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Communication about sexual problems and sexual concerns in ovarian cancer: qualitative study

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The assumption that ovarian cancer and its treatment (hysterectomy, oophorectomy, and chemotherapy) have considerable psychosexual effects is reasonable. Studies in other gynaecological cancers show that sexual activity is affected and that communication about this topic is poor.[1–4] These issues have been neglected in ovarian cancer, so this qualitative study explored its psychosexual impact and the level of communication between women and healthcare professionals about sexual issues.

Participants, methods, and results

Detailed interviews were conducted with 15 women with ovarian cancer (median age 56 (range 42-71) years, median time since diagnosis 18 (8-120) months) who were identified from a sampling survey as sexually active or as inactive for reasons related to the condition. Topics included pre-diagnostic and current sexual behaviour and response, satisfaction with sex life, and importance of sex. Interviews were audiotaped, transcribed verbatim, and analysed using grounded theory methods,[5] starting after the first interview. Each author read the transcript, noting themes and issues, and concepts pertaining to similar issues were grouped into categories. As more interviews were conducted, a thematic framework of the categories and their associated themes was produced, and this was systematically applied to each transcript, searching for evidence of the categories and themes. Semistructured interviews were conducted with the women and 43 clinicians and nurses in Leeds

Belief and reality regarding communication about sexual issues and concerns in patients with ovarian cancer

Patients' beliefs
Yes, medical staff should have talked to me about sexual issues:
- "it would help you understand that it is normal to feel like I did after the chemo and the operation"
- "I could have understood why I was having sexual problems if they'd have said 'you might have problems sexually because we've removed this or that"
- "it would have provided reassurance—light at the end of the tunnel"
- "you should know what's going to happen instead of it hitting you like a tonne of bricks"

Healthcare professionals' beliefs
Yes, we should discuss sexual issues with patients:
- "which sexual problems may occur"
- "why sexual problems may occur"
- "reassurance that sexual activity will not cause a recurrence"
- "reassurance that sexual problems are normal"
- "advice or help is available"

Patients' reality
No, medical staff didn't talk to me about sexual issues:
- "I didn't know much about how sex would be affected, I just had to go through and find out for myself"
- "you have no idea about how the cancer will affect you sexually"
- "nobody talks about sex and you wonder whether it is right that you feel different"
- "the doctor said that if I was having problems with sex the hospital had creams to help me, but nothing else was said"

Healthcare professionals' reality
No, we don't often discuss sexual issues with patients:
- "it's not my responsibility"
- "talking about sexual issues is too embarrassing"
- "I'm not sure what types of sexual problems patients experience"
- "I don't feel confident talking to patients about sexual issues"
- "there's nowhere to talk to patients in private"
- "there's no time to discuss sexual issues"
- "I wait until a patient asks about sex"

to determine their attitudes about, and experiences of, written or verbal communication about sex. Local research ethics committee approval was granted.

The condition affected women's sexual desire and raised fears about sexual activity (for example, fear of recurrence) and relationship concerns (for example, fear of rejection). The couple's ability to discuss sex, and the woman's perception that sex maintained normality or control, contributed to whether or not sex was resumed. The experience of physical problems (for example, dyspareunia or vaginal dryness) or psychological distress affected the continuation of sex, and the frequency of sexual activity was often reduced. Over time, physical problems reduced in severity, but the psychological distress persisted. For some women, sex never occurred again—the impact on their self esteem and relationship was devastating. Loss of fertility also caused distress.

Most women thought that a healthcare professional should have provided written information or discussed sexual issues with them. No patient received written information and only two received brief verbal information—a medical oncologist told one woman that the hospital had creams to help if intercourse proved difficult, and another woman vaguely recalled a surgeon saying something, but she still felt unsure about the safety of sexual activity.

The table shows women's attitudes towards communication about sexual issues compared with the reality that they faced. Some women felt uncomfortable discussing sex, but they felt that the benefits would outweigh any embarrassment. Women felt that time available to discuss psychosexual concerns was limited, but they did not seek extensive information—reassurance of the safety of sex, reassurance that their problems were not unique, and permission to discuss concerns was often all that was needed.

The table also shows the attitudes and behaviours of healthcare professionals. All but one thought that medical staff should discuss psychosexual issues; however, only four clinicians (25%) and five nurses (19%) did so. Knowledge about the impact of ovarian cancer on sexual functioning was lacking, with few healthcare professionals being aware of the problems that can occur.

Comment

Ovarian cancer affects sexual functioning, but healthcare professionals' knowledge about this is inadequate, as is their communication with patients about sexual issues. A larger prospective study starting from the time of diagnosis is planned to identify the prevalence, duration, and severity of sexual problems in patients with ovarian cancer.

Healthcare professionals need training to help them communicate more comfortably about sexual issues. Detailed discussion may be unnecessary—just a few reassuring words may be enough to relieve some of the fears and problems provoked by ovarian cancer and its treatment.

Contributors: MS, LF, JB, and PS designed the study. MS and LF designed the semistructured interviews. MS conducted the interviews, which were analysed and interpreted by MS, JB, and PS. MS drafted the first version of the report. All authors contributed to the final draft. JB and PS are the guarantors for the paper.

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A memorable patient

Effective communication

I never met my memorable patient. Indeed, he presented before I was born and, for all I know, he may have died before I even graduated. I was a house officer when my father, then a practising consultant physician and now retired, told me the story of the patient's unusual presentation and diagnosis, from some 30 years previously.

The patient, a tram driver in Liverpool, had been observed to struggle ineffectually with a simple task while working on the tramlines immediately outside the city's Adelphi Hotel. A smartly dressed stranger came up to the tram driver and presented him with a slip of paper which had a single word written on it, and he instructed the man to take the piece of paper to his doctor. This encounter occurred in the 1950s during a meeting of the Association of Physicians being held in Liverpool, when many of the foremost physicians of the time were staying at the Adelphi Hotel. A few days later, my father happened to be working in the clinic to which the patient presented, and he noted the clinical features of puffy face, dry skin, delayed reflexes, and mental lassitude. A month later, after he started taking thyroid extract, the life of the patient had been transformed. The single word on the slip of paper? Myxoedema, of course.

Why so memorable? I was taught not only the importance of simple observation in making a diagnosis, but also that the value of a communication bears little relation to its length.

David Bennett-Jones *consultant physician, Cumberland Infirmary, Carlisle*

We welcome articles up to 600 words on topics such as *A memorable patient, A paper that changed my practice, My most unfortunate mistake,* or any other piece conveying instruction, pathos, or humour. If possible the article should be supplied on a disk. Permission is needed from the patient or a relative if an identifiable patient is referred to. We also welcome contributions for "Endpieces," consisting of quotations of up to 80 words (but most are considerably shorter) from any source, ancient or modern, which have appealed to the reader.