Time is on the side of the outcast

Professor Julie Fish
Chair in Social Work and Health Inequalities
Director, Centre for Lesbian, Gay, Bisexual, Trans & Queer Research
“...time is on the side of the outcast... those who once inhabited the suburbs of human contempt find that without changing their address they eventually live in the metropolis”.
Quentin Crisp (1975)
The Naked Civil Servant
The nature of the suburbs

Legal
1967 Sexual Offences Act
1986 Public Order Act
1988 LGA s. 28
1990 Human Fertilisation Act
1994 Criminal Justice Act
2002 Housing law (case law)
2003 Employment protection
2004 Gender Recognition Act
2007 Equality Act Regulations
2010 Equality Act

Social Attitudes
UK councillor blames floods on gay marriage 2014.

Homophobic gestures
## The road to citizenship

<table>
<thead>
<tr>
<th>Civil rights</th>
<th>Political rights</th>
<th>Social rights</th>
</tr>
</thead>
</table>
| - Freedom of speech;  
- Right to justice;  
- Liberty of the person;  
- Civil rights necessary for individual freedom. | - Right to vote;  
- Freedom of assembly;  
- Participation in public life (e.g. take part in consultations about service delivery;  
- Access to information. | - Take full share in social heritage;  
- Access to healthcare, education and other institutions of the welfare state;  
- Right not to be discriminated against. |
Tensions around citizenship

• Treating people equally does not mean treating everyone the same;
• Equality of recognition and of resources;
• Citizenship is not only about rights, but also the formation of new subjectivities.


Equality vs Equity
Subjectivities: engaging in the social world

- Feelings, beliefs, desires, perspective, personal opinion;
- Interacting with the social world;
- Making choices about how to allocate meaning.
Scenario

• Imagine your partner is about to go into the operating theatre for surgery. They are worried about it. You are in a busy clinic.

• Would you think twice about kissing them?
Overview of study

- Funded by local cancer charity - Hope Against Cancer;
- Steering group included hospice staff and service users;
- Pilot study with LGB people with cancer and two carers.
Nathan (gay man with prostate cancer):
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 (the consultant) answer was well you won’t be saying that in four years’ time....
Nathan: 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?
Uncertainty about recognition

We were so worried the night before Tracy (lesbian with bowel cancer) went into her op, where actually you shouldn’t be worrying about something like that. She ended up writing a letter, even though we were civilly partnered... to say (my partner) Nigella can have full access to any clinical information or decisions made about me (Tracy) whether I am conscious or not. And I kept that letter in my handbag for months
Support and resources

We tried looking for LGBT charities or organisations to talk about our experiences but there were none, nobody dealt with cancer, nobody had any experience, there was no support being an LGBT person with cancer (Nick).
Accessing healthcare

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 ... I had to explain...quite assertively, he’s my partner. And I remember getting giggles. I said I’m not joking (Karl).

Not Just a Friend (Royal College of Nursing, 2003)
Expectations of care

• Tracy described her approach to accessing care using military metaphors;

• 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;

• 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.
Forming new subjectivities

• I do think that’s ...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 ....to not have any fears whatsoever of being out in those situations (Noel).
‘Moments that matter’

- Completing the pre-assessment form about next of kin;
- Being called from the waiting room to clinic (Mr & Mrs Jones);
- Being present as a couple together at any point in the cancer pathway;
- 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.
Leeds healthcare

• http://youtu.be/ylhxnYay0us
The back story

• Mixed methods: focus groups – survey – focus groups;
• 7 focus groups;
• Survey of 1066 lesbians;
• First national survey in the UK;
• Risk perceptions of cancer and experiences of screening.
• PhD 2002

Lesbians and Health Care: A National Survey
The back story: Topics & issues

Social Work
- Trans people in health & social care
- Children and young people
- Older people
- Mental health
- Disability
- Substance misuse
- Asylum seekers
- End of Life Care
- Carers

Health inequalities & cancer
- Sexual health
- Mental health
- Substance misuse
- Risk perceptions of cancer
- Cancer survivorship and quality of life
Improving the LGBT cancer care pathway: Using PPI approaches

- Policy briefing: *Lesbian and bisexual women with breast cancer*, produced by the charity;
- Key learning event with cancer professionals: case studies;
- Development of practice guidance: Supporting LGBT people with cancer.

Developing the organisational ethos: equality and diversity strategy, user audits of services, inclusive imagery and language.

Who? Two national cancer charities; two LGBT VCS; an Equality and Diversity Manager in the NHS; academics specialising in cancer; and cancer service users and carers.

What? contributed to the application for funding, developing research questions, designing the project, analysing the data and communicating the findings (process impacts).
Lesbian and bisexual women and breast cancer

As part of our health inequalities work we published a policy briefing highlighting the experiences of lesbian and bisexual women affected by breast cancer. Research has shown that they have poorer levels of patient experience (due in large part to discrimination), less specialist services available, and little data collected about them as a patient group.

We hope our briefing document will be useful to:

- policymakers concerned with ensuring health and social care is responsive to all, regardless of sexuality (or other differences)
- healthcare professionals working to provide the best possible care for their patients
- cancer charities and other groups providing services to women affected by breast cancer, including those who are lesbian and bisexual
- LGBT community and voluntary groups concerned with health issues in their communities.

Our recommendations are aimed at improving services. We hope they will be useful to all groups wanting to take action on this issue.

Download a copy of our report below:

Lesbian and bisexual women and breast cancer report (PDF)

All our services

Spotlight campaign

Improve care for patients with secondary breast cancer

Get Involved
Impact on policy and practice

- Stonewall
- NSPCC
- Leicester Open Mind service
- Public Health England
- ESRC Economic & Social Research Council
- Macmillan Cancer Support
- LOROS Hospice Care for Leicester, Leicestershire & Rutland
Future directions

• Promoting good outcomes in LGBT cancer care: a pilot study of patients’ experiences and professionals’ interactions in clinical oncology;

• Out with Cancer: LGBT experiences of cancer and supportive cancer care National Health Medical Research Council Australia;

• Reducing LGBT health inequalities – in 6 European countries (European Commission).
LESBIAN, GAY, BISEXUAL AND TRANS HEALTH INEQUALITIES

Edited by Julie Fish and Kate Karban

SOCIAL WORK IN PRACTICE series

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

JULIE FISH

improving the cancer journey for lesbian, gay, bisexual and trans people

Coming Out About Breast Cancer
Research Report February 2010

Lesbian and bisexual women and breast cancer

Sexuality Matters Community Strategy

UK Health Watch 2005
The Experience of Health in an Unequal Society
MANY THANKS