

AIDS Impact Special Issue

Strategies for improving mental health and wellbeing

used by older people living with HIV:

A qualitative investigation

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ABSTRACT

Recent research into “successful ageing” and “resilience” in the context of ageing with HIV highlights older people living with HIV’s (OPLWH) adaptations and coping strategies hitherto neglected by early research’s emphasis on difficulties and challenges. Yet “resilience” and “successful ageing” are limited by their inconsistent definition, conflation of personal traits and coping strategies, normative dimension, and inattention to cultural variation and the distinctive nature of older age. This article thus adopts an interpretivist approach to how OPLWH manage the challenges to their mental health and wellbeing of ageing with HIV. Drawing on interviews with 76 OPLWH (aged 50+) living in the United Kingdom, we document both the strategies these participants use (for example, “accentuating the positive” and accessing external support) and the challenges to these strategies’ success posed by the need to manage their HIV’s social and clinical dimensions and prevent their HIV from dominating their lives. This points to (a) the complex overlaps between challenges to and strategies for improving or maintaining mental health and wellbeing in the context of ageing with HIV, and (b) the limitations of the “resilience” and “successful ageing” approaches to ageing with HIV.

Keywords: Ageing, HIV, resilience, successful ageing, mental health strategies, wellbeing, interpretivist approach.

Introduction

While early research into ageing with HIV focused on challenges (see Sankar, Nevedal, Neufeld, Berry & Luborsky, 2011), recent research (Hutton, 2016) balances this deficit model with a concern for how older people living with HIV (OPLWH) achieve “resilience” (Furlotte & Schwartz, 2017; Halkitis, Krause, & Vieira, 2017; Subramaniam, Camacho, Carolan & López-Zerón, 2017) and “age successfully” (Emlet, Harris, Furlotte, Brennan & Pierpaoli, 2017; Solomon, Letts, O’Brien, Nixon, Baxter & Gervais 2017). Yet “resilience” and “successful ageing” as conceptual frames have been critiqued for their inconsistent definitions (Lamb 2014; Pruchno, 2015), normative dimensions (including in the HIV/AIDS context - Casale, 2011; De Santis, 2008) that portray the lack of effective or successful adaptation as moral failure (Luthar, Cichette & Becker, 2000), and inattention to such important factors as cultural variation (Martinson & Berridge, 2014), obstacles (e.g. ageism, structural constraints) to achieving “resilience/successful ageing”, and the distinctiveness of older age (e.g. that “advantages and disadvantages that accrue across the life course become more salient in later life” - Katz & Calasanti, 2014, p. 30). Moreover, research into “resilience” typically privileges decontextualized personal factors and adaptive capacities (Wild, Wilkes & Allen, 2013) over active strategic management, and transitions and discrete events over enduring circumstances introduced by e.g. HIV and other chronic conditions.

These limitations lead us to explore OPLWH’s mental health and wellbeing strategies without reference to the resilience and successful ageing frameworks. Instead, we apply an interpretivist approach (Broom & Willis, 2007) that gives analytic primacy to agency, reflection, lived experience, and practical action. In the interpretivist approach within medical sociology, “‘strategy’, in contrast to ‘coping’, directs attention to the actions people take ... in the face of illness, rather than the attitudes people develop” (Bury, 1991, p. 461). Accordingly, we focus here on OPWLH’s strategic management, rather than on these strategies’ role in achieving “resilience”

and/or “successful ageing” or on the relationship between specific strategies, personal attitudes and traits, and mental health outcomes.

Methods

The interview (n = 76) data presented here were gathered for a 2011-2013 multi-method study of the social support, mental health, and quality of life (QoL) of OPLWH (≥ 50 years) in the United Kingdom (UK). We recruited members of the UK’s three largest groups of OPLWH - white men who have sex with men, or MSM; black African heterosexual men and women; and white heterosexual men and women (see Table 1 for participant characteristics) - in London through HIV organizations, two HIV clinics, and one mental health clinic treating a high number of OPLWH. We excluded from the study OPLWH diagnosed for <12 months at the time of the study or who were suffering from a high mental health burden. Each interviewee, and another 24 OPLWH, completed a mental health/QoL survey.

TABLE 1

In semi-structured interviews lasting 90-120 minutes, participants were asked to describe their typical day, personal and medical histories, social relations, social support, and living and ageing with HIV. Interviews were recorded and transcribed *ad verbatim* before anonymization and open and closed coding, then uploaded into NVivo folders for final analysis using a thematic, constant comparative analytic approach (Glaser & Strauss, 1967).

