ACCESScare: advanced care equality strategy for LGB and/or T people

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Background: health inequalities

• Estimated UK population:
  • 5-7% identify of lesbian, gay or bisexual \(^{(DTI 2003)}\)
  • 1% of population are trans

• Sexual orientation and gender reassignment protected characteristics in UK \(^{(Equality Act 2010)}\)

• “Need to end health disparities and discrimination for LGBT people” \(^{(Lancet 2016)}\)

• Needs due to minority behaviours as a result of discrimination \(^{(Clark Am J Public Health 2001)}\)

• Require mandatory training to achieve respect and dignity \(^{(Garrison, Am J Public Health 2015)}\)
Disparity in outcomes & provision

• Sexual minorities in UK worse primary healthcare experiences and poorer general health
  \( (\text{Elliott J General Internal Medicine 2015}) \)

• Implicit preferences for heterosexual people versus gay and lesbian people by heterosexual healthcare providers
  \( (\text{Sabin Am J Public Health 2015}) \)

• NHS focus on LGBT health is on primary care, mental health and sexual health
  http://www.nhs.uk/livewell/lgbhealth/Pages/Gayandlesbianhealth.aspx

• Social exclusion is a problem in palliative care
  \( (\text{Ahmed Pall Med 2004}) \)
LGBT in context of palliative care

• Greater all-cause mortality
  (Cochran Am J Public Health 2016)

• Higher lifetime risk certain cancers
  (Clements Am J Public Health 2011)

• Less likely attend routine screening
  (Am J Public Health 2001)

• LGB people worse cancer care experiences
  (Hill J Cancer Policy 2015)

• Higher risk behaviours linked to discrimination
  – alcohol, smoking, drug use
  (Mayer Am J Public Health 2008)

• Systematic review LGBT palliative & end-of-life
  • heterosexually biased environments, lack of support, failure to involve partners in critical decisions
  (Harding J Pall Med 2012)
Older people and expectations

1967: Sexual Offences Act – decriminalised homosexual acts both over 21 in private

1988: Section 28 of the Local Government Act

1989: Stonewall UK set up to oppose Section 28 and other barriers to equality

2000: Restrictions on gay men/women in armed services lifted

2001: Lower age of consent to 16

2003: Section 28 repealed (England, Wales, Northern Ireland)

2004: Civil partnership act

2004: The Gender Recognition Act

2010: Equality Act makes discrimination against lesbian women/gay men in provision of goods/services illegal

2014: Same-sex marriage
What is good practice?

• The Health Equality Index
  
  “important for healthcare facilities to provide patients the opportunity to be identified as LGBTQ in health records, if they so wish”

• Person-centred care (South London HIN) 2015:
  
  “considering a people’s desires, values, family situations, social circumstances, and lifestyles; seeing the person as an individual”
  
  Underlying principles: “getting to know the patient as a person and recognising their individuality”.

• Dept of Health’s End of Life care Strategy Equality Impact Assessment 2008
  
  Sexuality/ gender identity “most likely” for inequality & discrimination
The importance of communication

• Most hospital complaints due to poor communication in later illness
  \( (\text{More Care, Less Pathway DoH; Mid Staffs Inquiry}) \)

• Staff fear causing distress, hesitate to have sensitive conversations \( (\text{Brighton, Postgrad Med J 2016}) \)

• RCN survey 2016
  • 13% of UK nurses feel prepared to care for Trans people
  • 1% had received any training
Previous efforts

The Evidence Gap:
no study to date aiming to develop evidence-based resources generated from original data collected with LGBT people with advanced disease
• Marie Curie report based on:

A. Findings from “ACCESScare”

B. National survey
   - N=153 responses, 9 hospices
   - 65% “more training needed”
   - Belief that non-discrimination is norm “I haven’t heard anything...”

C. Last Outing
ACCESScare related studies

1. Original data from UK-wide study of LGB and/or T people with advanced disease

2. Systematic review of bereavement experiences

3. Collaborative study of key populations’ healthcare experiences in Zimbabwe
ACCESScare aim

To develop and disseminate evidence-based mass media resources with the LGBT community to increase the demand for appropriate end-of-life care, and to improve supply of appropriate end of life care through development of training resources for integration within existing end-of-life care curricula for health care professionals.
ACCESScare objectives

PHASE 1

• To conduct qualitative interviews with lesbian, gay, bisexual and transgender adults with advanced disease, and their caregivers, to determine their views and guide the development of patient/carer-centred UK-wide resources

PHASE 2

• To integrate the evidence of the systematic review and findings from the qualitative study to develop mass media resources for distribution, drawing on our Project Steering Group
• To conduct field testing of the patient/carer-centred mass media resource and revise as necessary, and to disseminate widely through LGBT media and other consumer end of life care contact points

