

Psychological profile of patients with neglected malignant wounds: a qualitative exploratory study

Neglected malignant ulcerating tumours often result from failure to seek medical attention, even when the advancing tumour is visible to the patient and their friends and families. Although the appropriate wound treatment procedures are the same as for non-neglected malignant wounds, clinicians must take such neglect into account when planning the patient's care. Over a two-year period, 25 patients at the National Cancer Centre Wound Care Unit in Paris were identified as presenting with a neglected tumour; 18 of these agreed to participate in a structured interview with a psycho-oncologist for an evaluation of their neglect behaviour. Initial results demonstrate a frequent, but not systematic, presence of a wide range of psychopathological disorders

keywords cancer; malignant fungating wound; neglected cancer; psycho-oncology; psychopathology

As a team of specialist wound-care nurses and psycho-oncologists, our clinical practice at the Institut Curie sometimes brings us into contact with patients who have 'neglected' tumours. These wounds are defined as locally advanced ulcerating tumours that result from the patient's failure to seek medical attention, even though the wound is visible to both themselves and their friends and families. Such cases contrast with the common conception of cancer as an insidious disease that evolves over many years without obvious or visible symptoms. The reasons why these patients refrain from seeking medical attention, and then finally decide to do so, are poorly understood.

Malignant wounds appear when tumour cells infiltrate skin tissue or blood and/or lymph vessels. They can occur in a wide variety of forms (as fistulas, or as deep cavity and fungating wounds, or as superficial but extensive wounds) and can be life-threatening, either directly through haemorrhage or septicæmia, or through a more general progression of the disease. As they develop, these wounds may cause high levels of exudation, malodour, pain or even bleeding (Fig 1).

In our clinical experience, we have found that it is

often only when malodour becomes intolerable,¹ (**Wilson**) or when the wound starts to bleed that the patient finally seeks medical attention, perhaps because of fear of death, a feeling of losing control, or social exclusion or isolation. Feelings of distress and guilt are also frequently reported.² (**froman-**

tin) When a patient arrives at the oncology clinic with an untreated wound, the encounter can be disturbing for both staff and patient. Patients may become insecure because they feel judged. Indeed, practitioners often react with feelings of discomfort or rejection, and this can cause the patient to remain non-concordant with care recommendations (**reference?**).

We therefore conducted a preliminary qualitative study to improve our understanding of the issues involved, and determine whether a systematic psycho-oncological evaluation of these patients is feasible (**okay?**).

Background

The incidence of malignant ulcerating tumours resulting from patients neglecting to seek treatment is unknown. In 1983, Petreck et al. estimated the number of patients with a malignant wound in the

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Conflict of interest: none

absence of any previously confirmed diagnosis of cancer to be 13%.³ **<AQ: this author is not Petreck>** The figures relating to breast cancer, for which a number of countries have organised mass screening programmes that are both free and well publicised, are good examples: in the USA, locally advanced tumours are thought to represent 2–5% of all tumours identified during screening and as many as 30–50% of those diagnosed in some underprivileged population groups.⁴ **(Facione)**

Globally, the incidence of malignant wounds in breast cancer cases (not including cases of neglect) is estimated at 2–5%.⁵ **(lund-nielsen)** These skin lesions are found most frequently on the breast, followed by the head and neck, and around the genital area and the groin.⁶ **(dowsett)** In a study conducted in 2009 in Switzerland, it was found that 6.6% of patients with metastatic cancers were developing a malignant wound.⁷ **(probst)**

Local care and nursing care

In our clinical experience (okay?), the accuracy of the initial assessment may be impaired as a result of the type of dressing that the patient has been applying to the wound for months or even years. These can come in the form of cotton **<AQ Do you mean cotton wool or some other form of cotton?>**, sanitary towels and handkerchiefs, as well as the application of disinfectants or 'healing' ointments. The wound may be extremely contaminated, necrotic, malodorous or haemorrhagic (contact bleeding resulting from inappropriate care) and must be carefully washed and cleansed before assessment. In some cases, it may be preferable to delay descriptive evaluation and continue cleansing the wound repeatedly for 24 or 48 hours.