To assure anonymity, we identify participants by gender, sexuality, and ethnicity (men who have sex with men as MSM, black African and white heterosexual male participants as BAM or WHM respectively, and black African and white heterosexual female participants as BAF or WHF, respectively), age by decade, and status as recently or longer-term diagnosed (RD or LTD, diagnosed for <10 years or ≥ 10 years at interview, respectively).

Results

Participants used various strategies to maintain or improve their wellbeing in the face of such ageing and HIV-related challenges as the mutual exacerbation of ageism and HIV-related stigma, and consequences for financial security of disruptions to professional careers by HIV (Rosenfeld, Anderson, Ridge, Asboe, Catalan, Collins, Delpech & Tuffrey, 2015); disclosing HIV status, including to children (Rosenfeld, Ridge, Catalan & Delpech, 2016); and uncertainty over the cumulative health consequences of HIV, HIV medications, and “normal ageing” (Rosenfeld, Ridge & Von Lob, 2014).

These strategies (see Table 2) clustered around two broad efforts: shifting focus away from their own HIV to other aspects of their current lives and/or towards new activities and social contacts, and securing support from external agencies. Our analysis uncovered four strategies for shifting focus: comparing their own health with that of others (*making comparisons*); *volunteering*; valuing and pursuing positive circumstances and/or activities (*accentuating the positive*); and taking steps to attribute benign meanings to their HIV medications (*minimizing the role of HIV medications*). They also used two strategies to secure external support: *accessing support from mental health professionals*, *accessing support from HIV organizations*, and *avoiding HIV groups* to prevent HIV from ‘dominating’ their lives.

TABLE 2

These strategies often overlapped within single accounts, as in P6’s (RD BAF, 60s) description of moving from untreated depression to mental health treatment to attending HIV support groups (two instances of accessing external support), where she engaged in comparison work (a ‘shifting focus’ strategy): “I was in denial and depressed until I went on antidepressants ... the psychologist helped me a lot ... she told me to go to the HIV support group ... people could talk about their HIV, how their husbands had left them ... it lifted me up”. Here, we outline these strategies as described by participants to uncover their own agentic engagement with their wellbeing and the limits of the “resilience” and “successful ageing” frameworks for capturing them.

Strategies for improving mental health and wellbeing

I. Shifting focus

1. Making comparisons

Participants frequently compared the challenges they and other OPLWH faced with those of equal or greater severity faced by others. Some comparisons were with generalised others, as when (RD MSM, 60s) said, “We’re fit and healthy, probably healthier than half the people walking down the streets now”. Participants also compared ageing with HIV with “normal ageing”; as P4 (RD MSM, 50s) explained, “for a lot of older people, life’s a severe challenge anyway ... there are plenty of other severely challenging conditions”. Although participants considered HIV a distinctive condition due to its stigmatization, here they equated the demands of living with HIV with those of living with other medical conditions. As P57 (RD BAM, 50s) explained, “Diabetes, there’s some things you can’t do, HIV also”. Other comparisons were with HIV-negative and HIV-positive individuals whom participants knew personally. P13 (RD MSM, 50s) viewed his own health through the lens of a life-long friend’s “terrible problems with his joints”; when he saw him during a visit home, he thought “I’m HIV, but look at him, he’s worse than me”.

2. Volunteering

For several participants, volunteering provided a focus, purpose, and opportunities to make a social contribution and reciprocate for support they had received. P82 (RD BAF, 50s) volunteered for an HIV outreach program because, “As a survivor who was helped by my consultant, nurses, relatives, friends, I felt if they did that to me, why can’t I do it to others? ... You can’t just receive and then you don’t give away”. That volunteering kept P81 (RD MSM, 70s) “active, both physically and mentally” helped “the HIV situation because you can push it to one side rather than just sitting at home. But also, I really feel that I’m putting something back into society”.

When describing volunteering activities, several participants emphasized the added value of leaving the house, shifting the focus from their own circumstances to a wider world. P57 (RD BAM,

50s) started volunteering at an HIV organization when he realised that he “can’t stay at home not doing anything ... if I stay at home, that could lead to depression for me, just sitting down”.

3. *‘Accentuating the positive’*

This strategy consisted of taking note of and focussing on positive aspects of their lives – for example, actively valuing and/or pursuing relationships and activities that improved wellbeing.

