Evidence-based recommendations to reduce inequalities for LGBT+ people facing advanced illness and bereavement

Professor Richard Harding
Dunhill Chair of Palliative Care & Rehabilitation
Executive Dean, Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care

on behalf of the ACCESSCare team

Concept & evidence: person-centred care

BMJ Global Health

The empirical evidence underpinning the concept and practice of person-centred care for serious illness: a systematic review

Alessandra Giusti[1,2] Kennedy Nkhoma[1] Ruwayda Petrus,[3] Inge Petersen,[3] Liz Gwyther,[4] Lindsay Farrant,[4] Sridhar Venkatapuram[2] Richard Harding[1]

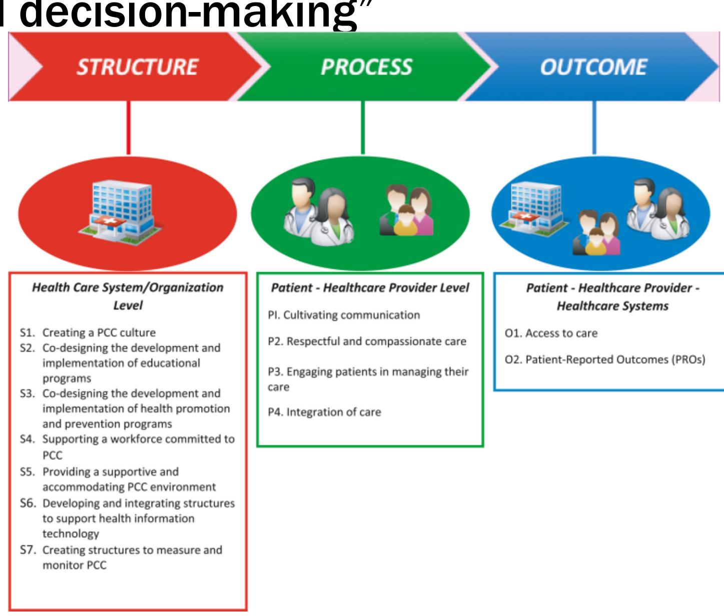
- Inductive coding to Santana's model of person-centred care:

CARE PROCESSES should include

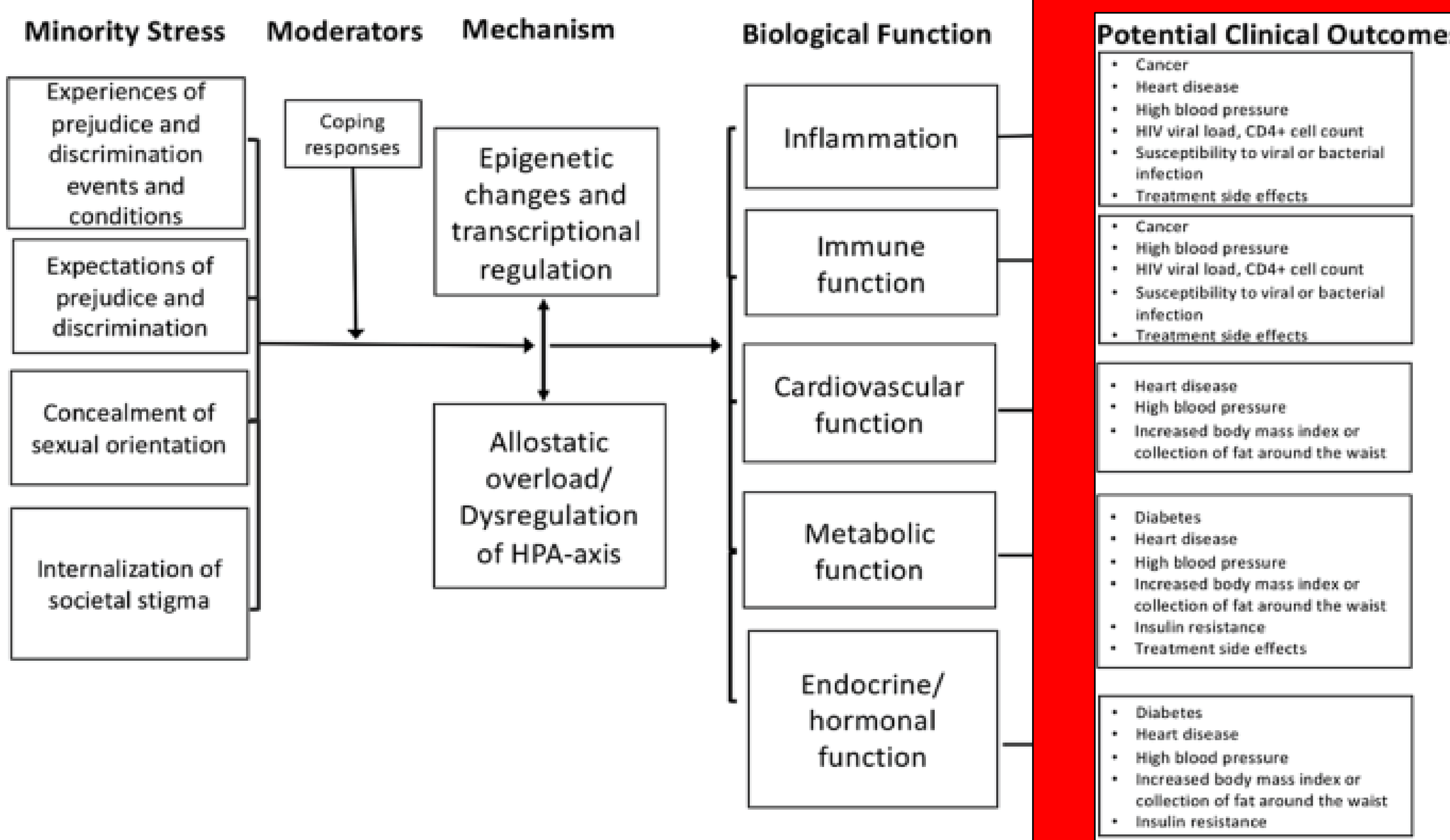
-"Promoting continuity of normality and **self-identity**"