Wound management is the same as that for non-neglected malignant wounds, which are often treated during the palliative phase of the disease.⁶ **(dowsett)** However, **based on our clinical experience (okay?)** neglected wounds have a number of specific characteristics:

- The wound should not be considered as secondary to the disease or the treatment as it is the patient's primary reason for seeking medical advice. Careful attention, therefore, must be paid to monitoring the wound and dressing selection. Some patients present with mutilating wounds such as **spontaneous mastectomy <AQ, please can you explain what you mean by this>** associated with general conditions such as anaemia. In that context, wound care requests priorities evaluation **<AQ: not sure what you mean by this, do you mean evaluation should be prioritised?>** (e.g. presence of a vital risk **of what?**, pain, malnutrition)
- The patient might have carried out some form of self-treatment for a long time — for example, by performing debridement with scissors or fingernails,

applying antimicrobial solutions or other substances, such as clay and leaves from the beech tree, with greater or lesser attention to the common rules of hygiene. For many patients, daily life is centred around caring for the wound, so they feel they should play an active role in its management. While this attitude should be taken into account, it must be tempered or even curbed when necessary. Nevertheless, the wound care protocol should be initiated in cooperation with the patient even where this approach may lead to differences of opinion

- Patients may feel judged or apprehensive about showing their wound to anyone other than the nurse who is attending them. Care must be taken to avoid an exclusive relationship, which may have a prejudicial effect as local wound care in itself is insufficient and practitioners from other specialties (for example, surgeons, radiotherapists and oncologists) must be involved in order to ensure that all aspects of the patient's needs are met
- Many neglected malignant wounds are primary tumours, which respond well to anticancer therapies such as chemotherapy and radiotherapy, and may heal within a few months once the patient has accepted and responded to the suggested cancer treatment. More commonly, malignant wounds arise from secondary or recurrent cancer, and these are incurable or difficult to cure. For this reason, **Bird** states that malignant wound care is necessarily palliative⁸
- Many patients are reticent about agreeing to daily wound care being performed by a home nurse and prefer to continue caring for the wound themselves. When this option is possible and practical, the patient should be taught to care for the wound at home, and should attend hospital for regular follow-up visits. However, many patients will be relieved to hand over responsibility for their wound care to a nurse.

The psycho-oncological approach

To our knowledge, no previous study has assessed the psychological mechanisms involved in neglect behaviour or tried to describe the psychopathological profiles of patients who exhibit this behaviour. It is very difficult to obtain an evaluation of these patients because they often decline repeated invitations from nurses to meet a **mental health (okay?)** specialist. However, an insight can be gained from the literature on malignant fungating wounds, although even here the evidence mostly comprises case reports published in the nursing and palliative care literature.

A small number of authors have studied the consequences of malignant wounds on quality of life;^{5,9,10,11} **(lund-nielsen, grocott 2007, naylor, goode)** these have reported physical problems (pain, infection, malodour, exudation or bleeding) ►

as well as psychological issues (anxiety about other people's perception of their wound discharge and malodour, impaired body image and feelings of disgust, shame and depression) and social repercussions (difficulties dressing normally, feelings of shame, exclusion and avoidance of social contact).^{9,12} (piggin, grocott 2007) In addition, the loss of feeling physically attractive can have a big impact on people's intimate lives and sexuality.¹³ (lund-neilsen)

Goode is the only author to have indirectly referred to neglect behaviour by describing the tendency of patients with malignant wounds to self-treat and refuse help, either due to a fear of diagnosis or a feeling of shame.¹⁴

A more recent case-control study has identified a link between locally advanced tumours and fatalism and an unwillingness to attend for screening. Mohamed et al.¹⁵ compared 11 women with locally advanced breast cancer with the same number of control patients who had stage 1 or 2 breast cancer, using a semi-structured interview and a battery of questions that evaluated anxiety and depression, locus of control, life orientations (i.e. tendency to optimism or pessimism), suicidal tendencies, coping styles (relating specifically to their need for information) and their use of religion to deal with stress (author, I've checked against the original ref and have rewritten this sentence accordingly). An original feature of this study is the inclusion of the women's partners (five in the study group and eight in the control group), who were similarly assessed.

Results of the psychological tests showed no significant difference between the two groups (okay? I've taken this from abstract). However, locally advanced breast cancer was associated with non-observance of routine breast cancer screening, denial, fatalism and stated confidence in alternative therapies. In addition, the partners tended to be more passive about their wife's medical care, and were more fatalistic and prone to denial. This study, although based on a relatively small sample size, demonstrates the need to evaluate the psychological functioning of these women and their partners. Such assessment will also help to promote concordance with cancer screening practices.¹⁶ (Ramirez)

Method

This preliminary study was developed by the Institut Curie's psycho-oncology unit in collaboration with the wound care unit of our interdisciplinary cancer patient supportive care department. It is a qualitative, exploratory study conducted with two objectives in mind:

- To describe patient profiles and obtain descriptive information that will provide a better understanding of specific psychosocial and personality characteristics of this patient group

teristics of this patient group

- To evaluate the feasibility of a more structured protocol that would permit systematic psycho-oncological evaluation and care wherever necessary.

