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Date :	**June 2016**

‘Clean or Dirty’ ? The changing experiences of care and treatment for MSM diagnosed with HIV

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Aim of the study

- Part of a broader study on exploring patient narratives about their HIV journey
- To explore the experience of changes in care and treatment of MSM among ‘generations’ diagnosed at different time points in the epidemic

Background

- The development of effective and streamlined HIV therapies has transformed the treatment of patients following diagnosis.

- Despite improvements in treatment and life expectancy PLWH's still report high levels of discrimination and stigma[a]

- 1 in 8 MSM in London are HIV-positive with no change in the number of newly acquired HIV infection amongst MSM, which remains high[b].

- Changes in the economic, technological, political and social climate over the last three decades has impacted on the composition and identity of the MSM 'community[c]

Methods

- Qualitative study – semi-structured in-depth interviews
- Recruited from two HIV clinics in London
- Adults over the age of 18 years
- Purposive selection of participants
- Four generations of HIV patients; those diagnosed – Pre-1996, 1997-2005, 2006-2012 and since 2013
- Data management using NVIVO 10; analysis using Framework

Sample demographics

Age

- 20-35: 7
- 36-50: 19
- 51-59: 6
- 60+: 5

Ethnicity

- White British: 22
- White European: 8
- Mixed: 4
- Asian: 1
- Other: 2

Generations

- pre-1996 (n=5),
- 1997-2005 (n=9)
- 2006-2012 (n=16)
- since 2013 (n=7).

Sample size 37

Results

Description of each generation in its context over time together with condensed patient vignettes to illustrate the experience:

- Time of Crisis – pre1996
- Time of Flux – 1997 - 2005
- A new dawn – 2006 - 2012
- Newly diagnosed – 2013 onwards

Internalised and externalised stigma and facing their own mortality is a constant across the generations

Time of Crisis – pre 1996

- Treatment not available
- Good access to professional and non-statutory support
- Patient ‘experts’ alongside clinicians form HIV community
- Public recognition of gay identity as a political force
- Patient involvement in HIV activism and volunteering
- Shared sense of crisis within gay community

Time of Crisis - the patient story

Ian, diagnosed at 21 in 1984, saw access to the HIV community as a life saver

> *“If it wasn’t for them I don’t think I would be here….the more I got involved with other HIV people the more I discovered what I should do or not do for myself”*

He kept healthy, doctor every 1 – 3 months, refused AZT. He describes the *“camaraderie”* in the bars talking all night

> *“so we were too tired to have sex anyway”*

By 1999 he was on ART *“I could relax”* and let the doctor take over.

He values his close relationship with his doctor *“you’re more honest”*

Time of flux – 1997 - 2005

- Treatment options welcomed but feared by patients
- Treatment available but complex with toxic side effects affecting body image
- Patients start to relinquish ‘expertise’ to doctors
- Involvement in activism less widespread
- Newly diagnosed not identifying with the old HIV community

Time of flux – 1997 – 2005 - the patient story

Gary lacked self confidence as a gay man. For him the1990's were sex and drugs. After each test he'd

"sweat it out for a week hoping it would come back OK" .

1999 diagnosed positive. He refused support

"If I stay here (support group) I'll become one of them and it will become my life".

He continued to work and party. He feared ARVs, too many bad stories of people

"shitting their pants, sleepless nights, horrific dreams"

By 2001 he was ill and needed meds *"It was horrific"* **but they worked. Today he counsels young MSM involved in chemsex.**

A new dawn – 2006 - 2012

- Treatment simplified, effective with few side-effects
- Promotion of the self-care model for Long Term Conditions
- Greater individualisation of HIV experience and non-disclosure within MSM community
- Rise of social media (e.g. Grindr) affecting social and sexual mixing within MSM community
- Labelling HIV as ‘dirty’ reducing willingness to test

A new dawn – 2006 – 2012 – the patient story

Eduardo tested every 6 months and used condoms. He was scared of being positive because of stigma

"People ask you are "Are you clean?" Its quite disrespectful and hurtful because they see it a s a death sentence ..I think the worst people are within the gay community"

He tested positive 2009, follow up support from the clinic was poor and he found it difficult to navigate the system

"I felt very alone"

He has not told anyone because he feels stigma is

"so significant and so substantial"

Now HIV is a small part of his life. He sees is clinician every 6 months. He likes his life

Newly diagnosed – 2013 onwards

- Reduced patient contact with HIV clinic and consolidation of remote and virtual clinical services
- Patients encouraged to access GP for non-HIV needs
- Patients less fearful of HIV as an illness; concern about Hepatitis C
- Increased prevalence of chemsex and informal market for ARVs used as PREP
- Return to the concept of peer support for patients

Newly diagnosed – 2013 onwards – the patient story

Shaun diagnosed18 months ago not on ARVs. Six monthly appointments. He thinks the doctor is for his medical care only

> *“I don’t really sense that you would go into your doctor and have a chat about how you are or how you feel. I’m in and out in 30 seconds..he could text me”*

He adjusted to being HIV quickly but he lives with uncertainty about the future and how he will cope

> *“I don’t think it’s a big black cloud, but..it’s going to have a negative impact at some point, drugs or no drugs, side effects, lifestyle, having to take them or getting ill”*

Conclusions

- In an effort to ‘normalise’ HIV clinical care is becoming more remote and patients are encouraged to take more responsibility
- This risks ignoring the growing social politics of HIV within the MSM community and how this acts together – having HIV and being MSM
- This needs addressing in the clinical setting otherwise it may impact on MSM willingness to test and on the effectiveness of the care pathway following diagnosis

Implications for nursing practice

Nurses have a key role to play in addressing these issues by:

- Ensuring the local care pathway incorporates a safe space and the time to enable patients to ‘tell their story’
- Restoring a holistic approach to developing self care within the new model of HIV care
- Developing and/or maintaining the individualised input from the HIV community

Acknowledgements

- All the patients who took part
- Helen Ward and Sophie Day for their advice at different stages of the research
- Chris Higgs and Jane Rowlands who conducted some of the interviews

This study is funded by grants from the Imperial NIHR Biomedical Research Centre and the Imperial College Healthcare Charity. No pharmaceutical grants were received in the development of this study.

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[b] Yin Z, Brown AE, Hughes G et al. HIV in the United Kingdom 2014 Report: data to end 2013.. November 2014. Public Health England, London.

[c] Zablotska I, Holt M, Prestage G. Changes in Gay Men's Participation in Gay Community Life. Implication for HIV Surveillance and Research . AIDS Behaviour March 2011