An intense and unforgettable experience: the lived experience of malignant wounds from the perspectives of patients, caregivers and nurses

Susan J Alexander

ABSTRACT

Malignant wounds occur infrequently, but are typically described as devastating and overwhelming. However, there has been little formalised research, and the vast majority of existing malignant wound literature comprises reports of health care professionals from their management of the physical symptoms. Few studies have investigated the lived experience from the perspectives of patients and nurses and none have investigated the experiences of lay caregivers caring for a patient with a malignant wound. As a result, there has been little mention in existing literature of the non physical issues associated with malignant wounds or how they might be addressed. The purpose of this study was to address this gap in knowledge by investigating the lived experience of malignant wounds from the perspectives of those living it. In-depth interviews were conducted with patients, caregivers and nurses. The data were analysed thematically within a hermeneutic phenomenological methodology to show four themes: (i) malodour; (ii) new mode of being-in-the-world; (iii) still room for hope and (iv) enduring memories.

Key words: Fungating • Malignant wound • Malodour • Phenomenology • Psychosocial

INTRODUCTION

This study will provide an outline of the major findings arising from the investigation of the lived experience of malignant wounds from the perspectives of patients, caregivers and nurses. Malignant wounds have already been recognised within existing literature as a distressing experience. Their relentless progress is characterised by high levels of exudate, offensive malodour and rapid cutaneous destruction to the extent that patients describe themselves as ‘rotting away’. Typically signifying advanced and incurable disease, the prognosis for patients with malignant wounds is grave and therapeutic options are limited. As a result, malignant wounds rarely heal and patient care is usually provided within a palliative framework.

Key Points

- malignant wounds are devastating and have the ability to impact severely upon an individual’s quality of life
- there has been little previous research into the lived experience of malignant wounds
- the majority of existing literature concentrates on physical symptoms and their management, with little mention of non physical issues or how they might be addressed
- findings confirmed those in existing literature which identified malodour as the biggest issue for patients with malignant wounds
- nurses are also personally affected by the malodour of their patients. In this study, they described methods they adopted to lessen the impact of the malodour
- findings indicated that psychosocial issues were prevalent amongst those living the malignant wound experience
- if health care professionals are to provide care that is truly holistic, they need greater knowledge of psychosocial issues and how they might be addressed
- the intensity of the impact of malignant wounds was reflected in nurses’ ability to vividly remember details of patients with malignant wounds, even though the patient may have died many years previously
- nurses recognised that patients with malignant wounds were amongst the most distressing and complex cases for which they had provided care
- if HCP are to effectively address patients’ psychosocial issues, they should themselves be provided with support for their own psychosocial issues

Author: SJ Alexander, BHlth (Nursing) (Hons), Faculty of Sciences, Engineering & Health, CQ University, Locked Bag 3333, Bundaberg, Qld, Australia

Address for correspondence: SJ Alexander, BHlth (Nursing) (Hons), Faculty of Sciences, Engineering & Health, CQ University, Locked Bag 3333, Bundaberg, Qld, Australia

E-mail: s.alexander@cqu.edu.au
The existential distress associated with a terminal diagnosis is often devastating (1). However, when that distress is compounded by the dire symptoms that typically accompany a malignant wound, and patients’ remaining days are dominated by the demands of a wet and smelly wound, it is easy to understand why some patients wonder what they have performed to deserve such a cruel departure from life. Even though management of the physical symptoms of malignant wounds comprises the bulk of existing literature, these interventions are often unsuccessful, and patients are exposed to the risk of heightened psychosocial distress – an area about which we know surprisingly little. When psychosocial issues are mentioned in the literature, it is usually a case of mentioning the possibility of their existence before moving on to clinical management of the physical symptoms of the malignant wound. However, if health care professionals (HCP) are to provide care that is truly holistic, they must also understand the associated psychosocial issues and be capable of assisting patients to address them such that their ability to adversely affect the patient’s quality of life is reduced.