We developed a semi-structured interview, based on the joint work of a panel of experts who had extensive clinical experience with these patients: an oncologist, a surgeon, a specialist nurse, a psychologist and a psychiatrist.

We aimed to recruit all consecutive patients presenting at the wound care unit over a 2-year period with a neglected malignant fungating wound. Those who agreed to participate were referred by the wound care unit to the psycho-oncologist for evaluation. Patients were excluded if they refused to meet the psycho-oncologist or were seen just once by the wound care unit for a second opinion but not treated at Institut Curie.

Patients included were informed about the study and gave oral consent to participate <AQ did they know the results might be submitted for publication?>. We did not ask for ethics consent before undertaking this first exploratory study as our intention was to present the psycho-oncological evaluation as part of a global clinical approach. Knowing the vulnerability of the patient group, we wanted to make the study as informal as possible.

The interviews were conducted by two psycho-oncologists, a psychologist and a psychiatrist, depending on their availability. The aim was to obtain a description of the family and social context of patients with neglected tumours and, whenever possible, the reasons for this neglect and the links between these reasons and various psychopathological variables, such as personality disorders, family difficulties and bereavement.

The semi-structured interviews were designed to elicit the information outlined in Box 1. We considered that use of a formal, validated questionnaire would pose a barrier to recruitment. Therefore, rather than conducting a structured diagnostic interview, we gave each patient the opportunity to talk freely about the tumour's history and the psychological dimension of the disease. This explains why clinical features are presented here as symptoms rather than diagnoses of specific mental disorders. Only a more structured interview, based on the Diagnostic and Statistical Manual of Mental Disorders (DSM), would allow more precise diagnosis of psychiatric conditions and personality disorders. <Author, please check that we have interpreted this correctly - thank you>

Data collection and analysis

Over the period 2004–2006, 25 patients were identified as presenting a neglected tumour: 18 agreed to take part in a structured interview as part of the global assessment and evaluation of their neglect

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Box 1. Information gathered in the semi-structured interviews

Name/age
Reason for consultation
Past and recent medical history of cancer; and history of neglectful behaviour
Feelings relating to the neglected tumour (e.g. social life, intimacy)
Feelings associated with the situation
Type of self-care performed by the patient
Use of alternative therapy (have i interpreted this correctly?)
Health habits
Beliefs about the cancer
Coping mechanisms relating to the cancer and neglectful behaviour
Overall psychological functioning
Whether the patient was open with the practitioner: if not, why not?
Physical history
Psychopathological history - should this be psychological history?
Current use of psychotropic drugs
Psychiatric diagnosis
Symptoms of depression
Contribution of depression to the neglectful behaviour
Initial relationship with parents
Socioprofessional situation e.g. educational level, culture, financial situation
Social isolation; type of personal resources/coping mechanisms (okay?)
Symptomatic exploration: psychopathological symptoms, body image, femininity, sexuality, intimacy
Relationship to health professionals
Potential influence of health professionals on the neglectful behaviour
Reaction to the suggestion of a second interview

behaviour. Of the seven patients who were excluded, four were already known to a member of the psycho-oncology unit and three refused to take part in the interview.

Nine of the 18 patients included in the study presented secondary reasons for a psycho-oncology consultation: five had refused specific cancer treatment, three were labelled as having psychiatric problems (behavioural disorders, depression or delusions), and one patient had requested a psycho-oncology consultation. The remaining nine patients agreed to meet the psycho-oncologist for an evaluation in order to help the health-care professionals understand the history of their disease.

Results

The vast majority of participants were female (17/18) and had a diagnosis of breast cancer (16/18); one patient had ophthalmic cancer and one had skin cancer. Participants were aged 43–81 years (mean 62.5; median 62; SD 12.25). Nine patients were living with a spouse (six) or partner (three). Eight had two or more children and four had one child. Nine patients were working and six had retired.

The main clinical elements identified from our qualitative analysis were as follows.

