

Long-term quality of life effects of genital warts – a follow-up study

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ABSTRACT

INTRODUCTION: Genital warts (GW) is one of the most prevalent venereal diseases in Northern Europe today. Previous research has shown that while present, GW can significantly reduce patients' quality of life (QoL). This follow-up study is the first of its kind to explore the possible physical and psycho-sexual long-term effects of having previously had GW.

MATERIAL AND METHODS: A qualitative research design was applied using individual interviews with six former GW patients who had been cleared for GW for at least one year. The semi-structured interview guide included questions and issues that were identified in two previous studies of the QoL of heterosexual and homosexual GW patients. The data were analysed using a discourse theoretical approach.

RESULTS: This study shows that GW may have QoL effects for a long time after clearance. The participants were persistently worried about GW recurrence, about being prone to develop ano-genital cancers and about the continual, negative effects on their sex and love lives. The women in particular suffered from permanent damage to their genital mucosa due to GW laser treatment.

CONCLUSION: The results of this study underline the need to disseminate knowledge about GW in order to optimize the use of preventive measures such as condoms and quadrivalent human papilloma virus (HPV) vaccination. Patients with GW have a considerable need for detailed information about the disease and for being involved in the choice of their treatment. Finally, persisting worries about GW recurrence and ano-genital cancers should be addressed when communicating with former GW patients.

It has recently been reported that 10.6% of Northern European women aged 18-45 years have had genital warts (GW) and that the incidence among young women is rising [1]. In Denmark, 17% of women aged 20-29 years have had GW [2]. Approximately 90% of GW cases are due to infection with human papillomavirus (HPV) types 6 and 11. A total of 30-40 types of HPV are associated with the mucosa and skin of the ano-genital area, including a number of high-risk types which have been shown to cause ano-genital cancers. In addition to HPV types 16 and 18 which cause about 70% of cervical

cancers, HPV 6 and 11 are also included in the quadrivalent HPV vaccination [3]. GW treatment is often lengthy and of varying efficacy [4].

GW is frequently perceived as a benign and non-serious infection, and few studies have explored the quality of life (QoL) of patients with GW [5-11]. Recent qualitative research, set in Denmark, supports and elaborates the results of those studies in revealing that GW can cause a significant reduction in heterosexual as well as homosexual patients' QoL [12, 13]. These two studies demonstrated that patients were primarily concerned about the negative effects of GW on their sex and love lives. Patients often felt anxious about the uncertain perspectives of recovery, and the stigma associated with the disease affected their self-perception and social lives. In addition, GW troubled participants who associated it with an increased risk of developing ano-genital cancers due to their vague understanding of HPV as a common causal factor in both types of diseases.

The present follow-up study aimed to explore the possible long-term effects of having had GW to ascertain whether some of the above-mentioned effects on patients' QoL persist after GW clearance. A PubMed literature search was performed, but no studies on the long-term QoL effects of GW were found. The objective of the present study was to explore such effects in depth by applying qualitative research methods.

MATERIAL AND METHODS

Following up on the two previous studies of the QoL effects of GW [12, 13], the present study was based on qualitative individual interviews with six former GW patients: two heterosexual women, two heterosexual men and two homosexual men. This methodology was chosen to obtain in-depth knowledge about individual narratives on past and present experiences with the disease [14].

The participants were recruited from private gynaecologists and dermatologists in Copenhagen, Denmark, and via internet-based homosexual media. Participants were eligible if they had no serious co-morbidity and had been cleared for GW for a minimum of one year. On average, they had first been diagnosed with GW 6.5 years ago (range 1.5-12 years) and cleared for GW for

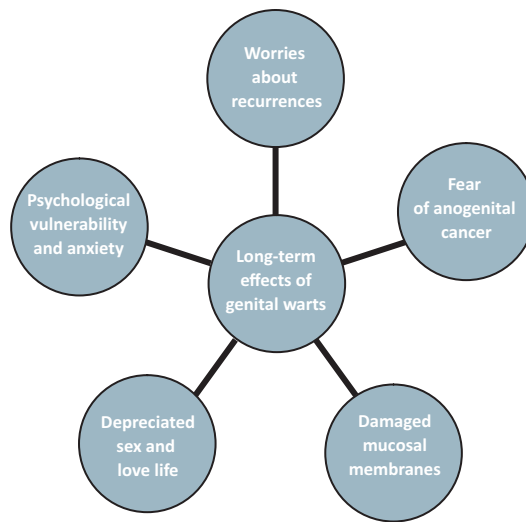
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 FIGURE 1

Long-term quality-of-life effects of genital warts.