Participants emphasized positive features of their current lives which, they suggested, helped compensate for the strains of living and ageing with HIV. Thus P42 (RD WHM, 60s) noted that he had “a job that I like, I have a girlfriend that I like, I have a TV, so I can see football - I have a very nice pub just over here”. Participants also placed on record the value of friends, family (“as a gay man to be a dad, I’m pretty lucky” - P44, RD MSM, 50s), and partners for their mental health and wellbeing: P32 (LTD MSM, 50s) valued the fact that has “a life, I have a bloke who loves me”, and P57 (RD BAM, 50s) attributed his “happy life”, in large part, to his “stable relationship”.

Accentuating the positive also entailed finding happiness in “simple things” (P13, RD MSM, 50s). For P37 (LTD MSM, 50s), “new things, little things, just going down to the river and having a walk” gave him “enormous pleasure ... I’m not waiting for death in a room on my own, which is what it could be”. Others, like P60 (RD MSM, 50s), “accentuated the positive” by deciding to “live in the moment; enjoy what you’ve got; accept what you’ve got, accept what your life is”.

Against the background of a wider discourse emphasizing HIV’s disruptive effects, some participants actively valued their ability to maintain their previous activities, identities, and roles: P1 (RD WHM, 50s) stressed that despite his HIV undermining his romantic prospects, he was “still the same person: I’m still outgoing, I can still have a laugh and a giggle, and I can still do what I’ve got to do”. Similarly, P43 (RD MSM, 60s) evaluated his life as “very good, because I can still function, I can think, I can create, I can take photos, I can go out for dinner, I can cook dinner - I can do what normal, or non-HIV people, do. We, apart from pills, are non-HIV people”.

4. *Minimizing the role of HIV medications*

Even after deploying the techniques described above, HIV medications, while essential for survival and wellbeing, continued to act as often painful reminders of living with HIV and led to low mood, a sense of emptiness, etc. For example, P12's (RD BAM, 50s) efforts to "encourage myself" to "be happy" allowed him to "sometimes forget that I have HIV", but "when I get home I think, 'Oh, I need to take this medication'". Thus, several participants took steps to ensure that their HIV medications took on benign meanings and, to P16 (LTD MSM, 50s), became part of "the background" rather than "a major part of my life". P50 (RD MSM, 60s) took "the pills like I do cholesterol pills. I don't say, 'Oh, those are the pills of HIV', or 'Look, every morning I'm HIV'". Similarly, by building his HIV medications into his daily routine, P49 (RD MSM, 50s) rendered his HIV "less and less significant to me ... Everything's like clockwork, I take the pills, I don't think about it, because I always have breakfast and I always take the pills with breakfast".

II. Accessing external support

Participants described support by external agencies as positive contributors to wellbeing. For example, all participants considered their HIV-specialist medical care essential for living positive, productive, and enjoyable lives. P4 (RD MSM, 50s) had "plenty of challenges in my life anyway and this is another one, but it's not overwhelming thanks to the marvellous care I've had here [in the HIV clinic]". Participants portrayed mental health services and HIV-specific support organizations as especially valuable venues for formal or informal therapeutic conversations with people who would listen to and support them, and for providing specialist HIV knowledge critical to managing the challenges of living and ageing with HIV.

1. Mental health services

While several participants seen mental health professionals pre-diagnosis, many only sought them out post-diagnosis for help with managing and talking through its repercussions. For example, P10's (LTD BAF, 50s) depression, caused by her diagnosis, improved after she secured mental health treatment: "Psychiatric, it helps. Now I'm okay. You become cool, they give you medication, you

become all right, they advise you what to do”. P17’s (LTD MSM, 50s) therapist “taught me cognitive therapy, so if I do wake up feeling a bit down, or a bit scared, I just sort it out”.

Participants often sought therapies to supplement support from friends, family, and/or partners. P60 (LTD MSM, 50s) saw a therapist because only someone “completely removed from my personal life” would speak to him without placating him or attempting to minimise his distress. For P70 (RD WHF, 50s), speaking to friends was helpful

up to a point but, obviously, they don’t quite understand what I’m going through, that’s why I felt counselling would help. Also, I didn’t want to bore them every time I went out, bore them with me issues. That’s why I did decide to have counselling, reluctantly.