PHASE 3

• To develop training resources from the systematic review, qualitative evidence and final patient-centred outputs, for delivery within existing end-of-life courses
• To implement a protocol monitoring impact through relevant metric
Recruitment

• Inclusion criteria:
  • Adults identifying as LGB and/or T
  • Advanced disease (1 year “surprise” question)
  • Their caregivers

• Recruited from
  • A) national media (community groups, email listings, twitter, gay press, radio)
  • B) KCH, GSTT, St Joseph’s, Trinity, St Christopher’s

• Purposive sampling frame:
  • Age, sexual identity, gender identity, primary diagnosis, relationship status, geography
Community Engagement

Sample characteristics

Sexual orientation/gender history:
- 19 gay men
- 1 homosexual man
- 1 gay intersex man
- 13 lesbian women
- 2 bisexual women
- 1 partner of bisexual woman
- 2 trans lesbian women
- 1 friend of trans woman

Interview type:
- 20 patients
- 6 informal carers
- 14 bereaved informal carers

Ethnicity:
- 34 White British
- 4 White other
- 1 Black British
- 1 Afro-Caribbean

Diagnosis:
- 21 cancer
- 16 non-cancer
- 3 co-morbid cancer/non-cancer

Age:
- Mean age 60
- (range 27-94)
Analysis

- Interviews transcribed verbatim throughout data collection period
  - Reviewed to iteratively refine topic guide
- Imported into NVIVO for analysis
- Thematic approach
  - Coded random sample of 5 interviews
  - 2\textsuperscript{nd} researcher double coded
  - Agreed code and presented to Steering Group
  - Applied agreed code to entire dataset
    - Split/merge as necessary with further consultation to ensure unified definition and internal consistency of codes
Visibility

‘They do a lot of articles from the point of view of a male partner, you know, how has he coped kind of thing and how his sex life...There's a big assumption that you've got some supportive male partner, so I think if you're single at all or if you've got another kind of partner, then it’s hard because of that assumption. I would ask them to look at their literature...There's also quite an assumption... that you want to look beautiful somehow to make yourself feel better which again is nothing really to do with sexuality but I think it does assume heterosexuality in a way...There's a lot of emphasis on makeup and come for a pamper evening and this kind of thing, as if you’ll feel better if you look better somehow, which I suppose is a by-product of heterosexuality...I wish that the literature and everything was a bit more geared towards us.’

Alison, 68, lesbian woman living with breast cancer
Sharing identity

When asked what change would have made the biggest difference to his care:
“Well to be recognised that I'm gay, to be understood that I'm gay. And I've got feelings about being gay. I umm, I like to be accepted.” Keith, 68, gay man living with prostate ca

When asked if healthcare professionals should ask about sexuality:
“I would tell them. If they asked me I’d tell them ((3 second pause)) I have no hang up after all these years in the closet, you heard the hinges creak all over Europe when I came out!” - Ian, 94, Gay man living with bone ca

“If it's pertinent to reveal, I will reveal, definitely... I don't mind being asked directly as long as, if I detected it's more personal curiosity I will use the "Mind your own business" response, or err, "Why do you need to know?". Is there's a reason for why you need to know then you need to know.” John, 52, gay man living with HIV and COPD

“No, because I don't think it's anybody else's business what you are. If you want to share it spontaneously then that's OK.” George, 77, homosexual man living with prostate ca
Sharing identity

‘Somebody of my age... my longer experience is one of...hiding my sexuality, and not acknowledging that in a formal way...so there is always at the back of your, well certainly at the back of my mind...there is always a concern that somebody will be negative about you. Make judgement about you...so you spend a lot of energy trying to work out at what point in the conversation do you actually acknowledge and do you state your sexuality.... It is not usually about the individual per se, it is about the risk assessment around that.’

Fiona, 53, bereaved partner of lesbian woman who died of ovarian cancer
Responding to discrimination with action

‘Yeah. It’s also very important to me to know there are policies and procedures in place. So that we are actually protected so if something did happen. You know that actually. That’s not ok.’

Rebecca, 38, bereaved partner of bisexual woman who died of breast cancer

‘The world has changed so much ...but I am sure there are still lesbians who are uncomfortable and not confident...and it’s about how do you reassure them that, it’s fine you are going to be treated the same, just be open because we’ve made sure that the professionals are going to have a problem with that...Um, and if you do have a problem, then this is who you talk to, to get it sorted. If you not brave enough to challenge someone, because not everybody is.’