-"Involving **family & friends** in information sharing and decision-making"

*"There remains a **need for primary data** investigating the **meaning and practice of PCC in a greater diversity** ....and a need to ground potential components of PCC within broader **universal values and ethical theory**."*



Minority stress & biological outcomes



J Beh Med 2020

JOURNAL OF PALLIATIVE MEDICINE
Volume 15, Number 5, 2012
© Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2011.0279

Palliative Care Review

Feature Editor: Vyjeyanthi S. Periyakoil

Needs, Experiences, and Preferences of Sexual Minorities for End-of-Life Care and Palliative Care: A Systematic Review

Richard Harding, Ph.D.,[1] Eleni Epiphaniou, Ph.D.,[1] and Jayne Chidgey-Clark, Ph.D.[2]

- Higher incidence of life-limiting and life threatening disease due to risk behaviours linked to discrimination[1-4]
- Higher risk of mental health issues linked to discrimination[5]
- Greater risk of certain cancers[6-7]
- Fears of discrimination lead to later presentation / entry to care[8-9]
- Experiences of discrimination from healthcare providers[10]
- Concerns regarding hostility from church affiliated providers[11]
- Recognised inequalities in access to hospice care[12]

The ACCESSCare studies: an overview

- ACCESSCare A
- ACCESSCare B(ereavement)
- ACCESSCare C(ommunication)
- ACCESSCare e(Learning)
- ACCESSCare Zimbabwe
- ACCESSCare-I (impact)

Original Article

Palliative Medicine
2018, Vol. 32(1) 23–35
© The Author(s) 2017

Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/0269216317705102
journals.sagepub.com/home/pmj

Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study

Katherine Bristowe[1], Matthew Hodson[2], Bee Wee[3], Kathryn Almack[4], Katherine Johnson[5], Barbara A Daveson[1], Jonathan Koffman[1], Linda McEnhill[6] and Richard Harding[1]

