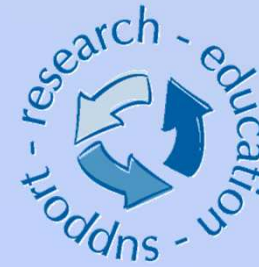


16th Annual Conference of the
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National HIV Nurses Association

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HIV & Faith: The role of spirituality and religion for people living with HIV in the UK

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Background

HIV

- Est. 100,000+ people now living with HIV in UK
- Mostly white gay men & black African people
- Gay men often acquire HIV in the UK
- Black African people frequently acquire HIV in Africa
- Overwhelming majority of black African people religious
- Many gay men spiritually influenced, yet history of religion being intolerant

Sociology background

- Spirituality ~ inner quest; understand & attribute meaning to life & sacred; a transcendent meaning; assumed to be universal human inheritance by some
- Religion ~ how social institutions organise spiritual beliefs, practices and communities; outward expression
(Koenig et al 2001, Moberg 2002, Miller & Thoreson 2003)

Sociology of religion & spirituality

- Complex constructs
- Early sociology (Marx, Durkheim, Weber): religion ~ illusion
- Western 'progress' ~ increasing secularisation
- But also religious revivalism (Lambert 2004)
- Religion & Western culture entwined (Davie 2007)
- The unprecedented rise of patient narratives ~ existential concerns (Hyden 1997)
- Treat spiritual narratives just like other 'meaning-making' narratives e.g. gay liberation/'coming out' (Davie 2007)

Prayer & health

Prayer and meditation ~ also complex constructs

- Prayer = vertical communication, verbal or contemplative, structured or freely composed
- Meditation = concentration & contemplation, a form of prayer (Roberts et al. 2006, Cochrane review), e.g. mindfulness, can be secular

Health & spirituality:

- Many studies show a positive link between health & spirituality/religion (e.g. Ellison & Levin 1998; Koenig 2000; Thoresen & Harris 2000; Stanton et al. 2000)
- Possible mechanisms: e.g. increase hope, social support, helpful ethics for living, clear rules, meaning-making
- But, can be negative (+ -spirituality-health link unclear)

Current research

- Need for research on links bt. spirituality – health
- Current research not concerned with ‘objectivity’
- As Arthur Frank points out, *“the truth of stories is not only what was experienced, but equally what becomes experience in the telling and its reception...”*
- ‘How are spiritual narratives woven into stories of living with HIV?’
- What is the role of prayer as a narrative device?
- How does prayer affect subjectivity? Coping?

Methods

- Healthtalkonline.org (Uni of Oxford)
- Participants > 18 y/o, diagnosed with HIV

In-depth interviews:

- 19 black African people (9 heterosexual men, 10 heterosexual women), one Eastern European heterosexual man
- 24 gay men (20 white UK and Irish)

Focus groups:

- 3 group interviews (black African people, 1 X male, 2 X female)

Sample:

- Recruited from variety of avenues e.g. HIV clinics, peer support groups, newsletters, Internet
- Maximum variation sample (e.g. length of Dx, locale, social class, age)

Methods cont.

Interviews:

- 44 open ended, in-depth interviews, clarified with focus groups
- ‘life story’ approach, use of topic guide
- 60 – 180 minutes
- All fully transcribed and checked
- MAXqda software
- Modified constant comparison
- All authors involved in debating final analysis

Findings...

Black African people:

- deeply spiritual/religious
- Rely on religion/prayer to cope with often severe difficulties
- Navigate high levels of misinformation/stigma
- Become adept at gaining support and leaving the rest...
- Unconditional compassion of Jesus narratives important:

‘God has not cast you out because of your condition. God loves everybody... The lepers were just at almost the same situation as ours... Jesus (put) out a hand and took them on.’

Findings cont...

Gay men:

- Recovering from the wounding messages of religion
- Deploy discourses for self-defence e.g. science, non-homophobic God
- Deep misgivings about organised religion
- In search for authenticity, many do not reject spirituality or all that religion could offer (e.g. may reject literal interpretations)
- Use of New Age discourses

‘...spirituality is that being, belonging... knowing there’s a reason but you don’t know what the reason is... being able to live in harmony with everything else...’

Findings cont...

Role of prayer and meditation: 6 level typology:

1. Simulated counselling
2. Constructing a compassionate 'life scheme'
3. Interrupting negative rumination
4. Promoting mindfulness
5. Promoting positive thinking
6. Getting results

Findings cont...

Simulated Counselling

- Talking about HIV in general seen as essential:
'Talk. Talk. Talk. Talk until you are blue in the face. Then talk again.'
- Prayer constructed as simulated counselling:
'I think when you pray, usually you feel relieved that you've talked to someone.'
- Talking to self ~ rumination loop
- Talking in prayer ~ create reflective space
- Special counselling benefits e.g. 'invisible hand'

Findings cont...

Simulated Counselling

“.... there’s that invisible hand, that support, that you feel, there’s that further support there.... And when you’ve had a pray and you can calmly reflect you know... you feel the sort of calm, you sort of feel calm. And knowing that somebody else is sort of looking after you it’s not just you and your wife... There’s another being that’s looking after... looking over your family and stuff...”

– Black African Male

Findings cont...

Constructing a compassionate 'life scheme'

- Heuristic/shortcut cognitive framework to interpret life events
- Construct universe as ultimately 'just'
- Context of extreme hardship & limited options for black Africans
- Favourable outcomes from prayer
- Elevation of prayer as *the* most effective approach (black Africans)
- Falls from grace & re-entry

Compassionate life scheme cont...

