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Are you handling genital oedema confidently?

Short title: Genital lymphoedema

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Abstract

Men, women or children can suffer from oedema (swelling) of the genitalia. When differential diagnosis has excluded acute trauma or pathology and swelling remains, the condition may be diagnosed as genital lymphoedema, a chronic condition which increases relative risk for cellulitis. The diagnosis can be delayed due to patient and health care professional behaviour, in terms of embarrassment, lack of confidence or lack of knowledge. A new international project seeks to identify the knowledge and training health professionals need to manage this condition more confidently.

Genital Oedema

Key facts:

- Genital oedema can cause physical and psychosocial difficulties and increases the risk of cellulitis.
- Diagnosis of genital oedema can be delayed for many reasons.
- The education need of health care professionals to confidently manage genital oedema is unknown.
- Basic skin hygiene measures can reduce the risk of recurrent infection and prevent undue worsening of the oedema.
- Referral to Lymphoedema services for advice and supported self-management can be helpful.

Are you handling genital oedema confidently?

Case Scenarios

Case scenario 1: A man you know well has coped stoically throughout life-changing surgery for penile cancer, only to find that he is left with a persistent genital swelling. He is too uncomfortable to wear his usual clothes, feels that people are staring at the way he walks and sits, he has started withdrawing into the home and you feel his mood is plummeting. He tells you he feels unable to discuss it with anyone because it is embarrassing and that although he should feel grateful that he is still alive, he wonders if he can go on living like this. Would you know what to do to help?

Case scenario 2: A woman in your community is getting repeated episodes of infection (cellulitis) in her legs. Although it seems to clear up with antibiotics, it returns, and with each episode the legs are getting bigger and heavier. As her mobility reduces her weight is increasing and she finds it harder to cope with being at work all day and to walk her dog. You know she survived a gynaecological cancer some years ago but she is reluctant to talk about it. She finally discloses to you that it is not just the legs that are swollen, it is also her genitals; passing urine, walking and sitting are all difficult and physical intimacy with her partner has completely stopped. Would you know where to start helping?

Background

Men, women and children can suffer from genital oedema. For some, it is temporary (acute oedema), a mild to severe discomfort lasting for days to weeks following trauma, hormonal treatment or surgery e.g. long-distance cycling, pregnancy, IVF or cancer treatment; or as part of a complex of symptoms in the final stage of palliative care (Noble-Jones et al 2018). However, for others it can become a chronic problem and may last a lifetime. It can affect multiple aspects of daily life and have an impact on psychological health and social well-being. Alternatively, the condition can be a primary deformity appearing at birth or at any later stage of development. It may be in association with leg swelling (Vignes 2018), presented as intestinal pathology such as Crohn's, or as part of a dermatological condition (Alexakis et al 2017; Hall 2019). It is important to note that there are many reasons for enlargement or swelling of the genitalia, therefore differential diagnosis is important (Weinberger et al 2007; Shim et al 2019).

Oedema is considered chronic when it has been present for over 3 months (ILF 2006), and may then be called *genital lymphoedema*, as it is indicative of an inability of the lymphatic system to adequately remove the excess extracellular fluid. Genital lymphoedema is defined as increased volume of the genitals, caused by lymphatic impairment (Vignes 2018). It may be internal as well as external and therefore it may include the scrotum, penis, and foreskin in the male, and vulva, vagina, clitoris, labia minora and majora in the female, and may affect adjacent areas, the pubis, groin and inner thighs (Figure 1). Here we will use the umbrella term genital oedema.

Prevalence and identification – self-reporting genital oedema.

Knowing how many people have chronic genital oedema is a problem. There is estimated prevalence for some types of genital oedema (Cormier et al 2010; Graf et al 2013), but these figures are likely to change (up and down) as cancer management techniques improve (e.g. European Association of Urology 2019) and as investigative technology identifies genital lymphatic dysfunction with greater accuracy (e.g. Mihara et al 2014). There remains however very little good quality evidence in the literature about conservative nursing or therapy techniques to manage genital oedema. As consequence, awareness of techniques to identify and manage genital oedema in community and acute nursing, as elsewhere, remains anecdotally poor.

Delay in identification and management of lymphoedema allows the condition to progress through worsening stages until the swelling can become hard with fibrosis and a potential risk to general health through infection (International Society of Lymphology 2016). This progression is made worse by a high relative risk of recurrent infection (cellulitis) in the lower limbs and genitalia (Rodriguez et al 2019). A clear national consensus on the management of cellulitis in lymphoedema exists on the web (Keeley et al 2016) but doctors in primary care are more likely to adhere to local antibiotic protocols or habitual practice

(Francis et al 2016). The development of a self-report tool for men after genito-urinary cancer was an initiative to overcome the embarrassment and fear which can lead to under-reporting of genital oedema (Noble-Jones et al 2014).

