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Ousey, K.; Roberts, Deborah

Journal of Wound Care

DOI:

[10.12968/jowc.2016.25.8.438](https://doi.org/10.12968/jowc.2016.25.8.438)

Published: 13/08/2016

Peer reviewed version

[Cyswllt i'r cyhoeddiad / Link to publication](#)

Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):

Ousey, K., & Roberts, D. (2016). Exploring nurses' and patients' feelings of disgust associated with malodorous wounds: A rapid review. *Journal of Wound Care*, 25(8), 438-442.
<https://doi.org/10.12968/jowc.2016.25.8.438>

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Exploring nurses' and patients' feelings of disgust associated with malodorous wounds: a rapid review

Authors

Karen Ousey, PhD., Professor and Director for the Institute of Skin Integrity and Infection Prevention, University of Huddersfield, Queensgate, Huddersfield, UK. E mail: k.j.ousey@hud.ac.uk Tel: 01484473462

Deborah Roberts, PhD., Professor in Nurse Education and Clinical Learning, and Head of the research centre for the School of Social and Life Sciences. Glyndwr University. Plas Coch Campus Mold Road WREXHAM. LL11 2AW

Key Words

Disgust; malodour; psychosocial; rapid review; wounds

The authors have no declaration of interest.

Abstract

Objective:

To identify primary empirical research related specifically to feelings of disgust associated with malodorous chronic cutaneous wounds.

Method:

A rapid review of the literature using the key words disgust; wounds; malodour and psychosocial.

Results:

A total of 163 papers were retrieved with seven being included for the final review. Themes emanating from the review were malodour, health-care professionals coping with malodour and disgust. Malodour is a concern to patients, which can sometimes go unreported by nursing staff; although the reasons for this remain unclear. The coping mechanisms developed by nurses in response to 'disgusting' wounds requires further exploration in order for a fuller understanding of these mechanisms to be achieved. This review has identified that both health-care professionals and patients can become distressed at wound odours, yet there is little evidence that is available to guide people as to how to manage these feelings.

Conclusion:

Hard-to-heal or chronic cutaneous wounds, such as leg ulcers and diabetic foot ulcers, are an increasing global health-care issue. While some research has been undertaken to explore the psychological impact of living with a fungating carcinoma; much less has been written about the management and mitigation of feelings of disgust for patients and families living with a malodorous wound or how health-care professionals can effectively provide psychosocial care.

In 2009 Gottrup et al.[1] estimated that almost 1–1.5% of the population of the industrialised world suffered from non-healing wounds, accounting for 2–4% of health-care expenses. More recently, a retrospective cohort analysis of patient records from The Health Improvement Network (THIN) Database has been published to further identify the burden of wounds.² The remit of this study was limited to open external acute and chronic cutaneous wounds; with surgical wounds (healing within 4 weeks) being excluded. The sample equated to 2.2 million patients who matched the study protocol's inclusion and exclusion criteria, equivalent to 4.5% of the adult population, in the study year. In total, there were 730,000 recorded leg ulcers, equating to 1.5% of the adult population having one or more leg ulcers in the study year. Furthermore, an estimated 169,000 people had one or more diabetic foot ulcers (DFUs), equating to 5% of adult patients with diabetes. Those hard-to-heal wounds can be both costly to health-care providers and impact greatly on health-related quality of life (QoL) outcomes for patients. The psychological stress that can be associated with malodorous wounds and negative effect on wound healing has been identified,[3,4] with some tentative links established between exudate, and associated odour with depression and anxiety.[5] Malodorous leg ulcers have been reported to have a negative effect on patients' social lives,[6,7] leading to higher anxiety and depression scores, lower life satisfaction and altered body image [8]. Bland [9] reported that patients were often embarrassed about the smell of their leg ulcer and thus did not leave the house with this being aggravated by the fact that bandaging on the leg prevented regular showers being taken. Malodour has been reported to cause distress for patients exemplified through involuntary gagging, vomiting, decreased appetite, weight loss, social isolation and withdrawal [10].

Yet there is little empirical research that has investigated and explored how to alleviate and manage feelings of disgust for patients and families living with a malodorous wound. The concept of disgust should not be mistaken for distaste where distaste is less closely linked to the sensory properties of a stimuli: for example, you do not need to taste a cockroach to be disgusted by it [11]. Although originally the notion disgust was associated with the rejection of foods [12]. Of all emotions disgust has been identified as the most relevant to healthcare [13]. Muris et al [14] stated that disgust is a universal, negative emotion which concurs with the earlier findings of Izard and colleagues [15] stating that the response of disgust provides a protective function of avoidance and withdrawal from unpleasant situations that can include evading contact with those people who have a malodorous wound.

