





COMING ASURV

YOUNG PEOPLE DISCLOSING CANCER TO NEW ACQUAINTANCES AND ROMANTIC PARTNERS

AUTHORS:

Dr Peter Lewist and Dr Julie Mooney-Somerst

'The Centre for Values, Ethics and the Law in Medicine, The University of Sydney On behalf of the Growing Up With Cancer Research Team: Associate Professor Ian Kerridge, Dr Christopher F.C. Jordens, Mr Kris Smith, Professor David Bennett, Dr Pandora Patterson, Ms Susan Cornish

Why did we conduct this study?

Cancer can be stigmatising for young people, especially when the physical markers of illness and treatment, such as scarring and baldness, are visible to others. Visible physical markers can draw unwanted attention. However, after these physical markers fade, young people still fear being stigmatised because they remain at risk of having their socially undesirable cancer history exposed to the scrutiny of others. Young people must choose who to tell about their cancer history and when and how they will make their disclosure.

Little is known about how young people choose to disclose their cancer history, the timing and methods of their disclosures and what the likely consequences of disclosure are for them as individuals and for the relationships that they seek to develop.

Aim

To describe the experiences of young cancer survivors when disclosing their cancer history to new acquaintances.

What did we do?

Growing up with Cancer was a research study funded by the Australian Government that aimed to examine the impact of cancer illness and treatment on the transitions through adolescence and young adulthood.

48 semi-structured interviews were conducted with 27 young people aged 16 to 29 years who were diagnosed with various cancers and haematological malignancies when aged 10 to 22 years. Thematic analysis of interview data was conducted from a symbolic interactionist perspective.

What did we find?

- Most participants felt uncomfortable about disclosing their cancer history to new acquaintances.
- Some managed this by avoiding social situations in which they might be called upon to disclose their cancer history.

... it's made me like a hermit, ever since l had the [cancer], I stopped going out. I don't spend much time outside of home. I sort of lock myself in from the world and I think that over the last 7 or 8 years has really, how do I put it, yeah damaged my skills to communicate with people ... (George, 29)

 As their period of survival progressed, some participants became less inhibited about disclosing their cancer history.

Now if I meet a new person I'll tell them [about my cancer] pretty quickly. I used to have this giant screening process where I had to make sure that I was close friends with them and all the rest. (Dilshara, 18)

 Others gradually disclosed their cancer history as their relationship grew.

[My wife] would have asked me as our relationship progressed. I had an 18th [birthday] video that was put together for me with a whole lot of home videos from when I was younger and part of that had pictures of me in hospital and things and I think it was just a gradual thing. I didn't sit down with her and say, "Oh, look this is me, I had this cancer and that cancer," it was progressively just talked about. (Mick, 29)

 Their disclosure of a cancer history was often positively received by new acquaintances.

I gave [my new boyfriend] the option to leave, to go find someone who he could have a family with. He stuck around. He was disheartened but he was like, "I'm here for you. I'm with you for the long run. So whatever the circumstances are, we have to live with it." (Erin, 24)

- Participants sometimes disclosed their cancer experience in the company of friends when new acquaintances entered an established peer group.
- Bill, whose leg had been surgically amputated to treat his osteosarcoma, now wears a prosthetic leg:

I went to another room [at a party] and then made a loud noise and I went down on the ground and then everyone was in on it except for this one guy and he came in and said, "What happened," and I had twisted my leg around and I was just screaming my head off and he almost cried [laughs]. (Bill, 18 years old)

 Overall, participants reported that their experience of disclosing their cancer history was better than they had anticipated.

I really wanted [my boyfriend] to know that I'd been sick. [So] I told him eventually. I was thinking about it for a while. Should I tell him now, or should I just wait a little while? I told him quite early on. Was telling him as bad as you had imagined? No, when I want to tell someone that I've had cancer, it's [not] too bad. (Mahalya, 22)

What does this mean?

Young cancer survivors often progress from a time when disclosure of their cancer history is unavoidable, because of physical markers that cannot be concealed, to a time when they must choose whether to disclose their cancer history or not. Therefore the choices about disclosing a cancer history to new acquaintances are an important part of life after cancer treatment. But many young people fear that disclosure will provoke adverse responses.

As disclosure appears to generally go well, some young people who are early in their period of cancer survival might benefit from opportunities to explore disclosure strategies with more experienced survivor peers. Meetings between cancer survivors to discuss this can be facilitated by cancer support groups and by staff in oncology follow-up clinics.

Contacts

The Centre for Values, Ethics, and the Law in Medicine The University of Sydney. Email: GUWC.research@usyd.edu.au Phone: +61 2 9036 3405