BACKGROUND AND LITERATURE REVIEW

The literature review conducted to determine the current state of malignant wound knowledge has been reported elsewhere (2–5). The review showed only two studies that investigated the lived experience of malignant wounds from the perspectives of patients (6,7) and another that investigated how malignant wounds affected the femininity, sexuality and daily life of female breast cancer patients (8). It was significant to note that psychosocial issues cited by patients in these studies vastly outnumbered the physical issues typically raised by HCP when discussing malignant wound management.

The current dearth of information has been recognised by a number of authors who have highlighted the need for further research into the lived experience of malignant wounds so that it might be better understood (9–11). Schulz et al. suggested that a greater understanding of the intensity and impact of malignant wounds upon the lives of patients would be an extremely valuable addition to existing literature (12). Although studying the impact of malignant wounds upon nurses, Wilkes et al. (13) acknowledged the need for patients’ stories to be told as well.

The study by Wilkes et al. (13) was the only one that specifically investigated the lived experiences of nurses caring for patients with malignant wounds. Nurses described malignant wounds as being difficult to manage, frequently personally distressing and often leading to feelings of guilt or inadequacy if they had not been able to manage the wound in a manner they considered to be acceptable. They were particularly affected when caring for somebody of their own, or their parents’, age or when young children were involved. They described dealing with their own psychosocial issues through peer support, debriefing and counselling (13).

Other studies did describe the management of malignant wounds as challenging for nurses but did not describe the experience in detail (14–16). A review by Palsson et al. (17) of nurses’ experiences of caring for patients in the home was significant because the only specific cancer condition identified as ‘especially trying’ (p. 68) was malignant wounds.

One cohort whose experiences of malignant wounds have been totally overlooked is the lay caregivers. Their mention in the literature to date has been confined to recognition that families of patients with malignant wounds are also likely to experience extreme physical and psychological distress (18,19). Young (20) also noted that the appearance of malignant wounds may be more distressing for caregivers than for patients who were usually more distressed by the meaning of the wound and its impact upon their lives. Given that the family is increasingly being recognised as the unit of care in palliative care (21), there is also an evident need for caregiver experiences to be investigated. This deficiency in the literature has also been recognised by Piggin and Jones (6) who suggested that phenomenological studies exploring the lived experiences of family and lay caregivers might facilitate the provision of supportive care of patients with malignant wounds.

What have been recognised in the literature are the effects of caregiving in general. They include high levels of ‘burnout’ amongst caregivers; their higher levels of morbidity and the propensity for their suffering and stress
to be even greater than the person for whom they are caring (22,23). Although it is reasonable to assume that these effects would also apply to those caring for a loved one with a malignant wound, it might also be reasonable to assume that they would be even worse as the caregiver, already burdened with their own physical and psychosocial issues, is required to simultaneously cope with the offensive smell and constantly soiled clothing, bedding and sodden and smelly dressings often associated with malignant wounds.

Thus, the challenge for HCP wishing to provide holistic care for their patients with malignant wounds is to recognise the existence of issues across all domains of the patient’s existence, rather than just the physical domain which has been the focus of contemporary literature. By presenting the totality of the experience from the perspective of those living it, the findings from this study can help clinicians to gain a greater understanding and to develop interventions that will address all of the issues of patients with malignant wounds.

METHODS

Hermeneutic phenomenology was selected as the appropriate methodology for this study because of its recognition as an ideal vehicle for the investigation of lived experiences. More than just describing what happened, phenomenology investigates what the experience was like for those experiencing it (24,25). It is particularly valued by researchers investigating the experience of ill health. The hermeneutic form of phenomenology expands upon the descriptions offered within the descriptive form by also interpreting the lived experiences to explicate the meaning embedded within them (25). Because of its ability to show otherwise concealed meanings, hermeneutic phenomenology has been described as ‘the art of understanding’ (26) which is an appropriate attribute for a project with the objective of understanding a specific human experience.