Methods

A systematic review has the potential to provide a robust, reliable, transparent, transferable and valid process of literature appraisal, that supports the application of evidence into practice and that

can subsequently influence policy development and innovations in care [16]. Whereas a rapid review allows for a form of knowledge synthesis in which components of the systematic review process are simplified or omitted to produce information in a timely manner [17]. A review was undertaken, searching the EMBASE, MEDLINE, PsycINFO, BNI and CINAHL databases using the following key words: disgust and wounds and malodour and psychosocial. Only papers written in English and those reporting research were included. No date limits were set. Literature reviews, case studies and comment papers were excluded. A total of 163 papers were retrieved. Following review of the abstracts, seven papers were included for the review [18,19,5,20–23]. We excluded 156 papers as they were single case studies, opinion papers or literature reviews. The papers were reviewed independently by KO and DR, and subject to thematic analysis. Themes were developed following initial coding of the data presented in the included papers and relevant to the objective. Codes were then examined and collated to reveal themes. Following discussion between KO and DR the themes were agreed as being relevant to the objective of the review and were named. Themes emanating from the review were malodour, health-care professionals coping with malodour and disgust.

Results

The seven papers identified included studies undertaken in Denmark, Sweden, UK, and Taiwan indicating the global interest in this subject. Sample sizes within the papers ranged from 10 to 101. Jones et al.[5] and LundNielsen et al. [19] used a mixed methods approach; with Lindahl et al.[18] and Lo et al.,[20] undertaking qualitative studies. Gaind et al.[23] reported on quantitative analysis from a prospective, observational study using the Haidt Disgust Sensitivity Questionnaire and the Wound Management Questionnaire from a sample of 101 patients

Malodour

Lund-Neilsen, Muller and Adamsen [19], in their mixed methods study of a four weeks wound care intervention with twelve women, diagnosed with fungating breast carcinomas, provided tentative but not significant findings to suggest that good psychosocial support from nursing staff may be linked to enhanced self confidence and independence. Jones et al [5] in their mixed methods study employed the Hospital Anxiety and Depression Scale (HADS) with 196 participants living with chronic leg ulceration and a further 20 interviews; although it is unclear if these were with the same sample. Odour and exudate were associated with higher HADS scores. Of the 196 participants 108 reported the presence of odour; with a statistically significant association between anxiety and odour ($P \leq 0.001$) and depression and odour ($P = 0.002$). Qualitative data extracts from three of the interviews are provided indicating the impact of the odour on daily life of the participants. Here the participants used the words '*disgusting*' and '*decay*' and phrases such as '*rotting away*', and '*terrible*,

like dying flesh.....like something dead in the same room', frequently to describe the smell and the associated feelings of disgust.

Lindahl et al.,[18] in their qualitative study exploring the meaning of living with malodorous, exuding ulcers, identified two main processes: being struck down and finding consolation. The authors explain that living with malodorous and exuding ulcers can be perceived as being trapped in a debilitating process that slowly strikes one down, thus the theme 'being struck down'. Within being struck down they further highlighted the themes: feeling dirty, being trapped, losing confidence, losing hope, becoming frustrated and protecting oneself. Within the theme of feeling dirty, participants voiced their concerns regarding the affect the wound and its odour was having on their families. They discussed their own feelings of shame and troubled conscience which made the participants feel dirty and contaminated on the inside. The authors translated these feelings as 'being trapped in a debilitating process that slowly strikes one down' (P.73). Social isolation created by living with a malodorous wounds has been investigated [20]. Analysis from their qualitative study highlighted that all participants (n=10) stated wound odour caused them distress both physically and socially [20]. Study findings also identified distress caused by physical symptoms of the wound that led to a significant psychological impact through the theme wound related stigma. The authors describe this as causing participants to become socially isolated because of their wound and feeling embarrassed because of wound odour and leakage.

Lo et al's study [22] examined the relationship between self-reported symptom burden and quality of life (QoL) outcomes using the Taiwanese version of the McGill quality of life questionnaire, in patients with cancer who had a malignant fungating wound. They reported that patients QoL decreased with wound pain, bleeding, exudate, malodour and sleep disturbance. Overall QOL scores and scores for three of the four QOL domains were significantly lower for the cancer patients with a malignant fungating wound. These findings echo those of Lund-Neilsen et al [19], who undertook a prospective exploratory study with a sample of twelve Danish women with advanced cancer. Prior to the four week intervention eight participants perceived their wound to be malodorous; at the end of the intervention period seven women had no malodour, two had a slight level of malodour, one had the same level of malodour and two had worsening odour. Interestingly, the women in the study were able to distinguish between the 'ordinary smell of wound liquid' and what they described as 'the odour of decay' (p71).

Healthcare Professionals Coping with Malodour

Non healing wounds can impact on professionals and can evoke feelings of helplessness and being emotionally overwhelmed (European Wound Management Association [EWMA], [25] indeed Lindahl

et al [21] surmise that when health care professionals come within close physical proximity to an exudating malodorous wound, it could become stressful for nurses to remain close to patients. In an earlier study they concluded that caring for people with malodorous exuding ulcers not only meant struggling to shield patients' vulnerability but also nurses' defencelessness [18]. Previously Wilkes et al. [26] demonstrated that nurses caring for patients with fungating wounds in patients' homes struggled to cope with these individuals' ulcers and bodily condition.

