

Positive smear and on: the partner's story

Susan Quilliam

Background

When Annie had a positive smear, her partner hit the Internet for 5 hours to find out exactly what that diagnosis meant and what the possible treatments were. When Beth had outpatient laser treatment, her partner packed their three children off to grandparents for a long weekend so that he could look after her. When Clare had cervical cancer, her partner took a month's leave of absence from work to be with her as she recovered from her hysterectomy.

On the other hand ... when Diana had a positive smear, her partner accused her of sleeping around. When Ellie had a radical cone biopsy, her partner brought her home from hospital, tucked her up in bed and went off on a fishing trip. When Fiona had a hysterectomy, her partner started working long hours and eventually took a lover.

I report these (true but anonymised) stories – and all the ones that follow in this article – not in order to blame or eulogise the partners concerned, but simply to make the point that cervical conditions don't just affect the female patient. For better or worse, they also affect that woman's partner – male or female – and then of course, in a vicious circle, they affect the patient herself. I've been interested in that emotional spiral for 27 years now, ever since my own brush with cervical cancer in 1981, and since then I have not only researched and written a book (*Positive Smear*, Penguin, 1989) but also maintained a constant awareness of the topic.

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The conclusion I have come to is this. Of course the patient's 'story' – of positive smear, of diagnosed cancer, of subsequent treatment – is paramount and takes centre stage, but behind that is the partner's story. Some partners react well, some react badly. But it seems to me that all react as they do because of the same cause: strong emotion. The partner, as well as the patient, is deeply affected by the diagnosis.

Strong emotion

On one level this is obvious. From the moment a positive smear is announced – and even if the development of the condition stops there – spectres appear. As one houseman, now an extremely high-profile gynaecologist, said to me after my own diagnosis: “When a woman has a positive smear, she needs to face up to issues around her sexuality, her fertility, her mortality”. What he could have added is that not only does a woman have to face up to these, but her partner also has to and – with our current awareness of the involvement of the human papillomavirus (HPV) – both

also have to face issues around fidelity and sexual continence. We open a 'Pandora's box' of difficult issues and it is a strong couple who delve into that box without flinching; fury at the condition, fear of the outcome, potential blame or guilt at who was the cause. All of these can eat away at love.

Interestingly there's also a huge swathe of mourning linked in with all this. Because even when a positive smear shows no sign of cancer, the fear of losing a loved one leads to the classic bereavement reaction, albeit pre-emptive, kicking in. Denial ... grief ... fear ... anger ... bargaining ... depression: partners feel all these things. And while grief may be paramount – “I just kept crying ‘Emma might die’” – often a partner's chief coping mechanism is to turn less positive feelings inward on themselves or outward to their spouse: “I felt so guilty because I had had other partners in the past” ... “I hated the rejection of not being able to make love after her op – and I took it out on her”.

Ignored emotion

There is, however, another way that partners cope, a way that is, if anything, more damaging. For while it is true that strong emotion is to be expected, it is also true that such emotion is often ignored or even unrealised. Men in particular are still conditioned not just to suppress external emotional reaction but also to suppress internal awareness of that reaction. Is he scared? Of course he's not! Is he frustrated or angry? How could you suggest such a thing? The result can be a slow and gradual withdrawal into himself in order to support the partner he loves, but also in order to protect himself from a constant and unmanaging terror that he may lose that partner. All very understandable.

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But not always helpful. At a time when a woman needs her emotional turmoil reflected – or at least not dismissed – a male partner in particular can, in his attempt to keep himself calm and effective, seem instead withdrawn and uncaring. He may actively deny that there is a problem: “He kept telling me I was making a mountain out of a molehill”. He may put up a front that is so strong and independent that it seems unfeeling: “You think you have to bear it alone ...”. He may literally absent himself from the scene, as mentioned in my first examples, by withdrawing into work or taking a holiday.