- Nine patients said they found it difficult to touch the wound, explaining their personal intolerance to such local care (five said this originated from the time the fungating wound had first appeared and four as a result its local development). Only one patient reported physical pain due to the lesion. Four patients had performed their own wound care prior to presenting at the clinic, and this was considered to be 'appropriate' by the practitioner in two cases. Two patients who used alternative therapies presented with psychotic disorders accompanied by delusional activity
- Four patients were identified as neglecting personal hygiene, with one case of very severe neglect. Five were very attentive to their body image. The other nine patients did not present distinctive characteristics in relation to this issue
- Patients' subjective perception of their neglect behaviour was difficult to assess, even when it was explored indirectly and unobtrusively. There was a diversity of responses: one third presented anxiety disorders (six patients with severe death anxiety and one with generalised anxiety disorder); four refused to talk about their neglect; three expressed feelings of embarrassment or shame; presence of major personal problems concomitant with onset of the lesion **<AQ: you haven't indicated how many patients in this group>**; while one patient demonstrated fatalistic and resigned behaviour in relation to the cancer and risk of death. **Author, to check, these results aren't in Table 1, are they?**
- There was also a wide range of responses relating to the representation of cancer. It was possible to analyse the responses in only 11 cases **(but 15 giv- ▶**

en in Table 1): cancer was associated with the idea of death (four patients), psychogenic origin (two), and delusional ideas (one). In four cases, the cancer was associated with anxiety considered by the interviewer to be 'appropriate'. In one case, it was considered unimportant (**author have we interpreted this correctly?**)

- One third of respondents considered that they benefited from social support and stated that they were able to talk about their disease with their family and friends. Another third reported the absence of social support for various reasons: inability to talk about the disease once it had been hidden (three patients); real social isolation (one case); family conflict (one case); three patients did not report any objective reason. **Again, I can't relate these numbers to those in Table 1. Do you think it would be best to delete Table 1 as it doesn't seem to correlate with the text. What do you think?**

The interview was also intended to assess the psychological functioning and defence mechanisms of the interviewed patients:

- Half of the 18 patients presented psychotic mechanisms (denial and projection) and one third presented neurotic mechanisms (avoidance and control). Two patients exhibited defence strategies based on irrational, personal beliefs without manifesting any genuine delusions; the functioning of one patient was characterised by a collapse of self-image, impaired self-esteem and depressive features
- Four patients had a known psychopathological history: one with psychotic disorders, one with a major depressive disorder, and two with anxiety disorder
- The psycho-oncologist diagnosed a psychiatric condition in one third of cases: three patients presented psychotic disorders with current delusional features, and another three psychotic disorders (**correct?**) with personality disorders. Half presented depressive disorders: major depressive disorder (two), reactive depressive features (seven). These features followed a bereavement in four cases. In these nine patients, the depressive disorders appeared to have contributed, either directly or indirectly, to the engagement of or persistence in neglect behaviour. Only two of the 18 patients were found to have a psychiatric comorbidity: one presented a psychotic disorder with depressive mood; another had an associated depression and personality disorder
- Investigation of early parent-child relationships was also difficult and could only be performed in 10 of the 18 patients. These included one case of maternal neglect, one case of dependence on the mother, and one case of an intrusive mother
- Disruptions in the private sphere and impairments of body image could be examined in only 11 of the

Table 1. Key characteristics and clinical features of the sample (n=18)

Gender	17 female, 1 male
Socio-economic categories (n=18)	6 were retired 2 were not working 4 had a professional job 5 had a clerical/manual/non-professional job 1 unknown
Marital status (n=18)	6 married 6 divorced (3 had a partner) 6 single
Children (n=18)	8 have 2 children or more 4 have 1 child 6 have no children
Tumour site (n=18)	16 breast 1 ophthalmic 1 skin
Declared presence of pain (n=18)	1
Effect of wound on daily life (n=18)	9 stated it had no effect (AUTHOR CORRECT?) 5 said it had caused difficulties 4 switched from (AUTHOR CORRECT?) saying it had no effect to saying that it caused difficulties
Wound care (n=18)	14 had not performed any wound care prior to presenting at the clinic 2 had performed appropriate wound care 2 had performed inappropriate wound care
Cancer representations (n=15)	4 adapted fears (what do you mean by this?) 4 associated it with death 2 indicated it had a psychogenetic origin 1 had a delusional explanation for it 1 said it was 'unimportant' 3 had no representations
Social support (n=9)	6 reported social isolation 1 had a perception of loneliness 2 had a perception of both social support and loneliness
Psychological disorders (n=18 but 2 patients had 2 disorders)	5 any - do you mean none? 3 had both psychotic and delusional disorders (okay?) 3 had personality disorders 2 had a major depressive disorder 7 had reactive depressive features
Psychological disorders comorbidity (n=2)	1 psychotic disorder plus reactive depression 1 personality disorder plus reactive depression
Psychopathological history (n=9)	4 psychotics disorders 3 personality disorders 2 anxiety disorders
Psychological mechanisms	1 had impaired self-esteem
Comorbidity of social isolation with psychological disorders (n=7)	4 experienced social isolation plus depression 2 experienced social isolation plus psychotic disorders 1 experienced social isolation plus personality disorders

18 patients. Six reported problems in these areas (five patients presented difficulties in physical <AQ: OK?> intimacy due to the progress of the wound and one described body image disturbance)

- Problems affecting the relationship with practitioners were identified in half of the group, mainly in the form of distrust (seven) or opposition (two). Three patients said they had failed to seek medical treatment due to fear of health-care professionals
- Fourteen patients agreed to participate in another psycho-oncological interview. Of these, 10 attended at least one further interview.