In a qualitative study consisting of a convenience sample of six nurses participating in conversational interviews, Lindahl et al [21] investigated ethical reflections of caring for patients with malodorous, exudating wounds. Striving to do good for patients and to be good nurses was seen as a major concern throughout the participants' reflections with effective management of malodorous wound care often causing dilemmas when attempting to 'do good' and 'be a good nurse'. Nursing students new to clinical areas are often shocked at odours that emanate from wounds and have to develop coping mechanisms to manage these situations. The participants in this study confided that nursing students must become sensitized to the needs of patients whose only choice is living with malodorous exuding ulcers [21]. The participants suggested there was a need for clear communication in establishing trust and effective co-operation around patients, as health care professionals encountering patients often communicate with body language. One participant stressed the need for awareness about and learning how we communicate with patients: what we say, how we say it and how we look - she continued with reflection on how patients can read our body language, which reveals what we really feel (P.18).

Lund-Neilsen et al [19] at the end of their four week evidence based intervention concluded that wound size had decreased in nine of the twelve participants. Within their study, the researchers managed odour with particular dressings. Whilst the authors suggest that good psychosocial care is important; there is no detail included within the paper to direct other professionals regarding such an approach. Interestingly, they also highlight that following the intervention six women said they had experienced malodour and yet this had only been recorded by the nurses as an issue for three of the women. This may serve to illustrate that nurses underestimate the impact of malodour or are failing to reflect this as a patient centred issue. Similarly, the participants in the study by Jones et al [5] wanted more frequent dressing changes in order to minimise wetness from exudate and prevent embarrassment caused by malodour. The authors suggest that it is important for nurses to gain a deeper insight into people's perceptions of the illness experience; however, the findings would indicate that the symptoms of odour are not well managed or controlled.

Disgust

Gaind et al [23] reported on analysis from a prospective, observational study using both the Haidt Disgust Sensitivity Questionnaire [24] and Wound Management Questionnaire (developed locally and not validated)] that attempted to assess characteristics of a wound and indicators of disgust. One hundred and forty six patients were approached to be a part of the study, with one hundred and one being included in the final analysis. Analysis from the study identified that sensitivity was higher in females compared to males and the mean disgust sensitivity was significantly lower in participants who were able to help with their dressing regime (45 ± 14) compared to those who felt unable to assist (53 ± 7). Similarly those patients who were able to do their own dressing at home were considered less sensitive (44 ± 14) as compared to those who relied on a healthcare professional to undertake the dressing change (57 ± 16). The mean disgust sensitivity was higher in participants who averted their gaze during the dressing in comparison to those who did not (56 ± 12 ; 47 ± 13). Furthermore the disgust sensitivity was higher in participants who were tearful during the consultation compared to those who were not tearful (58 ± 9 ; 47 ± 14). There was a high mean disgust sensitivity and response to wound size and severity that affected patient engagement in wound care; those with wounds $> 30\text{cm}$ were engaged in care, while just 38% ($n=8$) of those with wounds $> 30\text{cm}$ were similarly engaged.

Discussion

It is perhaps surprising that only seven papers could be identified that described primary research specifically examining the notion of disgust. The notion of disgust is not new, having been described by Darwin as referring to 'something revolting, primarily in relation to the sense of taste, as actually perceived or vividly imagined; and secondarily to anything which causes a similar feeling, through the sense of smell, touch and even of eyesight (p253; cited by Haidt et al., [12]. Despite an acknowledgement within the literature that patients with chronic wounds often experience self-loathing and disgust associated with their wound; suggestions directing nurses as to how to manage such feelings of disgust are lacking. The main approach to management within the papers reviewed appears to be one of using particular dressings designed to mask the odour and control exudate. There is little within the literature that provides a pragmatic guide for nurses regarding the best approaches to psychosocial care. Indeed in some cases it seems that malodour is a concern to patients which can sometimes go unreported by nursing staff; although the reasons for this remain unclear. The coping mechanisms developed by nurses in response to disgusting wounds requires further exploration in order for a fuller understanding of these mechanisms to be achieved. This review has identified that both healthcare professionals and patients can become distressed at wound odours yet there is little evidence that is available to guide people as to how to manage these feelings. The importance of providing healthcare professionals, patients and carers with the tools,

knowledge and skills to prepare them for feelings of disgust requires further exploration. The authors recommend that under graduate education examines disgust in detail and prepares students for the real world where they will encounter malodorous wounds, similarly there should be support for patients and carers as to how to cope with malodour and to prepare them for living with a relative or friend who has a malodorous wound. Furthermore there is an urgent need to involve psychology experts in the education of healthcare professionals to ensure that theories surrounding disgust can be related to clinical practice - never more has inter professional education been more important.

Conclusion

Healthcare professionals, families and carers often have feelings of disgust when they are exposed to a malodorous wound for the first time. This can be an upsetting experience and leave the patient feeling socially isolated, yet there is little research or guidance as to how to effectively manage these feelings. The authors recommend that more research is undertaken in this area and clear guidance and education provided to allow effective development of coping mechanisms.

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