Unstructured, open-ended interviews were selected as the most appropriate method of data collection because of the sensitive nature of the topic and the exploratory nature of the study. Such interviews are often referred to as narrative interviews because they follow the format of inviting the participant to tell their story of the experience of interest.

Ethical approval for this study was received from the Human Research Ethics Committees (HREC) of CQ University and the three health agencies through which participants were recruited. Informed consent packages were provided to staff at each health agency who were requested to refer eligible persons to the researcher. Sampling was purposive as eligibility to participate was restricted to people who were English-speaking, cognitively competent adults who either had a malignant wound or had provided care for a patient with a malignant wound. Interviews were arranged at a time and location of the participant’s choosing. Pseudonyms have been used for each participant. Prior to the commencement of each interview, the interviewer reviewed the contents of the informed consent package with the participant and obtained their informed consent to proceed with the interview. All interviews were conducted and transcribed verbatim by the researcher. The interviews were audio-recorded, with the exception of Gwen (patient) who expressed concern about how her information might be used in future. In this instance, shorthand notes were written during the interview and copious notes of all that had transpired were written after the interview.

In view of the sensitive nature of the research question, a workshop on research amongst vulnerable populations was attended by the researcher prior to conducting any interviews. She also reviewed the literature on the ethics and recommended methods for conducting sensitive research. Extra precautions were also adopted during the interviews. For example, at the commencement of interviews in the patient cohort, the researcher ascertained from participants their understanding of their illness as a guide to the terminology to be used and matters that might be discussed. Willingness to continue was ascertained before and during the interviews. At the conclusion of interviews, the interviewer checked again that participants were not experiencing any discomfort. Despite the sensitive nature of the research question, no participant expressed any discomfort or requested that certain matters were not to be discussed. In fact, almost every participant expressed appreciation for the opportunity to discuss matters that few people had been willing to listen to previously.

In spite of the wealth of evidence indicating that discussing sensitive topics is not only
Table 1  Patient demographics

<table>
<thead>
<tr>
<th>Patient name</th>
<th>Gender</th>
<th>Age</th>
<th>Site of malignant wound</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gerry</td>
<td>M</td>
<td>87</td>
<td>Left face/scalp</td>
</tr>
<tr>
<td>Gwen</td>
<td>F</td>
<td>≈70</td>
<td>Right breast</td>
</tr>
<tr>
<td>Jemima</td>
<td>F</td>
<td>56</td>
<td>Right breast</td>
</tr>
</tbody>
</table>

non maleficent but might actually be of benefit, difficulties were experienced in recruiting participants into both the patient and caregiver cohorts. Rather than allowing potential participants to decide for themselves, gatekeeper HCP overlooked patients’ rights to autonomy and unilaterally decided not to refer patients because of the sensitive nature of the topic to be discussed. Ultimately, only three patients were referred. The demographics of the participants are provided in Tables 1, 2 and 3.

Thematic analysis of the data fostered the emergence of themes that reflected the ‘flavour’ or ‘essence’ of experiences narrated by participants. Together, these themes illustrated the experience as a whole. The analysis occurred within a hermeneutic circle – a metaphor used to describe the dialectic movement between the parts and the whole of the research, both of which changed and influenced each other as understanding developed (24).

While listening to the interviews, the researcher identified codes that would inform the development of themes and sub-themes. In moving from the parts to the whole, the codes were grouped into sub-themes which, in turn, were grouped into overall themes that illustrated the lived experience of malignant wounds. In this way, as the researcher moved between the parts and the whole within the hermeneutic circle, themes emerged that captured the nature of the experience and facilitated a growing understanding;