Pauline, aged 63, bereaved partner of bisexual woman who died of ovarian cancer
Individualised Care – additional or different needs?
Clinical needs

‘Taking oestrogen increases the risk of blood clots. So now I’ve got these blood clots, I had a conversation with a consultant. The logical thing to do is to stop taking them to reduce the risk to a minimum for the future. So then we had to talk about how important it was psychologically, and I said that I think it is very important. I mean if someone said, “Your heart will stop in 10 minutes if you don’t stop taking them”, I’d stop, but I had to work with the gender clinic people and they said there is an elevation of the risk but it’s acceptable. It’s easy for somebody else to say it’s acceptable, I know, but, so we carried on.’

Bridget, aged 68, trans* woman living with lung disease
Psychosocial needs – societal views

‘It feels that society doesn’t validate the loss of a civil partner quite as much as they would understand and validate the loss of a husband. It’s more complicated, and a lot of people don’t have the imagination to understand that it’s the same kind of relationship.’

Rebecca, 38, bereaved partner of bisexual woman who died of breast cancer
Concerns about future care

“I really don't want to go into a place where, you know, I'm the only gay guy. Or you know, gay person. ........it would be so nice to be in place where you know, I could reminisce about ex-partners, instead of having to listen to their endless conversations about their children, and their grandchildren. It's very nice, I'm happy for them, but that's not my world.”

David, 62, gay man living with cerebella ataxia
Interactionally enacted barriers and stressors

(created in the consultation)
Hetero-normative assumptions

“it's usually been... if they're sort of getting background... They don't ask you about your sexuality, they ask about your heterosexuality, umm, ....Which is saying, I'm heterosexual and I wonder what your experience of heterosexuality is...And it's perfectly fair, perfectly, it's not, it doesn't offend me or anything like that. But it says I'm different...((10 second pause)) Basically it's, it's referring to sexuality as sexuality when in fact it's heterosexuality... ...and it's speaking in ways that assume that you already share that sexuality, rather than coming at the topic with an open mind that you might be gay.’

Andrew, 67, gay man living with lung cancer
Homophobic behaviours / lack of recognition of relationship

‘There was complete lack of recognition. The consultant even, on the tenth or twentieth time of being told I was his partner still referred to me as his brother. There’s no official next of kin because it’s same sex, and there’s a lot less desire to be flexible.’

James, 35, partner of Harry, 27, living with Motor Neurone Disease
Terminology

“If I think somebody's using 'homosexual' because of academic rigour then I'm perfectly fine with that. If I think somebody's using the word 'homosexual' as a pair of tongs to keep it at a distance then of course you (laughs) and you just sort of shrug your shoulders. It doesn't hurt, umm. But you feel a bit sorry for them.”

Andrew, 67, gay man living with lung ca
Transphobic Behaviours / Lack of sensitivity

‘Two, three, probably three occasions where somebody has used the wrong pronoun...
I think culturally it was probably a difficult, concept for him to grasp...
I think he read that I wasn't taking [my health] seriously.... and then he called me 'Mr' or referred to me as 'M’r to his underlings around the bed...And I took exception to it ..., he did it again, and I thought, I, just don't care anymore. So launched at him telling I didn't think his qualities as, his interpersonal skills were any good.’

Bridget, 68, trans* woman living with Interstitial Lung Disease

‘I’ve been in resus where I didn’t know if I was going to survive the event or not...where it has ten bays with ten patients, just with curtains. And you can hear every conversation...Some doctors have said to me, “How long have you been transgendered for?” And everybody has heard. As much as I can’t breathe, I’m like, “What the fuck?” And I’m lying there like, “I don’t want to be talking about this.” Do you know what I mean? And they’ve got no right to say that out loud in front of all the other patients.’

Louise, 51, trans* woman living with COPD
Interactionally enacted facilitators -
What does good care look like?
Making identity a non-issue

‘Expect to be treated equitably...expect to be treated as a couple...There’s something about having the confidence for it not to be an issue, because you don’t want to have to deal with that as an extra worry, as an extra concern, as something that inhibits anybody asking questions, or getting the right kind of answers.’

Pauline, aged 63, bereaved partner of bisexual woman who died of ovarian cancer
Asking about the relationship

‘Good care is when people don’t feel embarrassed to ask you questions. So, if they wanted a classification of, “Are you lovers?” they ask it. Clarity’s important. Good care is where it’s not patronising; it’s practical based, but it’s soft.’

Barbara, 51, bereaved partner of lesbian woman who died of cervical cancer

‘I was absent once, because I was doing a course of my own at the time, running in tandem with what was going on at home. I needed to be at college to do a presentation, and I couldn't be there for one of her appointments. The surgeon asked where I was and why I wasn't there, and that kind of thing. So yes, it was noticed when I wasn't there.’