ACCESSCare Study

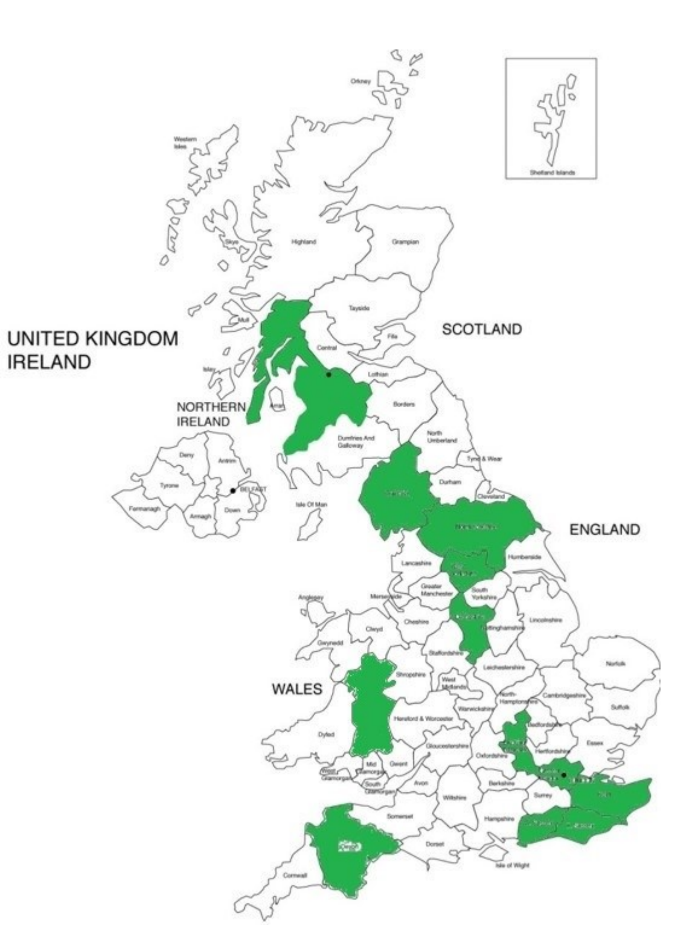
Aim

To co-design evidence-based resources with the LGBT communities to:

- Increase **demand** for appropriate end-of-life care
- Improve **supply** of appropriate end of life care

Resources

- Free downloadable and print resource for LGBT people facing advanced illness
- Training and education resources for health and social care professionals



Participants

Sexual orientation/gender history (self described):

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 Black African or Black Caribbean

Diagnosis:

21 cancer

16 non-cancer

3 co-morbid cancer/non-cancer

Age:

Mean age 60 (range 27-94)

Duration:

Mean duration 75 mins (range 19-152)

Individualised Care – additional or different needs?

Clinical needs

'I think it's no different. Because in every relationship, everybody has their role. If you take the gender out of it, and just treat the individual as the person who does X, Y and Z, and the other person does X, Y and Z, and to know where the resources are within that relationship, that is more important than actually trying to look inside a box called lesbian, gay, transsexual, and saying, "Right, what do I pick out of that box?" It's about what's outside of that box in terms of healthcare. ***What does everybody want? We want to be healthy. We want to be happy. We want to be content. We want to be comfortable. We want to be pain-free****. We want all the things that everybody else who is a mammal, feeling thing wants.'*

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

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, 68, trans lesbian woman living with lung disease

Psychosocial needs

'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

'The prognosis was shattering frankly. ***There is a slightly different dynamic between two women who had never even considered having a family as it really 'wasn't done'.*** *You're perhaps bound up in each other rather more to the exclusion of others.'*

Nicola, 68, bereaved partner of lesbian woman who died of ovarian cancer

Experiences with individual clinicians

*'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… 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

*'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**.'*

James, 35, partner of Harry, 27, living with Motor Neurone 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 lesbian woman living with COPD

Service and institutional level experiences

*‘**Not knowing what's out there...how do I know what question to ask**?...That's the difficulty that I have...if somebody came up to and said, "Right, OK, XYZ that's what you've got in front of you"... Then I can start asking the right questions...But **not knowing what's out there or what's going on out there, I find it difficult asking the right questions.’***

Edward, 64, gay man living with HIV and prostate cancer

*‘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

*‘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 wish that the literature and everything was a bit more geared towards us**.’*

Alison, 68, lesbian woman living with breast cancer

*‘She also got the company to get the OLGA … logo on the back of their brochure … So as to say, ‘We’re gayfriendly’, sort of thing … **I think that, just having that as a sort of logo is a signal, isn’t it?** You know, it’s a bit like, if you’re looking at hotels, you can google ‘gay-friendly hotels’, for example.’*

Trisha, aged 60, bereaved partner of lesbian woman who died of dementia

Summary of Findings

- Participants shared positive and negative experiences of sharing their identity in healthcare settings
- Many LGBT people are happy to disclose their identity if they feel it is pertinent to their care
  - However, even after disclosing, practice doesn't always recognise relationship
  - Participants described a 'risk assessment' of if and when to disclose (risk vs potential benefits)
- There is often presumption of heterosexuality in communication and service provision
- There a lack of sensitivity around needs and disclosure of identity for trans people
- Fear of, or previous experiences of, discrimination are brought into future interactions, and shape preferences for disclosure[14]

10 simple recommendations

All people facing advanced illness deserve individualised sensitive holistic care. We identified 10 simple recommendations to improve care for LGBT people[14].

