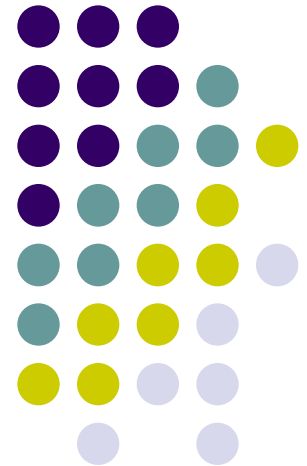


Exploring lesbian, gay and bisexual patients' accounts of their experiences of cancer care.



SAPPHIRE research seminar
University of Leicester
October 12th 2015

Professor Julie Fish
Chair in Social Work and Health Inequalities.



NHS
National Cancer Action Team



Coming Out About **Breast Cancer**

Lesbian and bisexual women's
experiences of breast cancer

Join us over a glass of wine and light refreshments for an evening to raise awareness about breast cancer in lesbians and bisexual women. This FREE event will be of interest to all women and organisations providing services to lesbian and bisexual women.

Professor Sir Mike Richards, National Cancer Director for England, will introduce the event and there will be a keynote speech from novelist, actor and comedian **Stella Duffy**.

Date: **6pm Wednesday 19 May 2010 • FREE**

Venue: **St. Anne's Church, Soho, London W1D 6AF**

RSVP by Friday 7 May to mnelson@dmu.ac.uk or by phoning

0116 257 7732. Places are limited so please book early.

Impact activities

- Presented to NCEI;
- Breakfast launch at Breast Cancer Care;
- 10 Downing St reception;
- Training for 4,000 Macmillan staff.





Overview of study

- Funded by Hope Against Cancer;
- Steering group included LOROS staff and service users;
- 15 interviews with LGB people with cancer and two carers.



Minority Stress Theory (MST) (Meyer, 2003)



- MST explains the everyday heteronormativity experienced by LGB people
- This conceptual framework includes:
 - prejudice events,
 - expectations of rejection,
 - hiding and concealing,
 - internalised homophobia and
 - ameliorative coping (Meyer, 2003: 674.)

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 -less optimal



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).

Integrated sense of self vs evaluative compartmentalisation



- Evaluative compartmentalisation:
- It didn't feel at that time it [sexual orientation] was anything that contributed to getting a better diagnosis or a better service... Now whether that was because my life is threatened and that's [my sexual orientation] sort of dropped down a number of notches (Norman).
- I think in terms of the care at the time I think medically it was very efficient and that's all you really care about when you are poorly, poorly (Tracy)

Ameliorative coping



- 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.

Conceptualising a person-centred approach to LGB cancer care



- Participants reflected on factors which they perceived were conducive to good quality care. Disclosing their sexual orientation meant that those who chose to do this did not have to ‘prevaricate around the question’. They talked about ‘immediately feeling more at ease’ and ‘I really do think it’s had a positive impact in that I feel comfortable’. Not feeling comfortable was considered *per se* to constitute a lack of appropriate care.

‘Moments that matter’



- Completing the pre-assessment form about next of kin;
- Being called from the waiting room in to the clinic (e.g. Mr and Mrs Jones);
- In the consultation room for the initial diagnosis;
- Being present as a couple together at any point in the cancer pathway;
- During the time it takes to push a wheelchair to the operating theatre;
- Being fitted for a wig following chemotherapy;
- Just filling in time having conversations about topics not related to cancer: people draw on their personal lives to initiate or sustain conversation with professionals or other patients;
- Being able to discuss the emotional impact of cancer with a professional;
- If a patient wishes to “proactively” address concerns e.g. the impact of prostate cancer treatment on a gay man’s sexual relationship/s;
- During visiting times when a partner or a group of same-sex friends visit the ward;
- Accessing other sources of formal or informal support e.g. through information resources or cancer support groups;
- Discussing personal circumstances (e.g. with Macmillan staff or a welfare rights adviser) to assess benefit entitlements.



Future directions

- Collaborative bid with Nottingham City, The Christie and UHL,
- Public & Patient Involvement/PE event;
- Inclusion of Transgender experiences;
- Trajectory to patient benefit;
- Hull Medical School and Cardiff School of Nursing – embed in qualifying curriculum.

LESBIAN, GAY, BISEXUAL AND TRANS HEALTH INEQUALITIES



INTERNATIONAL PERSPECTIVES IN SOCIAL WORK

Edited by Julie Fish and Kate Karban

Social work and lesbian, gay, bisexual and trans people Making a difference

JULIE FISH

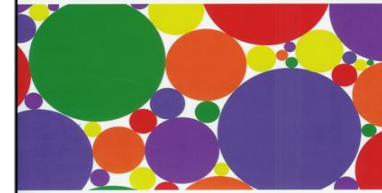
SOCIAL WORK IN PRACTICE series

HETEROSEXISM IN HEALTH AND SOCIAL CARE



Julie Fish

Reducing health
inequalities for
lesbian, gay, bisexual
and trans people



Briefings for health and social care staff

DH Department
of Health

BREAST CANCER REPORT, BREAST CANCER REPORT 2011 (2009 - 14.02.10)



Coming Out About Breast Cancer

Research Report February 2010

Lesbian and bisexual women's experiences of breast cancer



National Cancer Action Team



breast
cancer
care

Lesbian and bisexual women and breast cancer

ESRC knowledge exchange programme RES-192-22-0111



personal experience professional support



Prescription for Change

Lesbian and bisexual women's health check 2008



Cervical screening in lesbian and bisexual
women: a review of the worldwide literature
using systematic methods.

Julie Fish

