

Patients use normalisation techniques to cope with the quality-of-life effects of anal cancer

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ABSTRACT

INTRODUCTION: Anal cancer is a rare malignancy, but during the past three decades, its incidence has increased in both sexes. Approximately 90% of anal cancers are related to human papillomavirus infection. The primary treatment for anal cancer is radiotherapy or radio-chemotherapy. This quality of life (QoL) study aimed at obtaining in-depth knowledge about patients' experiences with anal cancer and its impact on their QoL.

METHODS: A literature study identified topics for qualitative interviews with six anal cancer patients who had received oncological treatment and were without recurrent disease. The interviews were analysed using a medical anthropological approach focusing on patients' health-related physical, psycho-sexual and social QoL.

RESULTS: The participants suffered from common sequelae of anal cancer treatment, mainly ano-genital pain, reduced sphincter function and sexual dysfunction. The participants employed a number of "normalisation techniques", including dissociation from other cancer patients, delimitation of the cancer to a perceived external and peripheral body part and fast resumption of their usual activities.

CONCLUSION: Anal sphincter dysfunction and sexual problems after radiotherapy for anal cancer may have a major impact on patients' QoL. By maintaining normalcy, patients tried to distance themselves from this tabooed cancer disease.

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Anal cancer (AC) is a relatively rare malignancy, but during the past three decades its incidence has increased throughout the world. In Denmark, it rose from 0.37-0.78 per 100,000 men and from 0.66 to 1.48 per 100,000 women from 1978 to 2008 [1]. The main cause of AC is infection with human papillomavirus (HPV), representing up to 90% of cases [2]. AC is about twice as common in women as in men, and the median age at diagnosis is 65 years [1]. Anal intraepithelial neoplasia is the precursor lesion for AC, and histological squamous cell carcinoma and its subtypes represent more than 95% of all ACs [3].

Anal bleeding, mass and pain are the most frequent symptoms at diagnosis and this similarity to benign con-

ditions such as haemorrhoids may delay diagnosis [4].

The primary treatment for AC is radiotherapy (RT) or radio-chemotherapy (RCT) depending on disease stage. Persistent or recurrent loco-regional disease occurs in 25-40% in which case surgery is indicated. The 5-year survival rate is 52-73% with the main prognostic factor being tumour size and lymph-node spread [5, 6]. The maximum dose of RT is targeted directly at the anal canal implying that ano-rectal, urinary and sexual function can be compromised. In one study, incontinence for stool was reported by 43% of the survivors from anal cancer and urgency was reported by 64% [7].

Studies on quality of life (QoL) related to AC and treatment with RT or RCT are sparse, and no validated QoL measure specific to AC exists. A range of quantitative tools have been applied such as the cancer-specific EORTC QLQ-C30 and the site-specific EORTC QLQ-CR38. Some studies have shown that long-term QoL is satisfactory to most, but that sexual dysfunction and impaired sphincter function remain important sequelae. A lower QoL is associated with chronic dyspareunia and faecal incontinence [8-11]. Others demonstrated that AC survivors suffered from reduced social and role function, fatigue and dyspnoea [12-14]. Problems with these issues may affect working ability, social life, sexuality and psychological well-being [15]. Some studies have showed more negative QoL impact in patients < 51 years old and in women who have a higher rate of chronic adverse events, most commonly dyspareunia and vaginal symptoms [9, 16]. To our knowledge, no qualitative studies have yet been published to examine patients' perspectives on their QoL focusing on the perceived relations between symptoms, treatment sequelae and everyday life impact [17]. However, knowledge about these issues is crucial for clinicians to meet their patients' communication needs. This study used a medical anthropological approach to examine how AC patients perceive AC and its QoL impacts on their physical, social and psychological well-being and daily functioning.

METHODS

The participants were recruited strategically by LL from the Anal Physiology Clinic, Aarhus University Hospital, a specialised colorectal surgical department in Denmark. Eligible patients had completed treatment 6-36 months

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 TABLE 1

Participant characteristics.

Participant	Cancer stage: TNM	Occupation	Current age ^a , yrs	Age at diagnosis ^b , yrs	Time since end of treat- ment ^c , months
Male 1	T2N0M0	Retired	69	68	9
Male 2	T2N0M0	Retired	64	64	8
Male 3	T2N0M0	Working	59	58	18
Female 1	T2N0M0	Retired	70	68	17
Female 2	T4N1M0	Working	64	62	25
Female 3	T1N0M0	Working/ studying	56	53	36

TNM = "tumour, node, metastasis" cancer staging system.

a) Mean: 63.7 yrs.; b) Mean: 62.2 yrs.; c) Mean: 18.8 months.

earlier as the acute radiation damage had then diminished and the more permanent sequelae were likely to be known. Participants had no relevant co-morbidity or recurrent disease, which implies that they had only been treated with RT or RCT, reflecting the majority of AC patients. Invited patients were considered able to describe their disease experiences and represented both sexes to capture any gender differences. When eligible patients came in for control; they received written and oral information about the study underlining that participation was voluntary, had no impact on their course of control and that all data would be treated anonymously. All invited patients accepted to participate. Individual qualitative interviews were carried out by GLM with three women and three men at the clinic immediately after their subsequent control visit in the period from September 2012 to December 2013.