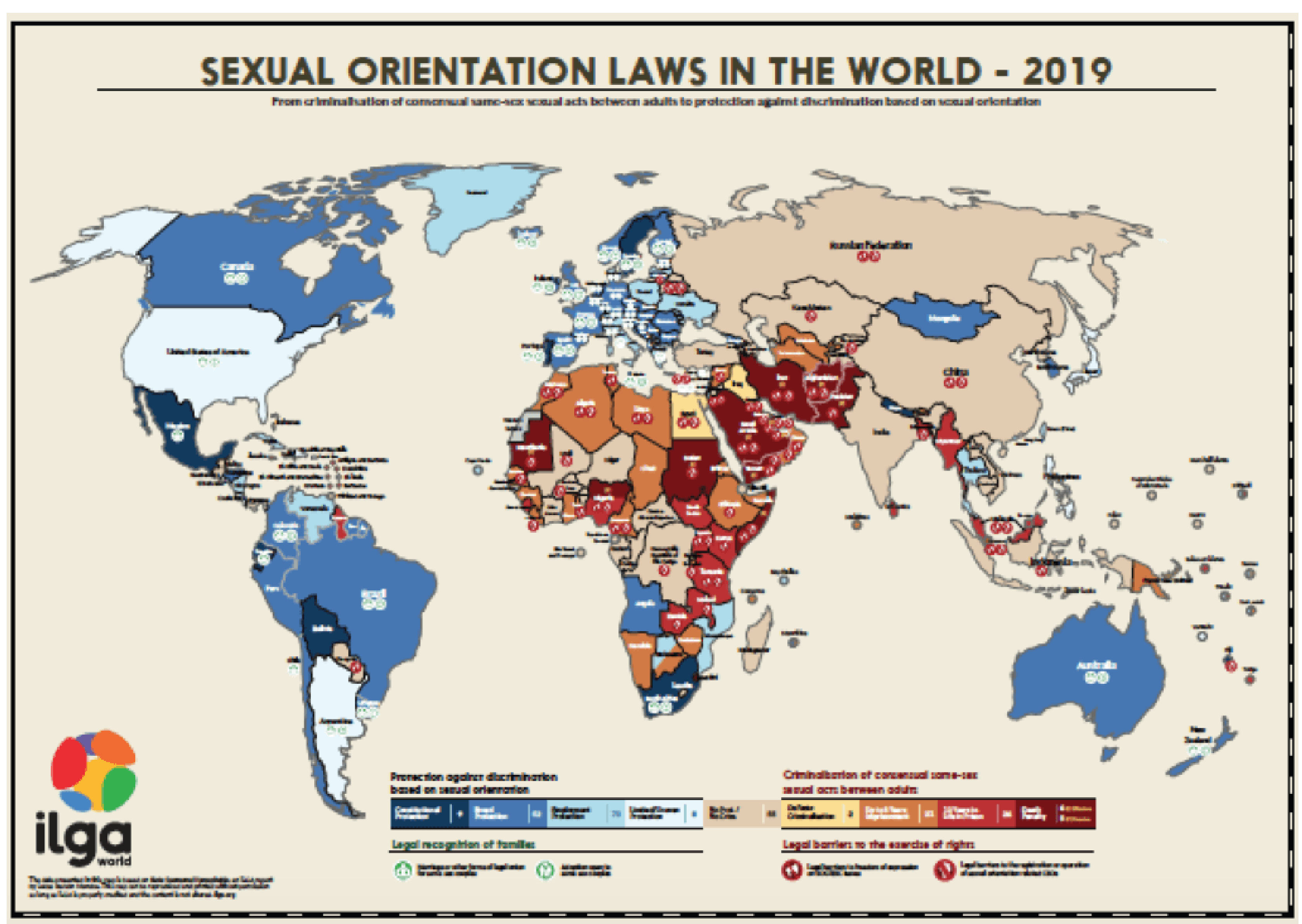
Individual Level

1. Avoid using heterosexually framed or assumption laden language
2. Demonstrate sensitivity in exploration of sexual orientation or gender history
3. Respect individuals' preferences regarding disclosure of sexual identity / gender history
4. Carefully explore intimate relationships and significant others, including biological and chosen family (friends)
5. Explicitly include partners and/or significant others in discussions