FINDINGS AND DISCUSSION
Across the three cohorts, it was obvious that malignant wounds had the propensity to impact enormously upon the lives of those affected by them. Patients and caregivers described living lives dominated by the demands of the malignant wound; lives that had been violently transformed as their previous, familiar existences were suddenly and irrevocably replaced by the new, unfamiliar and unwelcome existence. Although nurses typically did not experience the impact with the same intensity as patients and caregivers, they still described malignant wounds as ‘extraordinarily impactful’, ‘confronting’ and ‘emotionally draining’. This propensity to impact significantly upon the lives of those affected facilitated the development of an overarching theme of ‘Malignant wounds – an intense and unforgettable experience’. Below the overarching theme, the sub-themes were grouped into themes that encompassed the essence of the experience for patients, caregivers and nurses:

Table 2  Caregiver demographics

<table>
<thead>
<tr>
<th>Caregiver name</th>
<th>Gender</th>
<th>Age</th>
<th>Circumstances of care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lucy</td>
<td>F</td>
<td>≈70</td>
<td>Caring for her husband for 2 years</td>
</tr>
</tbody>
</table>

Table 3  Nurse demographics

<table>
<thead>
<tr>
<th>Nurse name</th>
<th>Gender</th>
<th>Age</th>
<th>Hospital/community</th>
</tr>
</thead>
<tbody>
<tr>
<td>Janice</td>
<td>F</td>
<td>39</td>
<td>H</td>
</tr>
<tr>
<td>Marion</td>
<td>F</td>
<td>≈50</td>
<td>H</td>
</tr>
<tr>
<td>Barb</td>
<td>F</td>
<td>≈50</td>
<td>H</td>
</tr>
<tr>
<td>Loretta</td>
<td>F</td>
<td>≈50</td>
<td>H</td>
</tr>
<tr>
<td>Linda</td>
<td>F</td>
<td>≈24</td>
<td>C</td>
</tr>
<tr>
<td>Roxanne</td>
<td>F</td>
<td>≈55</td>
<td>H</td>
</tr>
<tr>
<td>Mandy</td>
<td>F</td>
<td>≈50</td>
<td>H</td>
</tr>
<tr>
<td>Abby</td>
<td>F</td>
<td>≈50</td>
<td>C</td>
</tr>
<tr>
<td>Leanne</td>
<td>F</td>
<td>≈50</td>
<td>C</td>
</tr>
<tr>
<td>Cindy</td>
<td>F</td>
<td>≈40</td>
<td>C</td>
</tr>
<tr>
<td>Megan</td>
<td>F</td>
<td>≈40</td>
<td>C</td>
</tr>
<tr>
<td>Celia</td>
<td>F</td>
<td>≈45</td>
<td>C</td>
</tr>
<tr>
<td>Diane</td>
<td>F</td>
<td>≈45</td>
<td>C</td>
</tr>
<tr>
<td>Lynnette</td>
<td>F</td>
<td>≈50</td>
<td>C</td>
</tr>
</tbody>
</table>

Malodour
One of the few similarities between this study and existing malignant wound literature was the finding that malodour was the worst aspect of malignant wounds, capable of seriously eroding the quality of life of patients and those caring for them (15,20,27–32). One of the patients in this study (Jemima) highlighted her malodour-related distress when she raised the topic early in the interview, returned to it several times during the interview, and included it in her concluding remarks. She reported experiencing severe and unrelenting pain in the past, but even that level of discomfort was
An intense and unforgettable experience

eclipsed by the distress she experienced as a result of the offensive malodour emanating from her own body. To her, it was the ‘biggest thing’:

‘... it’s not that it’s causing me pain, discomfort, blah, blah, you can live with things like that. It’s definitely, definitely the consciousness and the smell ... the fact that everyone associates it like bad hygiene ... that is predominantly I guess my, my biggest thing’.

Malodour was also an issue for the caregiver:

‘The odour was terrible. It was terrible ... As soon as you walked into the room, you could smell it.’

