of carers, an interpretative phenomenological approach according to Heidegger was

chosen. This approach enables the researcher to understand the phenomenon of caring from the perspective of those giving care including their individual and common experiences [9, 10]. The goal of interpretative phenomenology is to explore how human beings make sense of a major life experience in its own terms. This approach enables an exploration of the impact of the experience, the reflection on the experience and the flow of the life experience from the perspective of the participants in the research [13]. Using interpretive phenomenology enabled the researcher to explore in great detail the experiences of carers and to make sense of what had happened to carers without bracketing out the researcher's experience, which was reflected on in field notes, as the primary researcher is also a wound care specialist. The researcher's goal is the description of the phenomenon of caring, how the carers experience unfolds and the essences of what was involved when caring for a loved one with this condition [9, 10, 14].

A purposive sample of seven carers from three Cantons of Switzerland (Zurich, Bern and Baselland) was recruited for this study from January to November 2009 (see Table 1). Initial contact was made in each Canton through a nurse or physician. Carers were included if they are or were involved in the care of a loved one in the management of a fungating breast wound. Semi-structured interviews in carers' home settings were conducted. Interviews lasted between 55 and 95 min. The interview questions were open-ended and focused on the lived experiences of the carer. The first few participants were interviewed, and the data from these interviews were transcribed and an initial analysis was performed. Emerging phenomena from previous interviews were asked at the end of each interview in an open-ended way to see if there are any communalities or differences between the interviewees. Analysis of the interviews involved four steps, following the steps described by van Manen (1990). Firstly, a verbatim transcription of the interview is made. This was done by the researcher. In doing so, 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 does not exist in Standard German, the Swiss German word was taken and

Table 1 Information about the carers

Name	Age (years)	Highest educational level	Was the carer employed?	Relationship of loved one
Adam	67	University	No	Wife
Claudia	81	Secondary school	No	Daughter
Marco	78	Secondary school	No	Wife
Michael	79	Secondary school	No	Wife
Paula	41	University	No	Mother
Peter	76	University	No	Wife
Philipp	61	High school	Yes	Wife

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 two research questions. During this phase of the analysis, all phenomena that responded to the research question were marked. This is how phenomenological reduction occurs, that is, pure phenomena are isolated and compared to phenomena that are already known [15]. Thirdly, after re-reading the transcript, the marked thematic phenomena were isolated and abstracted [13]. For example: “Once I was in the office and it was lucky that I was wearing a jacket over my blouse. I suddenly noticed that my bra and blouse were full of blood”. The abstracted version was: “Wearing jacket over bloody blouse and bra in the office”. Fourthly, the final step involves analysing how each phenomenon was categorised. Categorisation has to make sense of the essential meanings of the phenomenon. In doing so, common phenomena such as challenges of the wound management from the various interviews were identified and collated. The organisation and formation of the data were done with the qualitative computer analysis program MAXqda2®. Ethical approval was granted by the ethical committee of each Canton and by the Research Ethics Committee at the university.

Results

Living with and taking care of a loved one who has a malignant fungating wound due to breast cancer interrupted and suspended the existing relationship between the carers and their loved one. The carers were mostly husbands, but one was a daughter who took care of her mother, and another was a mother who took care of her grown-up daughter. Since the breast wound of the loved one had ulceration, there were dramatic changes in relationships, and roles in the family and life were put on hold. The carers report adopting a caring and supportive role as the loved one entered into the world of a patient with advanced cancer with many symptoms and feelings of distress. The reported experiences of the carers are subdivided into three categories: “Challenge for a lay person managing the wound”, “Wound put stamp of the course on everyday life” and “Caring a great deal for her”.

Challenge for a lay person managing the wound

Management of the wound was a serious challenge for all carers and the first time they had to care for their loved one in such a way and they tried to do their best. All interviewees mentioned that they struggled with wound-related symptoms, mainly wound odour, profuse discharge followed by

bleeding. The biggest challenge that carers faced was attaching dressings to the wound and choosing the appropriate dressing. The complexity of care of a fungating wound was noted in all the interviews with carers. As Peter reported:

The nursing aspect of this wound cannot be underestimated. It is a big challenge for me as a layperson to treat this kind of wound. I use lots of imagination to treat it. Every time I treat it, it is different. It is challenging. ... Furthermore, I had to join dressings together that would fit on it. I have never sewed before. But what else can you do.

This statement shows the kind of challenge that carers like Peter had to face. Peter found the wound constantly changing and he had to be creative, use his imagination and behave like a nurse to treat it. Peter went as far as sewing dressings together in order to fit the dressing to the wound and in so doing try to improve the comfort of his loved one.

Attachment of the wound dressing was a common problem in part because of the location of the wound on the breast but significantly more due to skin irritation arising from adhesion of the dressing to the skin. Adam reported his experiences:

My problem was that I could not attach it. The good thing was that the dressing stuck at least a little bit to it. But you had to attach it a bit anyway. Yes, to attach the dressing I used an adhesive from my local grocery store. It worked well. And when I had treated everything I put a net over it and then I took the adhesive off again.