Service / Institutional Level

6. Make clear statement of policies and procedures related to discrimination
7. Include content regarding LGBT communities in training on diversity and discrimination
8. Increase LGBT visibility in materials (in written content and images)
9. Provide explicit markers of inclusion (eg. rainbow lanyards or pin badges)
10. Initiate partnerships and/or engagement with LGBT community groups

Findings from this study have been used to develop materials for LGBT people, policy / training and recommendations for health and social care professionals.


SEXUAL ORIENTATION LAWS IN THE WORLD - 2019
From criminalisation of consensual same-sex sexual acts between adults to protection against discrimination based on sexual orientation
Canada
Russian Federation
China
Australia
ilga
world

Sister Study in Zimbabwe[15, 16]

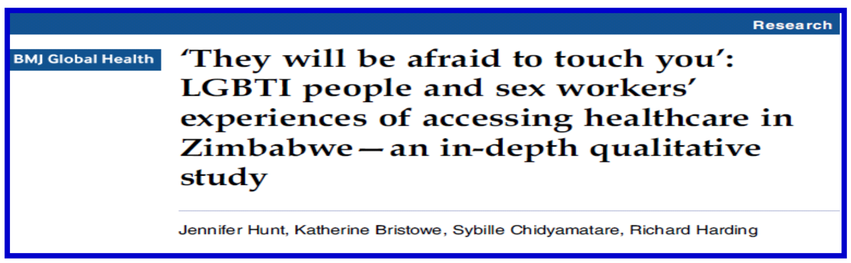
- Led by Jenny Hunt, collaborating with ACCESSCare
- N=60 interview / Focus Group participants
- To investigate attitudes and experiences of key populations (sex workers, MSM, LGBTI), palliative care providers and health workers with respect to accessibility and quality of health and palliative care for these key populations within Zimbabwe

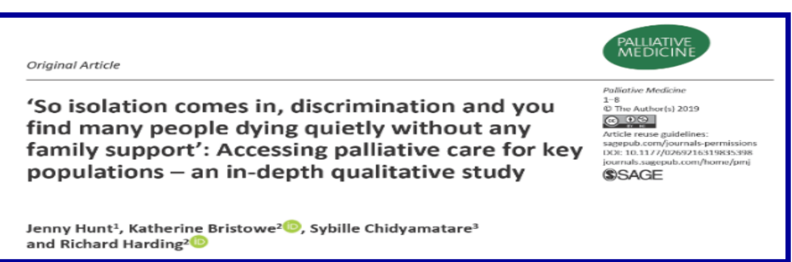
Results: 3 distinct themes

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


Research
BMJ Global Health
‘They will be afraid to touch you’: LGBTI people and sex workers’ experiences of accessing healthcare in Zimbabwe—an in-depth qualitative study
Jennifer Hunt, Katherine Bristowe, Sybille Chidyamatare, Richard Harding


Original Article
PALLIATIVE MEDICINE
‘So isolation comes in, discrimination and you find many people dying quietly without any family support’: Accessing palliative care for key populations – an in-depth qualitative study
Palliative Medicine
1–8
© The Author(s) 2019
SAGE
Jenny Hunt[1], Katherine Bristowe[2], Sybille Chidyamatare[3] and Richard Harding[2]

‘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’

Palliative Care 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'

Palliative Care 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'

Palliative Care 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 Woman

'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'

Palliative Care 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

ACCESSCare C(ommunication)

AIM:

To understand perspectives & preferences of LGBT+ people with serious physical illness, their significant others and their clinicians, regarding discussion of sexual orientation and gender identity and/or history.

QUESTION:

How should healthcare professionals incorporate exploration of sexual orientation & gender identity and/or history in care, & how should this be recorded in patient records.