In existing literature, nurses typically discussed the effect of malodour upon their patients, rather than themselves. At times, nurses in this study adopted a similar approach as they described the malodour associated with malignant wounds as being the ‘biggest thing’. They recognised it as one of the ‘main problems’ of malignant wounds and typically described it in terms of ‘rotting flesh’:

‘... it was putrid, absolutely putrid, this smell would just knock the socks off you and it was just rotting flesh ...’ (Abby).

What was unique to this study, however, were the nurses’ descriptions of the physical impact of the malodour upon themselves. They discussed altering their breathing patterns in an attempt to avoid breathing in the noxious malodour and cognised that it clung to their clothing and bodies, reminding some nurses of the patient long after the nurse had finished her shift:

‘... typical fungating smell of the wound and you, walk out of someone’s house and you think, you know, it’s like cigarette smoke. You think you go to the next house and people can smell it. It’s got like that ___ that smell of death to it ... it gets up your nostrils and basically in the pores of your skin ...’ (Linda).

Nurses discussed the methods they used to avoid others being able to detect the malodour after they had visited patients with malignant wounds. They described taking a change of uniform or leaving such patients to the end of their shift. Even so, there were times when others were affected by the lingering malodour:

‘... my husband came over to say, to say “hello” and I just, I can remember him reeling back as I opened the car door and he just said “oh”’ (Celia).

Nurses also discussed the methods they used to reduce the impact of the malodour upon themselves. They described scrubbing themselves, their clothing and their vehicles in an attempt to remove the malodour:

‘... as soon as I got home every day, you’d have to take everything off, wash everything in Napisan, shampoo and had to, you know, keep ... all the car seats sprayed because the odour was just horrendous’ (Celia).

Malodour was the only theme in this study that aligned with existing literature. That the remainder of the themes are all new is probably related to the fact that this study was one of the few that has investigated the totality of the lived experience of malignant wounds. It is also significant to note that the remaining themes fall within the psychosocial domain – an area not typically covered in existing literature.

**New mode of being-in-the-world**

Apparent very early in the collection of data and its subsequent analysis was the extent of the impact of a malignant wound upon the lives of those living the experience. Patients and caregivers described the impact of a malignant wound upon their existence as being so intense that they were suddenly thrust into new relationships with themselves, with others and with the world within which they existed. This theme aligned somewhat with the studies by Piggin and Jones (11) and Lo *et al.* (7) in which patients described altered relationships with themselves and others.

Still reeling from the disintegration of everything they once held familiar, participants described the feeling as if they had little input into their new and unfamiliar existence. It was as if their lives were suddenly being dictated.
by the malignant wound and its demands. Such radical changes frequently resulted in feelings of loss, confusion, disbelief and distress as victims mourned their old, familiar mode of being-in-the-world. Although some attempted to come to terms with the new mode and its concomitant demands, such adaptations generally take time—a commodity that was typically in short supply for the patients with malignant wounds. Even though nurses generally indicated a lesser impact than that experienced by patients and caregivers, they still described effects that suggested that their being-in-the-world had been, and was continuing to be, affected by the malignant wounds of their patients.

It is beyond the scope of this study to discuss the concept of being-in-the-world in depth. Serving as a brief overview, the concept can be described as the way in which people exist, interact with, and are connected to, the world in which they live (33). As such, the being-in-the-world of every individual represents the totality of their existence, incorporating the physical, psychosocial and spiritual domains.

Patients in this study discussed the ways in which the malignant wound had impacted upon their being-in-the-world. All three recognised the wound as signifying the end of their lives. They also expressed their consternation at the myriad unpleasant symptoms that characterised the wound and left them feeling fatigued and no longer able to recognise their previously independent, self-supporting and cognitively alert selves. They described experiencing shame, embarrassment, frustration, anger, fear, anxiety and depression. One patient described the shame he experienced when his facial malignant wound became infested with maggots.