3.2 years (range 1-8 years). Three participants had experienced 1-3 GW recurrences. One homosexual man had GW that were easily treated with topical cream and cleared within three months. The rest of the participants had a first incidence of GW with a duration of 0.5-2.5 years and had undergone various types of treatment: Both women as well as one heterosexual man received carbon-dioxide laser therapy after failed attempts with several topical creams; the other heterosexual man was treated with cryo-therapy and cream, and the last homosexual man received topical treatment as well as surgical excision (for more information on GW management options see [15]). No personal information about the participants was passed on to the author, and participants' anonymity was maintained throughout the study. All participants gave their informed consent to participate and the study did not require ethics committee approval.

A semi- and funnel-structured interview guide was used covering topics that were identified in the two previous QoL studies of GW patients [12, 13]. The questions were open-ended to capture as many perspectives as possible, including any that had not been envisaged by pre-interview hypotheses [14, 16]. The interviews were transcribed verbatim and analysed using a discourse theoretical approach to the relationship between language and meaning [17]. This approach is used to analyse a diversity of statements allowing clusters of meaning to form around a specific subject matter. Firstly, the data were coded according to the topics that were raised during the interviews. Secondly, the most important themes within each topic were identified. Finally, the frequency of and connections between topics and themes were analysed. This produced a pattern of the

relative meaning that the different topics and themes had for the participants, i.e. the approach identified the most significant ways in which their QoL was affected by having had GW.

RESULTS

The experiences of having genital warts

The present study supports the results of the earlier studies in showing that while present, GW cause a significant reduction in the QoL of Danish patients [12, 13] (Figure 1). In hindsight, participants said that treating the GW had been psychologically burdensome due to the time spent on repeated consultations, the varying efficacy and soreness following treatment. Laser therapy had been particularly painful. Having GW had been accompanied by feelings of shame, guilt and anxiety. The stigma associated with a venereal disease negatively affected the participants' self-esteem as well as their professional and social lives due to various manoeuvres to conceal undergoing treatment for the disease. Gay participants particularly stressed the need to avoid being targeted as disease carriers among peers within the small homosexual minority group. GW had damaged all participants' sex life due to a loss of sexual desire, soreness following treatment, feelings of being repulsive and fear of infection. Their love lives had been affected by the consequent loss of intimacy, and by suspicion of infidelity and insecurity when meeting new partners. Most participants had suffered from GW in solitude or shared it with only a few close friends.

Persisting physical damage following laser treatment

None of the male participants reported any significant lasting physical effects of having had GW. In contrast, the women reported persisting damage to the vaginal and vulvar mucous membranes following laser treatment. They still suffered from dryness, hyper-sensitivity and a porosity causing bleeding, soreness and pain which rendered having a sex life particularly difficult. A total of 12 years after receiving laser therapy, one woman still applied almond oil and anaesthetic cream twice a day to enable her to maintain her personal hygiene and have a sex life. The women were uncertain of the perspectives of full recovery and struggling to accept that they might have suffered permanent damage to the genital mucosa as a result of GW treatment.

Long-term effects on participants' sex and love life

To the women, the damaged genital mucosa was the worst consequence of having had GW. It was only possible to have sex if the partner was very gentle and plenty of lubricants and local anaesthetics were used. These measures and worries about pain did, however, come to mark the sexual act and reduced sexual desire.

To one woman, who had been single for several years, the necessary precautions had become an obstacle to meeting new men.

From fear of being stigmatised, neither of the two singles in this study had ever revealed to potential partners that they had suffered from GW. Once their GW had cleared they wanted to avoid two major problems: being regarded by others as well as regarding themselves as diseased individuals. Their situation thereby resembles that of HIV-positives who fear others' reaction to their status. Their sexual insecurity had caused self-imposed withdrawal and difficulties establishing new relationships.