SAMPLE: 74 qualitative interviews

- 34 LGBT+ people affected by serious illness
- 13 Informal caregivers/significant others
- 27 health and social care professionals

Open access publication – BMJ Quality & Safety

BMJ Quality & Safety

ORIGINAL RESEARCH

Communication about sexual orientation and gender between clinicians, LGBT+ people facing serious illness and their significant others: a qualitative interview study of experiences, preferences and recommendations

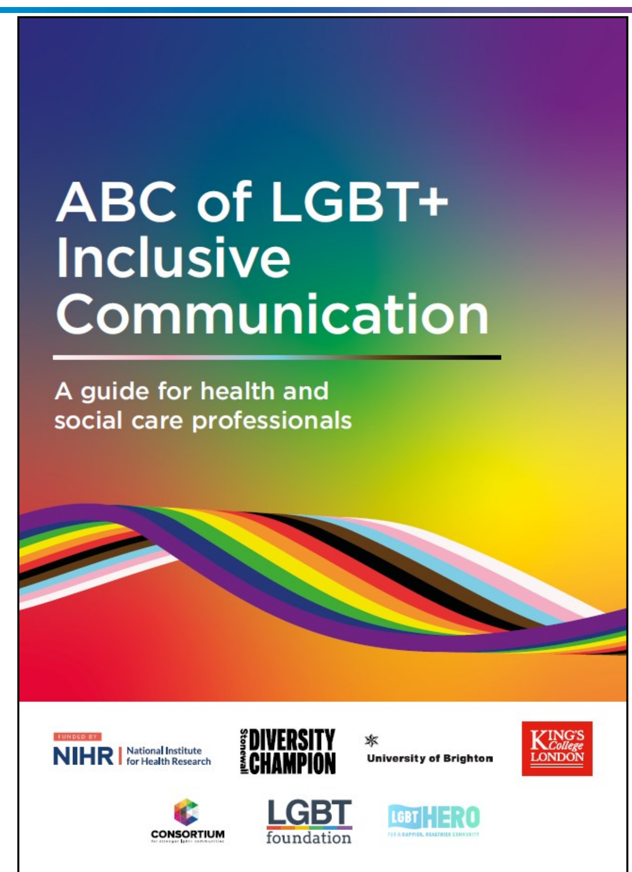
Debbie Braybrook,[1] Katherine Bristowe,[1] Liadh Timmins,[2] Anna Roach,[1] Elizabeth Day,[3] Paul Clift,[3] Ruth Rose,[4] Steve Marshall,[1,5] Katherine Johnson,[6] Katherine E Sleeman,[1] Richard Harding[1]

Evidence-based communication guide

Approach all interactions using inclusive language

Be aware of self & surroundings

Create inclusive opportunities for sharing



LGBT+ inclusive communication guide

"Approach all interactions using inclusive language"

"where someone doesn't know anything about my gender and doesn't want to make an assumption, if they **use gender neutral language**, like refer to me as a 'person' and use 'they' pronouns, then **that will make me feel more comfortable."**

- *Patient, queer non-binary woman, transgender, in their 30s*

"**when you've stated to them that 'this is my husband' it's better that they use that term rather than 'partner', or phrases like 'friend'** [...] in a heterosexual relationship, if you're introducing one as 'husband' and 'wife' you don't then generally say 'this is their partner' **because it implies that they're not married**. The fact that **we are, you know legally in the eyes of the law now**, then that should be respected as well"

- ***Significant other, gay man in his 40s***

LGBT+ inclusive communication guide

"when I say 'lesbian', **I'll look for a little micro-expression** behind the eyes, a twitch or- to see how sensitive they are to it." *- Patient, gender non-conforming lesbian, assigned female at birth, in her 60s*

"**B**e aware of self & surroundings"

"curtains are normally drawn around the patient. So, it's semi-private, but **sound does travel through curtains**. If it's anything delicate, you go off to the room and have a separate conversation."

- Doctor, in his 40s

LGBT+ inclusive communication guide

"**<u>it's important to, if you're *at all* unsure, that you ask. It is better to ask me 'What pronouns do you use?'</u>** rather than call a woman a man, or address a women with masculine pronouns or a man with feminine pronouns. So **<u>any sort of doubt at all, don't be afraid to ask which pronouns you're using.</u>** Now ***don't*** ask 'What pronoun do you prefer?' Because what you're doing is 'What do you prefer?' is like saying (pause) it's almost like you're making a concession."

