Uncharted Territory· a report into the first generation growing older with HIV

Terrence Higgins Trust

Introduction

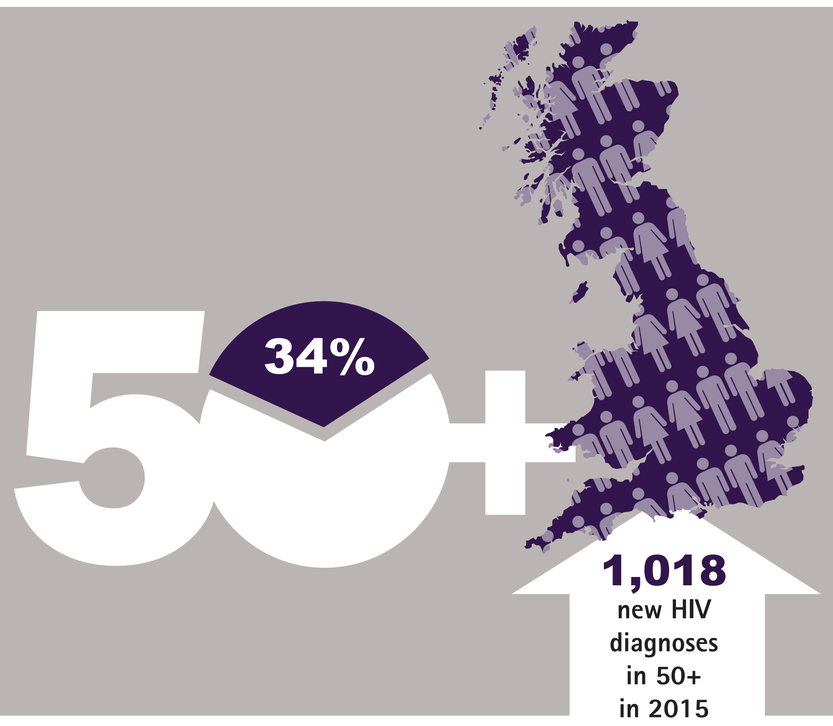
Due to the incredible advances in antiretroviral treatment over the past 30 years we are now seeing the first group of people growing older with HIV. People aged 50 and older now account for one in three of all people living with diagnosed HIV in the UK, as well as one in six of new diagnoses.

In 2010 Terrence Higgins Trust, in partnership with Age UK and the Joseph Rowntree Foundation, conducted the first National Study of Ageing and HIV (50 Plus).The findings from this research led to the development of Terrence Higgins Trust's Health, Wealth and Happiness programme, the first service in the UK specifically targeting the needs of HIV positive people aged over 50.

During 2016 we revisited this work and carried out a new piece of research looking at the experiences and opinions of people who are aged 50 and older and living with HIV today.

Research Aims

- Much has changed in the UK since 2010 and this project aimed to update our understanding of what it means to be growing older with HIV.
- It also aimed to provide an evidence base for Terrence Higgins Trust's policy work on HIV and ageing issues.



Methods

This project was designed as a peer-led research model. Inclusion criteria were that participants (and peer researchers) should be HIV positive, aged 50 or older and living in the UK.

Participants from across the UK were recruited to complete a comprehensive survey covering health, financial situation, emotional wellbeing and views about the future.

This was followed by a qualitative phase implemented by the peer research team. A total of 30 one-to-one interviews and six group workshops were conducted in seven locations across Britain.

Results

In total 307 individuals were included in the research. Ages ranged from 50 to 83 with a median age of 55, 22% of participants were women, 10% were from Scotland, 3% from Wales and 87% lived in England.

The impact of the availability of HIV treatment

Participants diagnosed before 1996 were more likely to be reliant on benefits and were more likely to have three or more health conditions in addition to HIV (with up to 11 additional health conditions reported). Those diagnosed in the age of effective treatment were twice as likely to rate their wellbeing as 'good' or 'very good'.