The participants were aged between 56 and 70 years at the time of the interviews. By then, they had completed treatment 8-36 months previously. All had received intended curative RT with a total dose of 64 Gy in 32 fractions to the tumour and 51.2 Gy to elective lymph nodes; one had three series of prior chemotherapy. Three participants were professionally active; three were retired (**Table 1**). Systematic HPV status testing is not standard in Denmark, and no participants knew their HPV status.

A literature study identified relevant topics for an interview guide aiming to explore patients' experiences

with AC. Medline, Embase and PsycInfo were searched using the key words of "anal cancer" or "human papilloma virus related cancer" and "quality of life/psychological burden/perception or experience". The semi-structured interview guide began with questions addressing the participants' initial symptoms and reactions to the AC diagnosis. The participants were then asked about their experiences with treatment and subsequent controls. Questions went on to focus on the disease impact on participants' physical, psychological and social well-being as well their ability to carry out their ordinary activities.

All participants gave informed consent and the study did not require ethics committee approval. The interviews were transcribed verbatim and analysed using NVivo (QSR). A narrative analysis was then applied focusing on the ways patients frame their disease experiences and relate significant elements – such as physical, emotional and social disease impact – to each other [18].

Trial registration: not relevant, but approval was obtained from the Danish Data Protection Agency.

RESULTS

Reactions to the anal cancer diagnosis

Most participants thought their initial symptoms were related to haemorrhoids and only saw a doctor after some time of anal bleeding or when a mass became increasingly uncomfortable. Three participants reacted with shock to the AC diagnosis. The word "cancer" recalled frightening images of friends and relatives having suffered from cancer. The alarm gradually subsided as they processed doctors' information that their cancer was likely to be curable and treatment began.

The physical impact of treatment

Half way through treatment, all participants had radiation damage with the ano-genital skin becoming fragile, burned and painful. One man had damage to the pouch skin; all women had damaged mucosa around the labia, urinary opening and one inside the vagina. The patient who received chemotherapy suffered hair loss. Ano-genital pain and fatigue was most pronounced at the end of and immediately after treatment. The first 2-6 months following treatment, all participants suffered from acute faecal urge. One woman needed reconstructive gynaecological surgery as her rear vaginal wall prolapsed due to radiation. Another woman had to manually tear up the genital skin several times a day as her mucosa pasted together during the healing process.

The lacking sphincter control gradually improved, and after a few months, faecal urge did not prevent any



TEXT BOX 1

"I had to lie on my back with the legs spread and lifted up [on a pillow]. But when the mucosa started healing, it grew together because there was no skin on. So I had to tear myself up down there several times a day. Gosh, that hurt! All the way from the anus to the clitoris, my outer labia, my inner labia, all the cavities ..." (Female 3)

participants from doing sports, socialising, or working, though they needed to use the toilet preventively or use hygiene pads. Still, most had experienced at least one faecal accident. At the time of the interviews, the participants' skin had mostly healed and the feeling of urge was subsiding. Most were content with the course of treatment, though two women had wished for more information on how to deal with the damage to their genital mucosa.

Relational disease impact

Most participants found the support from close relatives immensely important and none experienced any negative disease impact on these relations. To one man, the disease had affected his erectile capability, and another had severe pain in the ano-genital skin area initially preventing him from having sex. Two women gradually regained their ability to have sexual intercourse; one woman had not yet tried.

While no participants concealed their disease to friends and colleagues, they preferred to socially minimise the patient role. Significantly, no participants used the term "anal" during the interviews, but described their disease in vague terms, e.g. "the disease", and the location as "down there". Only one participant knew that AC may be caused by HPV infection, but did not associate this with social stigma.

Psychological coping with anal cancer

To cope with the AC, the participants mentally isolated the disease to a small and superficial area. They needed to conceive of their cancer as limited and external – contrary to metastatic disease affecting vital areas at the core of the body.

Past experiences with cancer affected the participants' perceptions of their own disease. Some were frightened by others' agonising cancer courses. One woman having lost her husband to cancer worried about her children's reactions and fell into depression. Others considered their AC as less serious and did not want to identify with other cancer patients.

Most participants wished to "stay normal" throughout the course of disease. Participants of both sexes had no great need to talk about their disease and "just wanted it over and done with". Trying to regain an active lifestyle was part of keeping "business as usual".

Our analysis showed that the possibility of upholding *normalcy* was central to the QoL impact of AC (Figure 1). Our participants applied a number of *normalisation techniques*, including dissociation from other cancer patients and psychologically delimiting the AC to an external, peripheral and constrained part of the body (Text boxes 2 and 3). "Staying normal" and "keeping business as usual" was crucial, and the participants only shared

! TEXT BOX 2

"Well, cancer is always serious. Cancer is an ugly word. I guess I have been lucky that mine was only in that area. My neighbour had it all over his neck and lymph nodes ... I always considered that mine was just that little lump with cancer inside. I don't think it has been so serious. My neighbour was really really sick and I haven't been, not yet, at least. It was that one spot. It was limited" (Male 3)

their disease experiences with their closest relatives. Thus, the sense of vulnerability could be reduced – most of the time. As AC is invisible to others, social stigma could be avoided [19].

