Improving the cancer journey for LGB people

LOROS seminars
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Overview of study

- Funded by Hope Against Cancer;
- Steering group included LOROS staff and service users;
- 17 interviews with LGB people with cancer.
What do we know about LGB patient experience?

Doctors never talked in front of patient as if they were not there

Always treated with respect and dignity by hospital staff

Never felt treated as a set of cancer symptoms rather than as a whole person

Hospital staff always did everything they could to control their pain

Patient was given information about support / self help groups for people with their health condition

Differences on 16 domains where LGB people reported less favourable treatment

DH Cancer Patient Experience Survey 2014
The awkward choreography of disclosure in LGB cancer care

Safe to come out to that person and by safe I mean emotionally safe, because if you come out to that person and you read or interpret that they’re disapproving of your sexuality or your life choice, you have to be emotionally strong enough to be able to deal with that reaction. So if you are feeling particularly low or you are just too exhausted with everything that is going on you might just not refer to it at all because you can’t be dealing with another blow (Nick).
Involving partners or carers in cancer care

You know in the pre-assessment that they have before you go into hospital, and it could happen a week before you go in... there’s been different degrees of, not exactly shock, but when you put down who your next of kin is, and on one of those occasions I had to explain... quite assertively, he’s my partner. And I remember getting giggles. I said I’m not joking, he’s my partner (Karl).
Patient experiences of cancer care

I said if the outcome is that I have to wear a pad everyday I’d much rather be here with a life and wearing a pad than not. And his answer was well you won’t be saying that in four years’ time…. And I must admit the first thing that went through my head is… do you know? are you saying it because you think I’m gay or not? or is that just your mannerism? (Nathan).
What is a person-centred approach?

I do think that’s it’s a, it’s a matter of feeling comfortable which I think in my own opinion is only by being out. It’s a matter of the right environment or to be out, to not have any fears whatsoever of being out in those situations (Noel).
Minority Stress Theory (Meyer, 2003)

‘Prejudice events’, ‘expectations of rejection’ and ‘hiding and concealing’ (Meyer, 2003) may mediate how cancer care is experienced. Participants’ narratives provide several examples of these three concepts: prejudice events included physical withdrawal, offhand responses, and refusals to involve partners in care; participants’ expectations of rejection meant that they moderated their behaviour, in many instances, by concealing their sexual orientation. MST helped to understand these experiences of stigma, which were often nuanced and mundane; participants asked themselves whether the treatment they received was different to, or the same as, that of other patients. The subtlety of the interactions, and their preference to keep things under the radar
Integrated sense of self vs evaluative compartmentalisation

- A fourth concept, included in the MST model, is that of internalised homophobia.
- Norman’s observation that because his life was threatened by cancer, his sexual orientation ‘dropped down a number of notches’;
- Tracy says that her medical treatment took priority above her social identity as lesbian.
- An alternative reading of these behaviours is that they are pragmatic responses to achieving the goal of the best possible care in the face of a life threatening illness, but the impact of concealing part of one’s identity may form a cognitive burden. In addition, internalised homophobia is sometimes related to difficulties in ‘intimate relationships and sexual functioning’ (Meyer, 2003; 14), both of which may be associated with a diagnosis of breast or prostate cancer.
Ameliorative coping

- Tracy’s first encounter with a health professional, who refused her partner’s access to the colonoscopy, appears to have an enduring impact upon of their expectations of health care. Tracy describes her approach to accessing care using military and combative metaphors: her defences were up; she responds to suboptimal care by going on the ‘offensive’; her partner quotes legislation to argue for optimal care;

- Toni actively engaged with staff including the ‘cleaners and porters’, she says ‘I’m really conscious that some people aren’t comfortable with it [sexual orientation] but if I need to come out I’ll try and do that in a way that would be sensitive to people who might not be comfortable with it’.

- Miranda talked about being in a waiting room with other patients and plugging herself into an IPad so that she didn’t need to be sociable.
Implications for end of life care

- The role of partners or carers in EOLC;
- Being comfortable and unembarrassed;
- Being aware of cues and signals;
- Proactively making opportunities to facilitate disclosure and recognition that some do not wish to disclose their sexual orientation;
- Promoting equality through patient information materials, positive imagery, knowing about support groups and resources.
Issues/ questions for discussion

- What do you think are the key issues in providing care for patients at LOROS?
- How might you make one small change in your practice for LGB patients following this seminar?