

Developing the person-centred needs informed model of care for people with HIV (NICHE) programme: findings from formative qualitative research

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BACKGROUND

People with HIV in England have a high prevalence of mental health conditions compared to the background population; almost 40% have ever been diagnosed with a mental health condition.¹ Intersecting vulnerabilities including psychosocial factors may exacerbate poor mental health and HIV outcomes.²

The Needs Informed model of Care for people living with HIV (NICHE) is a five-year research programme which aims to develop and test a new model of person-centred care to address unmet psychosocial need. As part of the formative work for NICHE, **we aimed to explore what 'living well' meant to people living with HIV, including challenges that can negatively impact quality of life.**

METHODS

We conducted nine focus group discussions between June and September 2023 in London, Devon, Sheffield and Sussex with people with HIV. This included specific focus groups for women; people who identify as lesbian, gay, bisexual, transgender, queer, questioning and more (LGBTQ+); people aged 60+; and people of Black ethnicities.

Topics included (i) challenges and concerns of living with HIV, priorities and support received/required; and (ii) feedback on a proposed new model of person-centred care. This poster presents findings from the first topic.

We analysed transcripts using an inductive approach³ which involved initial coding that was iterated and refined. Analytical notes were also written to see how narratives diverged or compared across individual participants and between groups.

We contextualised our findings in relation to intersectionality⁴ and narratives of biographical disruption.⁵

- **Intersectionality** relates to how an individual's multiple, intersecting identities may lead to experiencing inequities within systems of oppression.⁴
- **Biographical disruption** refers to how having a chronic health condition may impact on a person's sense of self.⁵ For example, a person with HIV could experience internalised stigma when first diagnosed.⁶ However, a diagnosis may also lead to **'biographical reinforcement'** or a positive change to their life (e.g. an opportunity for personal or emotional growth).⁷

RESULTS

Participants (n=37) were from diverse backgrounds (**Table 1**).

We identified three narratives (**Figure 1**) related to 'living well': 1) an unrestricted living; 2) emotional sexual health and intimacy well-being; 3) autonomy of health and healthcare.

Table 1 Summary characteristics of participants

Characteristic	Participants [n (%)]
Age	
18-34	5 (13.5)
35-44	4 (10.8)
45-54	8 (21.6)
55-64	16 (43.2)
65+	4 (10.8)
Gender	
Cisgender woman	11 (29.7)
Cisgender man	23 (62.2)
Non-binary	2 (5.4)
Non-binary transgender	1 (2.7)
Ethnicity	
White British	13 (35.1)
White Other (US, European, Eastern European)	8 (21.6)
Black African	8 (21.6)
Black Other (Black British, Black British-African, Black Caribbean)	4 (10.8)
Mixed/multiple ethnicities	3 (8.1)
Other ethnic group	1 (2.7)
Year of diagnosis	
1982-1995	7 (18.9)
1996-2005	13 (35.1)
2006-2015	13 (35.1)
2016-2021	4 (10.8)
Sexuality	
Gay or lesbian/homosexual	18 (48.6)
Heterosexual/straight	12 (32.4)
Bisexual	4 (10.8)
Queer	2 (5.4)
Asexual	1 (2.7)
Country of birth	
Born in UK	20 (54.1)
Not born in UK	17 (45.9)

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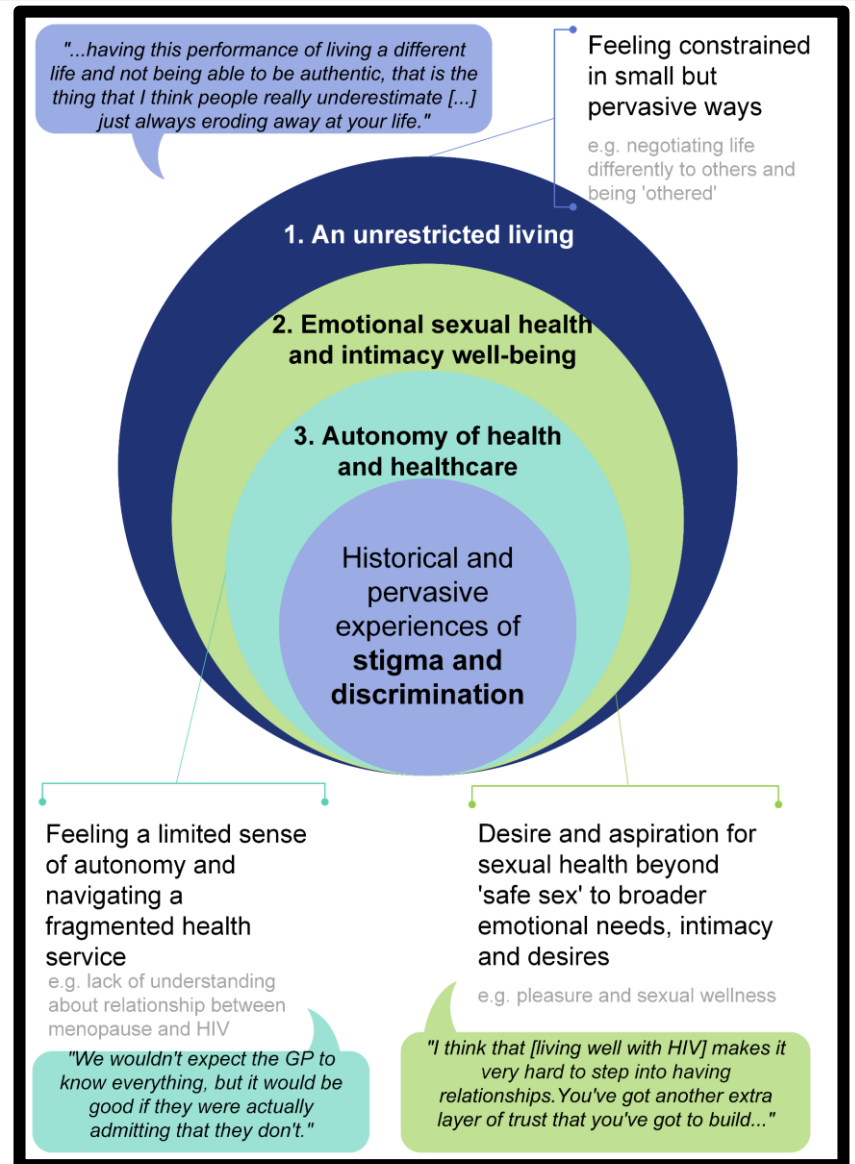


Figure 1 Narratives identified following analysis alongside illustrative quotes

CONCLUSIONS

Stigma has a persistent impact on the well-being of people living with HIV in the UK in multiple forms and manifestations. These experiences can have an impact on the hopes, desires and ambitions of people living with HIV. For example, there are ambitions for living well with HIV including having positive conversations around sexual health, wellness and intimacy.

Different forms of stigma interact with multiple identities, exacerbate social isolation and ultimately result in **biographical disruption and repair**. This occurs despite advancements in the treatment, prevention and life expectancy for people with HIV.

The findings of this study alongside a discrete choice experiment (**poster P384**) and theory of change workshops have been used to design a health and well-being coaching with social prescribing intervention.⁸

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