This statement shows what kind of skills the carers develop to manage the wound. Firstly, they had to manage the wound-related symptoms but then secondly were confronted with skin irritation due to the adhesion of either the dressings or the adhesive strip, but through trial and error, Adam was able find the necessary tools to treat the wound in a satisfactory manner. Symptoms such as leakage were attributed to the dressing material not corresponding to the wound condition.

Struggling with wound exudate was another challenge, which confronted Claudia and other carers. This means that they had to re-dress their loved one’s wound several times a day, and as a result, they could rarely leave the house and often became isolated. The problem of odour was another wound-related symptom that carers mentioned. However, wound odour had a repulsive effect on the carers as well on the patients and principally caused them nausea. Paula reported her experiences:

Well, it smelled quite strong. Everybody could notice it. But anyhow I dressed it as if nothing had happened; well I did not show any revulsion. ... That was very stressful but I wanted her to have a liveable life.

Pretending not to notice the actual situation was a major strategy employed by carers to make the best of things so that their loved one had a worthwhile life. By managing her revulsion, Paula is managing her emotions by keeping her non-verbal communication under control so as not to upset her mother.

Wound put a stamp on the course of everyday life

The eruption of the breast and the development of a malignant fungating wound changed the lives of the patients and their carers. Due to the intensity of the wound-related symptoms and problems, most of the time the carers put their lives on hold and adapted their lifestyle to the physical and psychological needs of their loved one and to the wound. The daily burden accelerated as the wound grew and wound-related symptoms increased. By and by, the wound became the focus of their lives and dominated daily living. Adam narrated his experiences:

We previously did a lot, like travelling, or went hiking. However, these trips decreased more and more with the progress of the wound. We were able to enjoy it if she experienced no physical exertion. During our walks, she never held me back. She always said I'll wait here for you. But I could not. I always stayed with her. Now we are not able to go out anymore. Well we can sit in our garden, the rest of the time we stay inside.

Peter's story is similar. He reported:

Usually we had lots of friends who came to visit us. But since my wife has this stinking thing we do not invite people any more. We do not want anybody to know about it. Also, we do not often leave the house as it is festering and stinking. Well, I have to dress it several times a day. And yes, so it is better to stay at home.

Both stories demonstrate how the breast cancer and its exulceration constrain the life of the patient and her carer, and there are feelings of shame related to having such a wound. The wound became a burden. Some carers withdrew from their social life because of the wound-related symptoms and the intensive labour required by the wound.

Caring a great deal for her

The diagnosis of breast cancer and the ulceration of the breast put the existing relationship between the carer and the patient in suspense. Most of the time, the carer adopts a supportive and caring role as the loved one has to deal with the illness and increasingly gets into the

role of a sick patient. This category highlights how the carers dealt with the new situation and with the changing relationship.

Most carers encounter difficulties in taking care of a wound. As Peter mentioned:

I have to say, it is easier to support somebody if the cancer is in an internal organ. In that case you have to see that the patient is taking the right pills. But here the thing is open. There I had to go over. I felt totally helpless, but I did not want her to notice it. I wanted to do it. Therefore I had to cut back my needs. ... Yes, it is the factor you want to do it for her and I wanted to help her so she could stay at home. Yes, just what needs is being there for her.

This statement shows how carers took upon themselves the burden of managing the wound by themselves despite feeling helpless. The pitiable sight of their loved one's body change shocked most of the carers. Due to the exulceration, the cancer became visible. This visibility was perceived as a dreadful experience. As Adam reported:

For me this wound was, and I believe this is the big difference from other cancer cases, was that it is visible. It was a sight to behold. It was not pleasant. That was the hardest thing. That is why this cancer was ever present. It is like plague. I had to look at it daily. It (the cancer) does not work invisibly. I have to repeat that in this sense this cancer accompanied me every day. This was very hard. I tried to forget it.

For Adam, once the cancer became visible through the wound, not only the loved one but also Adam was reminded of it when applying medications and dressings. This visibility meant that the carer could not avoid the illness of their loved one anymore. The illness became obvious and was shocking. They tried to explain how they experienced this visibility.

I really have to say, this wound nearly "ate" me. It looked so awful. I did not want to say that I had to bring myself to deal with it. Yes, I had to bite my tongue. I had to go through this situation. I have never ever in my life seen anything like this that was worse. And this had happened to my daughter. As dreadful as it was, it became my purpose in life.

This statement by Claudia demonstrates how dreadful the sight of such a wound could be and how taking care of the malignant fungating wound gave purpose to her life. Some of the feelings expressed by the carers are shared by the patient. However, this description is very vivid as though the carer is going through the same terrible situation as the patient.