- *Patient, bisexual female, transgender, in her 50s*

<u>"C</u>reate inclusive opportunities for sharin"g

"where possible **<u>give them the option to not answer</u>**, or rephrase the question if you think you need to, and just be aware that people might find that difficult"

- *Patient, pansexual male, transgender, in his 20s*

Marie Curie
Care and support through terminal illness

Review Article

Palliative Medicine
1–15
© The Author(s) 2016
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/0269216316634601
pmj.sagepub.com
SAGE

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 Bristowe[1], Steve Marshall[2] and Richard Harding[1]

Generic Experiences | **LGBT Specific Experiences**[13]

- Pain [6]
- Loss orientation / restoration orientation [4]
- Continuing bonds [5]

→ **LGBT Bereavement Experience** ←

Additional barriers and stressors
- Experiences around the time of death
- Legal and financial issues
- The shadow of HIV/AIDS

Additional considerations in provision of bereavement support
- Appropriate professional support
- Differing social and familial support
- The societal and community context

Acceptance-disclosure model of LGBT Bereavement[13]

Spoken

Societal acceptance

Overt exclusion

Accepted

Not accepted

Tacit acknowledgment

Invisibility

Unspoken

Psychological Medicine

cambridge.org/psm

Original Article

Does the impact of bereavement vary between same and different gender partnerships? A representative national, cross-sectional study

Liadh Timmins[1,2], Alexandra Pitman[3,4], Michael King[3,*], Wei Gao[1], Katherine Johnson[5], Peihan Yu[1], Debbie Braybrook[1], Anna Roach[1], Steve Marshall[1,6], Elizabeth Day[7], Ruth Rose[8], Paul Clift[7], Kathryn Almack[9], Deok Hee Yi[1], Katherine Bristowe[1,†] and Richard Harding[10,†]

*Professor Michael King was a co-applicant on this grant and contributed to all elements of this study, from design to completion. He sadly died in September 2021, after

National population-based survey

Death Registration data

'Heterosexual' sample:

- Relationship = 'husband' OR 'widower' AND gender of decedent = 'female'
- Relationship = 'wife' OR 'widow' AND gender of decedent = 'male'

'LGB' sample:

- Relationship = 'civil partner'
- Relationship = 'husband' OR 'widower' AND gender of decedent = 'male'
- Relationship = 'wife' OR 'widow' AND gender of decedent = 'female'

Quantitative Post-Bereavement Survey

- **512 bereaved partners**
  - 329 Same Gender
  - 233 Other Gender

Qualitative In-Depth Interviews

- **~20 bereaved partners**
  - LGBT+ and/or;
  - LGBT+ partner

Measures

Grief Intensity	Inventory of Complicated Grief - ICG	Prigerson et al. (1995)
Psychiatric Symptoms	General Health Questionnaire - GHQ-12	Goldberg et al. (1997)
Loneliness	Three item loneliness scale	Hughes et al. (2004)
Social Support	Modified Medical Outcomes Study Social Support Survey - mMOS-SS	Moser et al. (2012)
Caregiver Burden	Zarit Burden Interview - ZBI-6	Higginson et al. (2010)

Table 3. Betas, 95% CIs for linear regressions

	Grief Intensity		Psychiatric Symptoms	
	B [95% CI]	*p*	*B* [95% CI]	*p*
Bivariate association (unadjusted associations)				
Model 1c		Model 1d		
Same-gender Partner	1.16 [−1.14 to 3.46]	0.321	**1.07 [0.39–1.77]**	**0.002**
Model 2c		Model 2d		
Adjusted for potential confounders[a] (final model)				
Model 2c		Model 2d		
Same-gender Partner	1.86 [−0.91 to 4.63]	0.188	**1.54 [0.69–2.40]**	**<0.001**
Adjusted for potential confounders and potential mediators[b]				
Model 3c		Model 3d		

Table 2. Odds ratios, 95% CIs for logistic regressions

	Complicated Grief caseness		Psychiatric caseness	
	OR [95% CI]	*p*	*OR* [95% CI]	*p*
Bivariate association (unadjusted associations)				
Model 1a			Model 1b	
Same-gender partner	1.34 [0.95–1.90]	0.098	1.42 [0.97–2.08]	0.069
	aOR [95% CI]	*p*	aOR [95% CI]	*p*
Adjusted for potential confounders[a] (final model)				
Model 2a		Model 2b		
Same-gender partner	1.56 [0.98–2.47]	0.059	***1.67 [1.02–2.71]***	***0.043***
Adjusted for potential confounders and potential mediators[b]				
Model 3a		Model 3b		
Same-gender partner	1.28 [0.76–2.15]	0.363	1.36 [0.79–2.34]	0.269