“...I used to pray, I used to get angry with God. Say ‘Why, why, why me? Why my, especially my child, why my child,’ you know what I mean? And then I stopped. Then I used to, then I went through a phase where I was trying to ask the impossible, I was asking for miracles. Yeah? Which was, you know can you get rid of this thing [HIV]? And then, now I've stopped all that. Now I just say just keep us safe, healthy, as long as we're healthy we are fine.... That's all I care about, when I see my child at church playing and stuff and he's healthy and stuff I think that's good. That's good enough for me.”

– Black African Male

Findings cont...

Interrupting negative rumination

- Negative rumination = destructive, repetitive, (often unconscious), stories (Segal et al. 2002)
- CBT says: rumination → -ve mood, depression
- Prayer/meditation ~ displaces -ve rumination
- E.g. Using the Rosary to break rumination:

Interrupting -ve rumination cont...

“This mind person exists, like I talk, and somebody else is talking to me in my mind. It's happen during at nights. I won't sleep. I'll talk to myself. And I will answer. The person who is responding to me, it is me, but it's in my mind. But it's always negative. If I say, 'Why do I have to kill myself?' Then, then, I hear another voice say, 'Yes, you have to kill yourself because you're, you are, you are dirty, you are virus, you can't change anything yourself.' For some... I don't know. I don't know. I do lots of pray. I read the Rosary and everything. I have some courage... I stop having a conversation with myself.” – Asian Gay Male, Mid 30s

Findings cont...

Mindfulness

- Mindfulness discourse & practice discussed by gay men e.g. living now, focus on quality of life
- Draws from New Age discourses

‘Yes by all means think about who you are going to send Christmas cards to. Or who you are not going to send Christmas cards to. But only actually worry about it when you're doing the writing. Plan next January's holiday by all means. But enjoy the planning, because now is the time you're doing it. The holiday might never arrive!’ – white gay male

- Reported benefits of mindfulness e.g. (ironically) a better future

Findings cont...

Promote positive thinking:

- Very wide currency in narratives in general

‘For me, 90% of getting well, it’s in your brains. It’s in the mind’

- Faith and prayer is one path to positive thinking:

‘What faith teaches you is to stay positive and fight on.’

- Limitations e.g. fear of what happens after death:

‘I worry about being dead... What, what is beyond death?’

Findings cont...

Getting results:

- Prayer/meditation linked to outcomes in the real world
- Improvement in thoughts, feelings, sensations
- Common subjective shifts reported (greater calmness, insight, strength, processing of grief).
- Prayer as a subjectivity modulator:

'I became strong. And I am still strong up to today... there are a lot of things that change you in prayers.'

Getting results cont...

“But the fact remains it’s [neuropathy] damn painful. so with breath control I can sort of help it..... it’s an old Buddhist breathing thing that basically I use it through abdominal breathing.... And the extraordinary thing is if you can get through that process, the pain suddenly vanishes.”

– White Gay Male, 50s

Getting results... processing grief

But when [my husband] was on his death bed, he said to me, 'I am sorry, I am sorry. I am leaving you with children, please look after our children, I am sorry for what I did to you.' I didn't know what he meant.... When I was diagnosed... because I knew no men besides him, that is when I realised. When I was diagnosed I was bitter. I cried, I was angry, I said, 'What did you do to me? You knew, why didn't you tell me?' So to me he had killed me, even my children... I had to learn to forgive him. I went to churches, because I was angry... trying to pray and it would just come into my mind and then I would start crying, cussing and calling him names. Yeah. What am I to do, he is gone? I said I have to forgive him and go on, and leave the past, and look after my children. That is how I got over it.

– Black African Female, Early 50s

Conclusion

- Nurses ideally placed to care for diverse/complex UK spiritual groupings (Hodge 2013)
- Skilful use of spirituality/religion/prayer e.g. using Jesus as inclusive narrative, anti-literal Bible interpretations
- Unskilful narratives remain dangerous (e.g. children as 'possessed' (Tedam 2014))
- Prayer works at a number of levels to modulate subjective experience
- At least 6 levels at which prayer operates

Conclusion – different

typologies..

Subsequently, Szaflarski et al. 2012 found in factor analyses 8 dimensions of spirituality/religion in patients with HIV:

- Meaning/peace
- Tangible Connection to Divine
- Positive Religious Coping
- Love/Appreciation (e.g. I appreciate beauty in nature)
- Negative Religious coping (e.g. has God abandoned me?)
- Positive congregational support (e.g. feel included)
- Negative congregational support (e.g. feel rejected)
- Cultural practices (e.g. religious meetings, prayer)

Conclusion cont...

- Collective Christianity of black Africans ('self' submits to God)
- New Age discourses used by gay men 'radically private symbolism' that focuses on self development (God in 'self') (Hanegraaff 1999; Davie 2007).
- Ethnicity central to shaping spirituality/religion (Sadler et al. 2013)
- Mindfulness discourses taken up by gay men (even if mindfulness is not!)
- Mindfulness linked to prayer - concentration

Conclusion cont...

- Prayer could be recast as a ‘do-it-yourself’ health promotion technology
- Patients report it is effective in modulating subjectivity cf. “crutch’ discourse
- Spiritual narratives promote “positive growth since HIV diagnosis” discourses (Dibb & Kamalesh 2012)

Finally....

- Published online: Ridge, Williams, Anderson & Elford, *Sociology of Health & Illness*.
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