Patients and health professionals delay the discussion

When the patient first presents to their doctor or nurse there is a need to first eliminate acute or life-threatening causes of swelling. Thereafter onward referral will often only occur if the HCP is aware of possible treatment/management and of suitable local services, (a directory is available at www.thebls.com). Graf et al (2013) identified a protracted period of around 5-6 years being common in diagnosis of lymphoedema after lymphadenectomy for gynaecological cancers for example, despite removal of lymph nodes being a clear risk factor. Similarly, men in urology clinics may find specialist nurses who are aware of the potential help (see Box 1). Even when genital oedema is accurately diagnosed, it may still take some time to get the care and advice needed. This is due, in part, to variability of access to lymphoedema services across the UK and that the lymphoedema specialists themselves may have barriers to conversations about genital oedema with the patient (Noble-Jones et al 2018). The barriers identified by Noble-Jones et al. were about the timing of asking the patient about genital swelling and a preference for the patient to mention it first. However, patients reported that it would be easier to disclose problems with chronic genital swelling if the health professional confidently asked about it as part of their assessment. It was reported that this hesitation on both sides of the therapeutic relationship could lead to weeks of delay. In addition, for the health care professionals managing patients with genital oedema a lack of assurance in the validity of assessment tools for genital oedema and a lack of confidence in their knowledge and skills could produce further barriers to treatment.

Moving forward – identifying health professional education need

Developing on these findings the current Tenovus Cancer Care funded project aims to identify the support and education needs of nurses and allied health professionals who find themselves managing this group of patients. First, an international online survey will be available to health professionals through the International Lymphoedema Framework (www.lympho.org), the British Lymphology Society (www.thebls.com) and national lymphoedema organisations in other countries and through some urology groups. This will enable respondents to describe the level of confidence they have in their knowledge of genital oedema, their previous training and their education need in relation to managing genital oedema. In addition, there will be an opportunity to recommend good learning resources they have used. The survey will be followed by focus groups in many of the participating countries. These will explore particular aspects of the survey findings, the HCP sense of capability and confidence, the perceived impact on patient care and how best to provide new learning resources.

The aim of the project is to produce an international picture of the education need in this topic, the type of resources people are currently using in their learning and what they would find useful in the future. The findings will also be reported by country, so that nation specific recommendations for genital oedema education of HCP can be made.

Case scenarios responses

Case scenario 1: The man in the first scenario needs emotional and practical support. I would encourage the patient to discuss his feelings and the swelling with his GP and, if he has seen a Macmillan HCP during his cancer journey, to contact them. If there is a delay in getting an appointment I would encourage him to speak to one of the anonymous

telephone support services, such as those provided by Samaritans or Macmillan Cancer Support. Alternatively I could ask the patient's permission to refer him back to his surgeon or specialist nurse for further advice, as the swelling may be unavoidable soft tissue deformity from his surgery. I would investigate if there is a lymphoedema service locally to seek interim advice and refer him to. In practical terms, I would ask the patient if I could assess the swollen area to check for signs of infection, consider the need for antibiotics and discuss how he is passing urine. Then I would encourage meticulous skin care by washing with a pH neutral soap or emollient, pat dry, and apply a protective emollient to reduce the risk of infection.

Case scenario 2: Similarly, with the woman in the second scenario I would encourage her to discuss the persistent swelling and discomfort with her GP, perhaps asking for a female doctor if she would be more comfortable and one is available. She may not have had any contact with cancer support services if her oncology follow up period is over. However, it may still be possible to refer her back to the surgeon or specialist nurse for further advice and to exclude recurrence. There may also be Sex Therapy/Sexual Health specialists who could help both physically and psychologically. I would ask the woman if I could inspect the swelling and if it is clearly an oedematous swelling I would investigate if there is a lymphoedema service locally and ask their advice on management until she can be assessed by their specialists. I would encourage meticulous skin care, washing with a gentle soap or emollient, patting drying and applying a protective emollient since the risk of infection in gynaecological oedema is high.

If you would like help in starting a conversation with a man who you think may have genital oedema then you can find the free to use **self-report tool for men** on the BLS website: <https://thebls.com/public/uploads/documents/document-74291520589744.pdf> (pages 3 and 4).

There is also useful information for you and your patients on the website of the Lymphoedema Support Network www.lymphoedema.org

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Box 1. Service improvements for men with genital oedema in Uro-oncology and community.

LD, is a Uro-oncology CNS with 13 years' experience within oncology, including over 5 years with urology cancer patients such as prostate, penile and testicular cancers.

Currently, it is unusual for lymphoedema to be mentioned to men who are at risk of developing genital oedema. There is a great need for knowledge and awareness to be increased in this area. Nurses need to look at ways of improving the information for patients who are at risk of genital oedema and making sure that the right questions are asked post treatment. Within our service patients complete a Macmillan Holistic Needs Assessment (HNA) prior and post treatment; this asks the question about any swelling but in the future we are hoping to develop a HNA which is more specific for urology cancers such as prostate, penile and testicular and it will include a specific question about genital swelling.

Urology nurses are not perturbed by embarrassing conversations, but the lack of knowledge and awareness of lymphoedema is a barrier which prevents these conversations from being initiated. However, the persistent swelling of lymphoedema may not be obvious until later on in the patient journey, which means that community and practice nurses need to be aware of which patients are at risk. The recent development of treatment summaries specifically for urology cancers, will help to improve communication between cancer

services and primary care. They will provide a simple summary of a patient's cancer diagnosis, treatment and ongoing care plan. If the patient is at risk of developing genital oedema this information should be included.