Mutual blame

All of this, it must be stressed, is not necessarily a sign of the partner's lack of love – in fact sometimes the stronger the love, the more the need to cut off in order to survive. Plus, of course, the condition can throw up strong challenges to that love. Given current links with HPV, both partners may withdraw from each other because they suspect betrayal; if a partner has previously been unfaithful then even if this infidelity has been 'worked through' and seemingly resolved, a positive smear may cause it to rear its ugly head again. “I thought I would kill him – I was

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convinced I'd caught the virus from him after he had that fling". Of the many cancers, cervical is perhaps the most emotionally charged in this regard because of the implications it carries with it.

Partners may also cut off from their own distress as a direct – and in fact appropriate – response to a woman who is so distressed herself that she has no energy to spare to support him. She can't reach out emotionally, while sexuality has become not only painful but often distasteful; to spare her he may keep his distance or may turn elsewhere. Here I am absolutely not excusing sexual betrayal nor am I putting the blame at the door of a woman patient who feels unable to share her feelings or her bed. What I am doing is trying to explain the situation as a systemic spiral of distress. She feels bad so he withdraws. He withdraws so she feels even worse. She feels worse and withdraws further so he withdraws further again. And so on and so on.

Partner help

That said, I don't wish to suggest that the 'partner's story' is always doom-laden. So far I have given sad examples, but over the past quarter century I have also heard many tales of victory. "Dan seriously got into the research – it was so useful." "He was there for me every step of the way." "She held me every night as I fell asleep."

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The partner who, though terrified, is able to channel fear into action is often able to offer invaluable practical support: whether garnering useful information, chauffeuring to and from hospital, or taking the lion's share of child care, such action is doubly beneficial, not only helping the patient to feel supported but the partner to feel useful and needed.

The partner who, though furious, can aim his or her anger at the condition not at his spouse is often able to remove guilt from both sides. "It might have been me ... it might have been her ... it didn't matter." It helps for both sides to remember that, in this day and age, neither partner is likely to have come into the relationship with no other sexual experience, and so pointing the finger of blame at one or the other is not only harmful but also likely to be incorrect; if HPV is involved, it could have been caught from a contact of either partner decades before they even met.

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The partner who though sexually frustrated stays engaged in other ways is often able to sustain the relationship and even make it stronger. "We haven't had a normal sex life for years, but actually we feel closer and closer." And here the patient can help: allowing their partner access to their emotional journey, confiding how they feel, welcoming support rather than themselves shutting off. Sometimes being vulnerable around those we love is the best way to bond with them. "I was so relieved to hear that he was hurting too." "I felt Peter and I were doing it together."

Box 1: Helping patients and partners to work together

- Encourage partners to attend consultations
- Suggest joint exploration of resources
- Normalise negative feelings such as fear, fury and guilt
- Initiate conversations about sexuality, past, present and future
- Reframe topics that may trigger blame or guilt
- Suggest ways partners can support patients
- Suggest ways patients can involve partners
- Model out a positive attitude

Further information: Jo's Trust (a charity providing information and support for women with cervical cancer)
www.jostrust.co.uk

What can we do?

Unusually for a Consumer Correspondent column, I have not devoted most of this article to the role of the health care professional, because to some extent we are on the outside here. It is primarily the patients and partners themselves who make their journey, who negotiate what they can give and take. We can't tell people that they should love each other, or how to manifest their love. But I would argue that, quietly but effectively, there is a lot we can do (Box 1).

We can right from the start permit – indeed facilitate – partners to be at consultations. We can encourage couples to access resources together. We can normalise in partners as well as patients the fact that they may feel strongly and negatively about the problem and encourage each side to accept those emotions in each other. We can raise the issue of sexuality and suggest ways that it can be made more comfortable and more desirable. We can explain clearly the issue around HPV, stress that it may be down to previous rather than current partners, and encourage couples not to blame themselves or each other. We can make suggestions to partners about how they can help – and to patients about how they can ask for, accept and reward that help. We can use our position of authority to model out for all concerned an attitude of concern, of trust, of equal responsibility and of mutual co-operation.

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Finally – and obviously – we can generalise from this particular issue. For though this article and the work it is based upon has been concerned with cervical cancer, that last paragraph could well serve as a mission statement for the treatment of many other conditions and diseases that we Journal readers deal with. Because where sex is involved, almost always partners are involved. And where partners are involved, there is always a need for making illness an opportunity to build – rather than undermine – the relationship bond.

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Author's note

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