Discussion

This study investigated the lived experiences of carers who took care of their loved one with a fungating breast wound where carers describe dealing with several emotions such as shock, disgust, nausea with the odour as well as the physical demands of managing symptoms and assisting with activities of daily living [16]. According to Alexander (2010) and Kristjanson and Aoun (2004), carers are responsible for making available most of the physical and emotional care of the loved one. They have to manage complex symptoms in the home and have to organise and coordinate health services [17]. In the current study, carers had to help with physically managing the wound particularly adapting dressing materials and securing the dressings in place. In addition, inaccurate recognition and management of problems may result in increasing the suffering of the loved one and creating more distress for carers [18]. Furthermore, being responsible for symptom management is described in the literature as an aspect of care that may create a considerable burden [19]. Caregiver burden refers to people's emotional response to the demands and changes of giving support to each other [20]. Generally, the more time-consuming and less flexible the care tasks are, the more burden is experienced by the carers [21, 22]. Alexander (2010) illustrates in her study which included one carer how the carer had to deal with emotional issues such as anger and frustration from her husband who could not accept that nothing more could be done about his wound causing tension in the relationship. The results of the current study underpin the findings of Nijboer et al. and Alexander that carrying out care is a time-consuming task and results in being tied to the home and social isolation and the need to manage emotions. Nijboer et al. describe that the more ill the loved one, the more demanding and extensive the care tasks required. This links to the findings that carers experience a worse quality of life when their loved one needs palliative care compared to those receiving curative treatment [23].

Malignant fungating wounds are the visible evidence of the advanced nature of disease. This visibility of the wound was a dreadful experience for all participants as the illness became visible, thereby and in addition, they were reminded of the illness every time they changed the dressings. Carers experienced revulsion towards the odour coming from the wound and other substances emitted from the unbounded body of the loved one, and the serious consequences of malodour are discussed in other studies and are described as sometimes worse than pain for patients [8]. The breakdown of the body surface through the fungating wound on the surface of the breast results in an 'unbounded body', which refers to the literal erosion of the patient's physical boundaries through the malignant wound [24]. This study demonstrates that carers like Peter and Claudia play an

important role in the context of malignant fungating wounds in that they manage and hide their emotions and revulsion towards the wound so that they are supportive to their loved one, and this maintains a close relationship between the couples and binds them together.

Through the intense labour of love when managing the physical aspects of the wound, the carer became a supportive carer. They support their loved ones around the clock. This meant that the carers had to cut back on their own needs such as taking care of their own chronic disease, social life or work. Having a life-limiting illness like a malignant fungating wound involves a series of progressive losses [25]. Rhodes et al. named the losses through illness by giving up social and leisure activities or even social roles. Rhodes et al.'s findings correspond to the experiences of the carers of the current study. Here, the care of the loved one cuts back on the time of the carers who then cut back on their own needs. However, they tried to do their best to achieve something good for their loved one through help with a demanding and all-consuming wound. 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 experiences of seven Caucasian Swiss German-speaking carers.

Conclusions and implications for practice

Due to increasing cancer survival rates, palliative care becomes a more and more important subject not only for health care professionals but also for the whole society. It was demonstrated what kind of burden the carers take over to care for a loved one with a malignant fungating wound. It was hard for them to manage the wound-related symptoms of their loved ones. Symptom experiences and quality of life were deteriorating over time for both the patient and the carer. Symptom work was physical and psychological and had palliative care consequences. The role of the carers shifted from a partner to a supportive carer. They had to acquire the tasks of palliative wound care to manage their loved ones' wound. The wound became a burden for the carers. Through the intense labour of coping with the wound, the carers gradually experience a worsening of their quality of life as the demands of the wound became overwhelming. Malignant fungating wounds are a visible sign of advanced cancer. This visibility of the wound was described as a dreadful experience for all the carers and caused psychosocial and emotional distress. In addition, carers were reminded of the illness every time they changed the dressings.

Carers are managing a very challenging situation with little support and practical information from health care professionals. Health care professionals need to offer

support to carers. For example, they need to include carers by providing information and advising them on how to manage the wound, how to choose appropriate dressings, where to source dressings from and how to secure the dressing to the breast without causing further problems and how to cope with odour and bleeding. Carers also need good emotional support as there is a risk of social isolation for some of the carers due to a lack of knowledge on how to manage odour and other problems that cause emotional distress and lead to social isolation. To improve the support of carers of those with a malignant fungating wound, a broader holistic and patient/carer-centred approach is needed. Taking a palliative wound care approach may help carers cope with practical as well as emotional concerns and navigate further help and support. The results of this study indicate that carers are unprepared for the task of supporting their loved one with this type of wound. Essentially, they learn to cope with the wound by giving time and by a system of trial and error. It is imperative that this group of carers receive adequate information about how to manage a fungating malignant wound, and this would enable a palliative wound care approach and offer carers a practical form of empathy.

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