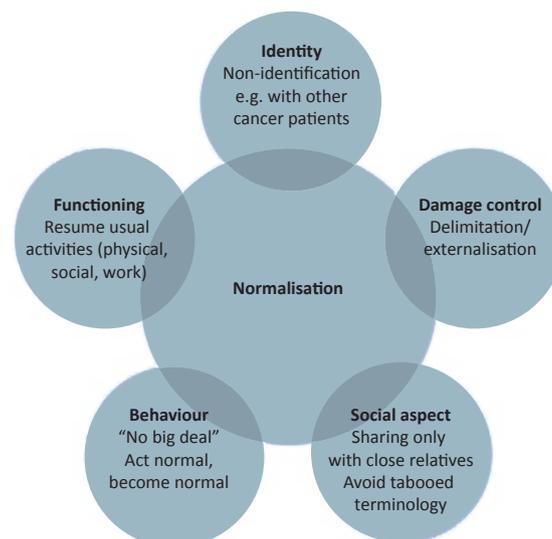
Although several participants felt that, in the big picture, they "got off cheap", anal sphincter dysfunction and sexual problems did result in reduced QoL. Today, none had daily worries about dying from cancer. Still, when it was time for controls, some apprehension of recurrent disease appeared. Overall, the participants became more optimistic with every successful control. A main remaining disease impact was an awareness of the need to appreciate the moment and do things they liked with their loved ones.

DISCUSSION

The incidence of AC has been rising over the past three decades. It is, however, likely that HPV vaccination will reverse this trend, especially if and where males are included in HPV vaccination schedules. Today, the prevention of AC is included in the indication of quadrivalent HPV vaccine [20].

FIGURE 1

Normalisation techniques of anal cancer patients.





TEXT BOX 3

“The patient hotel was filled with sick people and I wasn’t sick as such. It was mostly for cancer patients and when we [the patient and his wife] saw that, I thought ‘I’m definitely not going in there’. Well, we stayed one night ... Some of the people there got chemo or something like that, and they wandered back and forth. Some had to be fed. They felt terrible, those poor people. I couldn’t bear to look at that. I only got radiation half an hour each day, so why stay there for the rest of the day? No, I would rather take the trip [a 2.5 hour drive each way from his home]” (Male 3)

AC survival rates are high, and knowledge of patients’ perspectives of their QoL is important to support satisfactory doctor-patient communication. To contribute to this area of sparse knowledge, we used qualitative research methods to examine how AC patients treated with RT perceived their disease and its impacts on their everyday lives.

Our participants suffered from well-known side effects of RT, mainly ano-genital pain and skin damage, reduced sphincter function and sexual dysfunction. Unsurprisingly, these sequelae were most pronounced during and immediately after treatment. The individual QoL impact of AC was highly contextual, however. As others have argued, patients’ assessments of their sexual functioning depend on factors such as couple status, age and pre-existing sexual functioning [9]. We showed that while damaged genital mucosa and sexual dysfunction may not severely affect intimacy in long-time married patients, it may affect single patients’ hopes of ever finding a partner. Lacking sphincter control was mainly relevant when it limited patients’ functioning in subjectively significant activities, be it work, physical exercise or active grand parenting. A final main result of this study is that upholding normalcy was crucial to our participants who applied the normalisation techniques such as disease delimitation and distancing from other cancer patients.

Adding to the theoretical generalisability of our study, this echoes Goffman’s observations of stigma management and Juel Hansen’s descriptions of AC as a disease with a tabooed and unmentionable character from which patients try to distance themselves [15].

The strategic selection of participants may have introduced selection bias as our participants may be more well-functioning and communicative than is generally the case. Also, interviewing patients 8–36 months after treatment implied that their experiences of the treatment phase were represented in hindsight, while long-term disease effects were yet unknown. Others have shown that AC patients may suffer from severe long-term effects such as bowel problems, lacking concentration and fatigue with a higher impact on working ability, social life, sexuality and psychological well-being [19].

Using qualitative methods has the strength of eliciting in-depth knowledge about the qualities of the phenomenon and thus allowing analytical generalisations. However, as they do not show any frequencies of the phenomenon, they are not statistically generalisable [17]. The results should be confirmed in larger studies, with data collection continuing until saturation point. For instance, a larger sample may shed more light on age and gender differences that were not very distinct in this study. Further quantitative studies would benefit from the development of a disease-specific tool to increase their validity and comparability.

Using a qualitative methodology enabled us to confirm the main sequelae that AC patients may endure and describe their association with QoL, i.e. the significance attached to them. Knowledge about the patient perspective on AC is crucial to support relevant communication and meet patients’ information needs.

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