Social Science & Medicine 344 (2024) 116616

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

Between loss and restoration: The role of liminality in advancing theories of grief and bereavement

Katherine Bristowe[a,*], Liadh Timmins[b], Alexandra Pitman[d,e], Debbie Braybrook[a], Steve Marshall[a,c], Katherine Johnson[f], Michael King[d,1], Anna Roach[h], Deokhee Yi[a], Kathryn Almack[i], Elizabeth Day[g], Paul Clift[g], Ruth Rose[g], Richard Harding[a]

Original Article

Palliative Medicine
2023, Vol. 37(2) 221–234
© The Author(s) 2022

Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/02692163221138620
journals.sagepub.com/home/pmj
SAGE

LGBT+ partner bereavement and appraisal of the Acceptance-Disclosure Model of LGBT+ bereavement: A qualitative interview study

Katherine Bristowe[1], Liadh Timmins[2], Debbie Braybrook[1], Steve Marshall[1,3], Alexandra Pitman[4,5], Katherine Johnson[6], Elizabeth Day[7], Paul Clift[7], Ruth Rose[7], Deokhee Yi[1], Peihan Yu[1], Wei Gao[1], Anna Roach[8], Kathryn Almack[9], Michael King[4*] and Richard Harding[1]

www.kcl.ac.uk/palliative

The ACCESSCare PPI members

"I am one of the few transgender people who are enough in the public eye to influence public awareness of what needs to be done for equality, care and understanding. It is a role I am happy to fulfil." – *Ruth Rose, trans woman*

"The project is really inclusive. I feel respected and valued and that my voice matters."
– *Liz Day, queer lesbian and supporter of trans rights*

"My experiences of being part of this particular research project have been more than enjoyable, they have been experiences of learning." – *Paul Clift, gay man*

ACCESSCare-I(mpact)

Funding Scheme: Marie Curie Research Impact Fund 2023

Title: ACCESSCare-I(mpact). Driving inclusivity for LGBT+ people facing serious or advanced illness, end-of-life or bereavement: co-design for impact

Team:

Co-applicants: Debbie Braybrook and Richard Harding (Co-PIs), Katherine Bristowe, Sabrina Bajwah, Katherine Sleeman, Stewart O'Callaghan (PPI co-applicant)

PPI team: Hameed Khan, Liz Day, Paul Clift, Ruth Rose

Collaborators:
Michael Brady - *NHS England National Adviser for LGBT Health*
Alex Matheson - *NHS Rainbow Badge Programme Manager, LGBT Foundation*
Dan Bailey - *Co-chair of the KCH King's & Queers LGBTQ+ Network; Consultant Geriatrician, KCH*

AIM: To achieve research impact through codesigned resources, activities and implementation strategies to improve person-centred inclusive care for LGBT+ people facing serious illness, advanced illness, end of life and bereavement.

Marie Curie
Care and support through terminal illness

EAPC Task Force for LGBT+ people

What are we doing? Identifying best practice globally to improve palliative and end of life care for LGBT+ people and the support to those close to them.

So far…

-Developed an international network, currently involving 33 professionals from 13 countries, interested in improving palliative and end of life care for LGBT+ people.

-Identified examples of best practice internationally.

-Drafted evidence-based recommendations with international network.

What is next?

Finalise and share evidence-based recommendations on LGBT+ palliative care globally.

www.eapcnet.eu/eapc-groups/task-forces/improving-palliative-and-end-of-life-care-for-lgbt-people/

Impact through policy, press, education and resources

- Marie Curie. Hiding Who I Am: the reality of end-of-life care for LGBT people[18]
- CQC Thematic Review. A different ending – addressing inequalities in end-of-life care[10]
- Question raised in parliament by an MP to Secretary of State for Health on planned Government response to ACCESSCare
- Presentations to UK & Welsh Parliaments
- Over 120 articles in national and local media, and BBC reports
- Presented nationally to over 1800 health and social care professionals across UK
- Freely available patient resource co-designed with LGBT community
- E-learning to further disseminate to health and social care professionals
- Ongoing work to develop additional resources with Marie Curie
- Led to two further successful grant applications through Marie Curie and NIHR
- National NHS alert for ABC
- Dept of Health NHS LGBT health Tsar workplan