‘... got up many times through the night of course. I never got much sleep ... up and down for him all the time ... You’d no sooner clean him up and, then, you’d have to clean him again, wash all the clothes, you know, I don’t know how much washing I did those days. Terrible ... showering him all the time, then helping him to dress him and, then doing his, um, dressings all the time, it was a full time job ...’

Despite the enormity of her input, however, Lucy still believes at times that she had let her husband down because she had not been able to do more for him.

Like the nurses in Palsson et al. (17), nurses in this study cited caring for patients with malignant wounds as being amongst the most complex and traumatic cases they had managed:

‘Right up there, near the top . . .’ (Barb).

The emotional impact was often the greatest, particularly when the patients’ social circumstances added to the poignancy:

‘... that was very devastating, very devastating ... that one, that one was devastating to us. The day we found out what had happened, I don’t think there was a dry eye ... we’re only human’ (Mandy).

‘... I guess the fact that her, her age and the two small children and, um, yeah, it was the whole situation was just ... pretty um, just generally extremely upsetting, really, really, upsetting . . .’ (Celia).

In some instances, body parts fell away while the nurses were dressing the malignant wound. Not surprisingly, they found these instances to be particularly traumatic. Other aspects they found stressful included the need to hold difficult conversations with patients, particularly those related to the patient’s terminality or the possibility of an arterial haemorrhage:

‘It’s draining. I find that exhausting ... my heart’s in my throat when I’m having a conversation which is so confronting ... it’s awful’ (Barb).
Nurses described experiencing hopelessness, helplessness, frustration, inadequacy, sadness, guilt and even anger because they were not able to care for their patients with malignant wounds in what they considered to be a suitable manner.

The ability of malignant wounds to impact upon nurses was shown by a very experienced nurse who was so affected by the malignant wound of her patient that she perceived the development of physical symptoms of her own. She was so concerned about the possibility of developing a malignant wound herself that she frequently consulted her doctor to seek reassurance that she was not about to develop a wound.

Still room for hope
Although hope is recognised as an important part of human life, often playing the part of a coping strategy for people experiencing suffering or trauma, there has been scant coverage of its influence on those living the experience of malignant wounds. Comments by patients in this study confirmed its importance as they hoped for a peaceful and pain-free death or maintained the hope that a cure might be found.

One unexpected finding was the lack of understanding of the concept of hope and its operationalisation. The resultant misunderstanding often manifested in ineffective communication between patients and HCP. In the majority of cases, because HCP understood the value of hope, they attempted to foster it in their patients. At the same time, because they also recognised the inappropriateness of false hope, they experienced tension as they tried to find a balance between the two poles. There were some instances, however, where HCP appeared certain that their view was the correct one – a certainty that rendered them less willing to listen to the view of the patient. One such area where the divergence between the views of HCP and the hopes of patients was particularly noticeable was in the concept of a ‘good death’:

‘We were wanting her to spend quality time with her children but she was out trying to get these alternative therapies happening, right to the very last minute …’ (Diane).

‘… it’s about time you [the patient] start to face and accept … you wanted to prepare, start preparing her — but she … just wouldn’t have it …’ (Celia).

Although nurses stated that they were trying to help the patient, it appeared that the spectrum within which such help was available was somewhat restricted at times and determined by the nurse. Contemporary palliative care recognises the importance of not forcing patients to adopt pre-determined dying trajectories and accepting, instead, their need to progress in their own way. Even so, the phenomenon of HCP expecting patients to comply with a HCP-defined model of a good death has been reported previously (34–36).

Yet to be investigated is whether the nurses in this study typically responded in this manner or whether the impact of the malignant wound was so intense that it altered their usual mode of practice.

The caregiver described being in the role of mediator between two opposing views. She accepted the HCP prognosis as realistic but still wanted to foster hope in her husband. Unfortunately, his adamant refusal to accept that a cure was not possible meant that there was no common ground where a compromise between the two views might be developed and tension became a frequent characteristic of their relationship:

‘He was always very angry with everybody because he thought that the doctors weren’t doing anything to help him … he used to get really angry with me … he just couldn’t ever get through his head why there was nothing that they could do for him … he thought there must have been something they could do …’ (Lucy).