Discussion

This exploratory study enabled us to identify the difficulties associated with conducting this type of research with patients with neglected tumours. Although the interviews were semi-structured, considerable clinical skills were required to conduct them, taking account of factors such as the difficulty experienced by patients in submitting to a detailed assessment of their history, **their denial of their referral by the wound care unit <AQ: do you mean their refusal to seek treatment prior to referral?>** and their unease when called on to examine the origins of their neglect behaviour. The interviewers frequently had to remind them that the main purpose of this exploratory project was the 'need to understand', while avoiding any expression of judgement. This is a particularly sensitive issue in such patients as they often find that practitioners adopt a 'moralising' attitude towards them, or perceive them to do so. It was also often difficult to persuade the patient to go beyond a purely factual account in order to reveal more affective and emotional dimensions.

This preliminary analysis reveals a frequent, but not systematic, presence of a wide range of psychopathological disorders. It should be noted that there was only a moderate frequency of these disorders within this population (one third exhibited psychotic disorders and personality disorders), whereas we had expected the majority would have them.

A major finding was that half of the patients attributed their neglect to depressive disorders and evoked their inability to look after themselves or envisage any form of treatment during this period of depression. One third also reported anxiety disorders that may have contributed to their neglect behaviour, especially in cases where they perceived practitioners as 'dangerous' and were unable to tolerate the idea of treatment.

With regards to defence mechanisms, one half of the patients appeared to exhibit archaic, psychotic mechanisms, while a third seemed to rely on neurotic mechanisms. The difficulty of accepting treatment may therefore be related more to the subject's mode of psychological functioning than to diagnos-

tic factors (**you mean diagnosis of psychopathological disorders?**).

The fact that the behaviour of most of the patients was not genuinely psychopathological in nature suggests that it may be necessary to reconsider the health-care trajectories followed by such subjects. In addition to the follow-up provided at the psychiatric and/or diagnostic level, it would also seem necessary to review the way the health care of these patients is organised as they are less likely than other patients to adhere to the 'standard' health-care trajectory. They therefore require a more complex organisation which, although it may sometimes lead to less successful therapeutic results (**why?**), will nevertheless ensure that care is administered equitably and will take full account of the ethical dimensions of health-care provision. **Briefly, in what way do you think this organisation would be more complex?**

Due to the patient sampling and lack of a control group, the study has a number of limitations. The small size of our sample, obtained in a single centre, does not allow for any clinical generalisation. Many studies have demonstrated a correlation between low socioeconomic status and inequalities of care. In our sample, there is no over-representation of patients from disadvantaged socioeconomic backgrounds, but there could be a bias of over-representation of those from high socioeconomic levels due to the location of the Institut Curie in the centre of Paris and its semi-private status.

It was not possible to undertake a structured psychiatric interview, or to administer psychopathological and personality disorder questionnaires. The information obtained through our informal approach therefore represents an important limitation.

Because these data were collected after a period of health neglect, they do not allow for determination of the extent to which the psychological factors contributed to the wound outcomes. Only a case-control study with a much larger multicentred sample will provide this information.

In addition, the absence of a comparison group of patients who had not neglected their wounds means that our data do not provide a context for understanding the extent to which psychopathological disorders are greater among patients who neglect their tumours. At this was the first step of our research, the priority was to assess the feasibility of such a study, but only a case-control group study design can answer these essential questions.

Implications and suggestions for future work

The study aimed to improve our knowledge and clinical understanding of patients with neglected malignant tumours. The next step will involve setting up a case-control study to compare women ►

with early breast cancer and those presenting with advanced breast cancer. By studying a uniform population and using a case-control design, it will be possible to make a more precise psychopathological assessment of neglect behaviour. This will help improve health care delivery to these patients, whose problems need to be addressed on an individual basis. A case-control study will also enable us to identify factors predisposing individuals to neglect behaviour. This might make it possible to identify these subjects at an earlier stage and to offer them appropriate health care designed to compensate for their neglect behaviour and limit any further harmful effects. ■