'50+' is not one category

There were notable differences observed between those aged 50-60 and those aged 65+, with those aged 61-64 showing a mixed picture. People aged 65+ were over twice as likely to rate their wellbeing as 'good' or 'very good'. People aged 50-60 were more likely to experience higher levels of both HIV and age–related self stigma and were more concerned about all aspects of the future.

'I think I've just reached a point in my life now where I'm settled in myself, what will be will be ...you expect to get ill when you get old so that doesn't really bother me. You stop caring what people think I suppose.'

Male, 73, white British, bisexual, diagnosed 2012

Finance

In total 58% of participants were found to be living on or below the poverty threshold[1], which is double that observed in the general population of the same age. Altogether, 37% of participants were dependent on benefits as their sole or major form of income. Those receiving benefits self reported lower wellbeing and higher HIV self-stigma. Two thirds of participants did not own their home.

'Finances... well I don't have any, well nowhere near what I need to be healthy - for the medication to work properly, you need to eat well - but eating well, eating enough costs money, money I don't have. Friends as well, how do you see your friends with no money?'

Male, 52, white British, gay, diagnosed in 2001

Social care

In total 82% of participants were concerned about accessing adequate social care in the future. Concerns around a lack of knowledge, as well as stigma and discrimination, in care home settings were frequently reported. Finance is perceived as a key barrier to accessing adequate care, with 88% of participants having made no financial plans for future care.

One resident living in a care home was told that she had to avoid contact with other residents, could only sit in the same chair, and when she tried to use the TV remote it was taken away and wiped with anti-bacterial wipes.

Case study from London-based care home

Co-ordinated long-term condition management

Participants reported on average three times as many long-term health conditions, in addition to HIV, compared to the general population of the same age[2]. A key concern for the future was around memory loss and increasingly complex health management affecting one's ability to manage one's own health.

65% are taking medication for health conditions in addition to HIV.

Social isolation and loneliness

One third of participants were found to be socially isolated with 3% experiencing severe isolation[3]. Altogether, 82% of participants were found to exhibit moderate to high levels of loneliness[4].This is compared to 50% of the general population of the same age experiencing no loneliness at all[5].

Women

Women reported higher levels of concern for the future and lower levels of self reported wellbeing compared to men throughout the research. They also had a lower average income and were more likely to be careers.

Conclusion

There is huge diversity in the experiences of this cohort spanning from the beginning of the epidemic through to very recent diagnoses. Many people will need little support as they grow older with HIV. However for others who experience complex health and care needs, poverty and poor emotional wellbeing, additional services and support are needed. A well equipped and informed primary health and social care sector, supported by third sector organisations, will be vital.

Health & Wealth & Happiness

Supporting over 50s living with HIV

[1] Defined as £283.80 per week, Institute of Fiscal Studies, 2016 Living Standards, Poverty and Inequality in the UK [Online] Available at: www.ifs.org.uk/uploads/publications/comms/R117.pdf

[2] Barnett, K., et al., (2012) Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross sectional study in The Lancet 380(9836) and Beach, B. (2015) Serious illness in the over 50s published by The International Longevity Centre.

[3] Social isolation was measured and given a score using the Social Isolation Index developed by UCL for use in the English Longitudinal Study of Ageing (ELSA) {Shankar, A., et al. (2011) 'Loneliness, social isolation, and behavioral and biological health indicators in older adults.' In Health Psychology Volume 30(4)).

[4] Defined as a score of 4-9 on the scale (Hughes, M E., et al. (2004) 'A short scale for measuring loneliness in large surveys: results from two population based studies' in Research on Ageing Volume 26(6)).

[5] Shankar, A., (2012) Social Isolation and Loneliness [Online]. Available at: www.ifs.org.uk/conferences/AShankar_ELSA_Presentation.pdf and Banks, J., Nazroo, J., Steptoe, A. (2012) The dynamics of ageing: evidence from the English Longitudinal Study of Ageing 2002-10 (Wave 5) [Online]. Available at: www.elsa-project.ac.uk/reportWave5