Nurses also experienced tension as they attempted to maintain what they considered to be a realistic outlook while still fostering hope in their patients. They tried to remain positive for the sake of the patient and family but found that approach to be emotionally draining:

‘It’s really hard even for the staff to go out … you’ve got to keep a bright face … and be positive for the family and it takes a toll on them [the nurses]’ (Leanne).
An intense and unforgettable experience

Enduring memories
One of the findings of this study that was particularly significant, yet not recognised anywhere else to date, was the propensity for the experience of caring for somebody with a malignant wound to leave the carers with vivid memories of the experience. What was also notable was the ease with which these memories were triggered and their enduring nature, sometimes over many years. Frequently accompanying such memories were the emotions (typically negative) that nurses had experienced while caring for a patient with a malignant wound. Indeed, the unforgettable nature of malignant wounds was highlighted in the overarching theme for this study which recognised them as an intense and unforgettable experience. As a result, it is a central argument of this study that the impact of a malignant wound is so intense that it becomes an unforgettable experience.

The caregiver in this study was emphatic that she would ‘never, never forget that terrible, terrible wound’. She described how her memories were triggered on a daily basis because she was still living in the home she had shared with Bill until his death. Although the malignant wound always seemed to be in her thoughts anyway, these triggers intensified her memories and she found herself ruminating over the wound several times each day. Lucy tried to redirect her thoughts but was not always successful, particularly at night when there was little else to distract her:

‘I often sort of lie in bed of a night and think it sort of goes all through my mind all the time. How, what he was like and how he changed . . .’ (Lucy).

Every one of the 14 nurses interviewed for this study remarked upon their ability to clearly remember the details of patients with malignant wounds for whom they had provided care:

‘This other lady we had who I’ll never forget . . .’ (Abby).

‘The one that sticks in my mind the most was a very young man . . . who refused to let his family into the room to see him . . .’ (Mandy).

‘. . . we easily recall from our entire career that were incredibly complex and stayed with us . . . I recall that with such vividness . . .’ (Loretta).

The lengthy periods over which some of the nurses’ memories had endured were clearly evident:

‘. . . this was probably in 94, 95, so I’m not talking last week and I can, I can still remember what she looked like, I can still remember what her breast looked like, and I can still remember the smell . . .’ (Lynette).

‘. . . probably about twelve years ago . . . I’ve never forgotten her and I don’t think I ever will forget her and the sadness . . .’ (Loretta).

‘. . . ten, twenty years later, we can still recall with absolute clarity . . . they are the sort of things that don’t, they don’t fade . . . I will never forget their faces, their names, the circumstances of the situation, doesn’t matter how long it is’ (Barb).

‘. . . this lady, you know, she stands out in my mind because her wound was particularly horrible’ (Marion).

Marion did not specify the period of time over which she had retained this memory. However, she did state that she had nursed the patient early in a nursing career spanning over 35 years.

Nurses did discuss the strategies they had adopted to cope with the enduring memories. The value of formal counselling services was recognised but it was also acknowledged that such services had only become readily available over the last few years. Nurses believed that such support assisted them in avoiding disturbing memories and in dealing with the memories if they were recalled.

CONCLUSION
This study was one of only four to specifically investigate the lived experience of malignant wounds. However, it was the first to do so from the perspectives of patients, caregivers and nurses. A similarity of all these studies was the predominance of psychosocial issues –
HCP will be affected as well. Patients as it is likely that lay caregivers and malignant wounds is not the sole province of more, this study has shown that the impact of these themes supported the overarching theme arising from this project: that malignant wounds are an intense and unforgettable experience. Furthermore, this study has shown that the impact of malignant wounds is not the sole province of patients as it is likely that lay caregivers and HCP will be affected as well.

REFERENCES