The GW had established a cognitive link between sex and disease and made the participants more attentive to protecting themselves from venereal diseases. At the time of the interviews, three men were in steady relationships. One heterosexual man still suffered from a lack of sexual desire. He said that he lost the habit of sex while he had GW and now feared an undetected recurrence of the GW that could infect his girlfriend with HPV and cause her to get GW or even worse: cervical cancer.

Fear of cancer and recurrence of the genital warts

Most participants feared having become prone to developing ano-genital cancers after having had GW. Their uncertainties about the exact risk and connection between GW, HPV and ano-genital cancers caused a great deal of anxiety. One father of four children, for instance, was particularly worried about dying before his children were of age.

In addition to fear of cancer, GW recurrence was one of the greatest concerns among the participants. The three participants who had previously experienced recurrences stated that this had increased their awareness that the risk of recurrence would always be present. With the exception of the one man whose GW had been easily treated, all patients appeared equally worried about recurrence. Two participants, one man and one woman, had developed mild disease phobias. The woman was repeatedly having smear tests performed for cervical dysplasia. They all frequently checked for reappearance of new GW. To the women, the experiences with laser therapy had been traumatic and played a major role in her near-panic of recurrences.

Long-term psychological effects

Most participants linked having GW to feelings of being alone with the concerns about the disease. The women, in particular, felt that their intimate boundaries had been grossly exceeded in connection with laser treatment. One was still furious because she felt that the physicians had made decisions on her behalf that

had ruined her body for the rest of her life. She had not been told about possible side effects and felt that she never had the opportunity to make an informed decision.

Today, the persisting effects on most of the participants' sex and love lives made it difficult to put the course of disease behind them. Also, the ever-present fear of cancer and recurrence were significant GW sequelae. Many mentioned that GW had played a role in shaping the persons they had become (insecure and worried) and how they related to others (with withdrawal and concealments). Some still felt vulnerable after the experience which had included a lack of disease control and threats to vital parts of their body and life.

DISCUSSION

In this study, qualitative methods were used to obtain a nuanced insight into the experiences of former GW patients. The method of recruitment may have introduced some selection bias because people with more negative experiences may be more likely to volunteer their participation. The interview situation in itself also entails a risk of a negative bias even though it was made clear that all experiences, good or bad, were relevant to the study. Qualitative research can produce knowledge of the meanings that patients ascribe to a given disease. The results can be generalised analytically, though not statistically [16]. This study involved a limited number of participants. Consequently, while a clear pattern emerged of long-term effects across all participants, such as fear of recurrences and cancer, a larger number of participants would be required in order to confirm the suspicion raised in the present study that women may suffer persistent damage to their mucosal membranes. The literature is sparse on this subject and it mostly reports positive results from GW laser therapy. It does stress, however, that laser therapy requires specialised surgical skills and that if it is not performed with great accuracy, it has been shown to cause severe thermal damage to the underlying tissue and dyspareunia in female patients [18].

This follow-up study underlines a substantial need for dissemination of knowledge about GW to optimize the use of preventive measures such as condoms and quadrivalent vaccination against HPV. In line with previous research, it shows that in comparison to other sexually transmitted infections – and in marked contrast to the high prevalence of GW – knowledge about GW and HPV is generally very poor [19].

This study also stresses the need for improved doctor-patient communication among those already affected with GW. Although GW might not be considered a serious disease from a medical point of view, it may

have wide-ranging effects on patients' QoL. The QoL effects of GW on the participants in the present study show that compassion is needed when addressing this disease. Previous research has shown that most patients are not involved in decisions concerning the treatment of their GW [6]. Our results point to a need for patient involvement and detailed information about the disease and the possibilities of relieving the long-term effects of laser therapy on the genital mucosa. Finally, all participants had persistent worries about GW recurrence and about developing ano-genital cancers. These worries should be addressed.

As a first of its kind, the present study has shown that GW not only reduces the QoL of patients while the GW are present, but may have more enduring consequences. While certain long-term effects may be inevitable, such as emotional vulnerability after illness, others might be mitigated via improved doctor-patient communication. As other studies of the effects of HPV information in cervical screening have shown, the methods of communication are decisive to patients' coping with HPV-related disease [20]. Knowledge about the high prevalence of HPV may reduce the stigma associated with HPV-related diseases, and whereas a vague understanding of HPV may cause fear of cancer, clear information could reduce unnecessary concerns and improve preventive health behaviour.

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