Elaine, 61, bereaved partner of lesbian woman who died of head and neck cancer
Summary

- Patients are happy to disclose if they feel there is relevance, and gain not risk.
- Even after disclosing, practice doesn’t always recognise relationship.
- There is often presumption of heterosexuality in communication and in service provision.
- Fear of discrimination may be brought by the patient.
2. Bereavement systematic review
The bereavement experiences of lesbian, gay, bisexual and/or trans* people who have lost a partner: A systematic review, thematic synthesis and modelling of the literature

Katherine Bristowe¹, Steve Marshall² and Richard Harding¹
Acceptance – disclosure model of LGBT bereavement experiences

23 articles, 13 studies
Clinical implications of level of acceptance/disclosure

Bereavement experiences were shaped by disclosure and level of acceptance of relationship:

- **Overt acceptance** – spoken and acknowledged
  
  *e.g. lack of exploration of partner’s needs*

- **Unspoken acceptance** – not spoken but acknowledged
  
  *e.g. exclusion from bedside or funeral arrangements*

- **Overt exclusion** – spoken but not acknowledged
  
  *e.g. lack of social recognition of loss as ‘widow’*
Gaps in the LGBT palliative and bereavement literature

- Research is predominantly carried out in urban areas.
- Much of the research focuses on the experiences of gay men.
- Bisexual and trans* people very poorly represented in the literature.
- LG research is often extended to the B&T communities.
- Sexuality is often poorly described – e.g. “25 LGB people”.
- Much of the research focuses on white, middle class LGBT people.
- Little consideration of intersectionality – e.g. how ethnicity, faith, culture and sexuality collectively shape experiences.
- Selection bias – research attracts those who may be more open to sharing their identity.
3. Caring for increasingly diverse patient populations
Aim

• Led by Jenny Hunt, collaborating with ACCESScare
• N=60 interviews
• To investigate attitudes and experiences of key populations (sex workers, MSM, LGBTI), palliative care providers and health workers with respect to accessibility and quality of health and palliative care for these key populations within Zimbabwe
Results: 3 distinct themes

1. Illnesses caused by ‘bad behaviour’: brought illnesses on themselves through sexual behaviour, deserve blame not compassion

2. Access to health and palliative care conditional on conforming to sexual norms: must pretend, deny or lie about sexual identity/behaviour

3. Health care and support by health workers determined by personal attitude rather than professional ethics
‘Bad behaviour’, ‘deserve what they get’

• “...there is a prostitute that lives down there who is now having HIV and AIDS, she used to take other people’s husbands. Most people will say, let her suffer, it’s her time now, she used to make others suffer so it’s her time” (PC nurse)

• “They say we are doing something illegal which is prostitution, so you won’t get the medication. So they won’t give you the medication when they have it” (Sex worker)
Personal attitude overrides professionalism

• “This is a taboo, an abomination. What are you doing? No wonder you are in this situation” (PC nurse)

• “in the first place I think to be lesbian or gay it’s a sin…. I think it emanates from how I understand the Bible. My view comes biblically that it’s a sin” (PC nurse)
Lie, hide, pretend so can access services

• “..they would ask where your partner is for them to do the tracking system....So I could not take my girlfriend to the clinic with me and I would take any man on the road to go with me so I could get treated” (Lesbian)

• “Our social history just goes to, ‘are you married?’ If yes then we take it that they have one sexual partner....as a nurse I have never had anyone telling me directly that they are gay” (PC nurse)

• “So it’s very hard for them to speak about their sexual identity and we don’t ask...we generally assume that everyone is heterosexual” (Hospice administrator)
Dissemination

• “Hiding Who I Am”
  • 112 national/local press articles
  • Northern Ireland Minister for Health foreword for local publication
  • Question raised by MP to Secretary of State for Health on planned Govt response to ACCESScare
  • Presentation to UK & Welsh Parliaments
  • Presentation nationally to around 600 medical care trainees
    - Need for communication guidance

• ACCESScare
  • National gay press, radio
  • Patient + family resource field testing complete
Summary & recommendations

• All people living with advanced illness deserve individualised, sensitive person-centred care
• Care experiences for LGBT people could be improved through:
  • Avoiding assumptions of heterosexuality
  • Consideration of potential different or additional needs
  • Consideration of barriers and stressors created in the consultation
  • Increased LGBT visibility and responding to discrimination with action
  • Supporting clinicians with training and resources to address sexuality and gender history
• Findings from this study are being used to develop materials for LGBT people, training for healthcare professionals
• Further study is needed to assist staff in use of language
Acknowledgements

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http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/research/living/access/index.aspx

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Y ddarolith nesaf: Nos Fawrth, 28 Chwefror 2017
Cymunedau Tosturiol
Y Prif Siaradwr: Yr Athro Allan Kellehear, Prifysgol Bradford

Next lecture: Tuesday 28 February 2017
Compassionate Communities
Keynote Speaker: Professor Allan Kellehear, University of Bradford

www.mariecurie.org.uk/WelshLectures