2. HIV organizations and support groups

For most participants, HIV organizations and groups improved their wellbeing by providing practical help and guidance regarding e.g. housing and other benefits, managing medications, and deciding whether and how to disclose their HIV. But these organizations and groups also provided connections to other PLWH which countered participants’ isolation and distress, especially in the period immediately following their diagnosis. Participants emphasized the therapeutic value of meeting and learning from others living with HIV: for example, when P82 (RD BAF, 50s) met her now-best friend at an HIV support group, “she told me, ‘This is a journey. Never give up. Look at me, I’m surviving. I want you to be a survivor, a role model. Take your tablets, listen to your doctor, your nurses, your consultant, and any group that can help you get the knowledge’ ... That’s what I did, and yes, I’m still surviving”. HIV groups also provided a sense of belonging, membership and social solidarity which buffered or assuaged many of the stresses introduced by living and ageing with HIV. By attending these groups, P61 (RD WHF, 60s) came to realise that “I’m not totally isolated because I’m connected to HIV people, HIV groups” and “that the fundamental connection from one human being to another is absolutely imperative to being alive and feeling alive, and pursuing or finding happiness”.

HIV groups also provided opportunities to engage in the comparative work described above. For instance, P47 (RD WHF, 50s) contrasted her medications' "few minor side effects" with the "horrendous time" that some PLWH experience with "all sorts of issues: pneumonia, neuropathy", adding that seeing "some people looking really unhealthy" at "these HIV groups" made her think, "'Oh my God, I hope this doesn't happen to me'. I think, 'Actually, I'm really lucky'". HIV groups also exposed participants to OPLWH who were "doing well", and thus showed them they, too, could live and age well with HIV. When P18 (RD BAF, 60s) met other OPLWH at HIV organizations, "I said 'Is that person sick?' You couldn't believe it. I said, 'Well, if they're sick, then I'll be okay'".

3. *Avoiding HIV support groups*

For some participants, however, attending HIV groups undermined their goal of minimizing HIV's role in their present and imagined future lives, which they considered essential for good mental health and wellbeing. These participants avoided these groups to preclude an "endless focus on that issue" (P45, RD WHM, 50s) that negated other strategies' effectiveness. Thus, for example, P42 (RD WHM, 60s) did not attend these groups because "the less you talk about it, the less you think about it". Several participants had attended HIV support groups post-diagnosis but had gradually scaled back their involvements, both as a result of learning to manage the challenges of living and ageing with HIV and as a strategy for doing so. P59 (RD WHF, 60s) stated that the newly-diagnosed "go through a phase" of focussing on their HIV, but that lingering within that phase risks makes a 'career out of being HIV positive' – a practice she avoided because "I don't want it to dominate my life".

Discussion

Unencumbered by the limitations of the "resilience" and "successful ageing" frameworks, our analysis uncovers a range of cognitive, interpretive, and practical techniques that OPLWH use to limit the negative impacts of living and ageing with HIV on their mental health and wellbeing. Except for professionally-prescribed strategies (e.g. cognitive behavioural therapy), participants used strategies developed by OPLWH themselves, often in collaboration with other PLWH. These

strategies thus represent both participants' deep engagement with their own wellbeing as OPLWH and a local culture of survival.

They also reflect challenges to wellbeing emanating from the very strategies for improving mental health and wellbeing in which these participants engaged: securing information and solidarity from HIV support groups, and adhering to HIV treatment regimens. Thus, the complexities of living and ageing with HIV limit OPLWH's ability to achieve "resilience" and "successful ageing" as defined by researchers, not because of OPLWH's failure or disinclination to conduct difficult strategic work such as that outlined above, but, rather, as a consequence of this work itself.

This points to complex overlaps between challenges to and strategies for improving or maintaining mental health and wellbeing in the context of ageing with HIV, as available strategies become just the sort of obstacles to "resilience" and "successful ageing" that these frameworks fail adequately to consider. Our findings thus confirm the problematic nature of these conceptual frameworks for, here, living and ageing with HIV. Future research would benefit from considering these overlaps and the difficulties they introduce as factors that shape OPLWH's lived experiences and challenge the utility of the "resilience" and "successful ageing" perspectives for studies of ageing and/or HIV.

Limitations of the study

While our sample represents the three largest groups of OPLWH in the UK, our exclusion criteria limit our findings' generalizability to OPLWH who are not experiencing severe mental distress. Although our sample includes OPLWH who had been diagnosed in later life, it does not include a sufficiently large number diagnosed aged 60 years and older to allow for robust conclusions as to potential effects of diagnosis in these older ages on OPLWH's wellbeing and mental health strategies. Further, more targeted research adopting our interpretive approach would provide a more inclusive picture of this population's mental health and wellbeing practices.

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TABLE 1: Participant Characteristics

| | |
|-------------------------|---|
| Number of participants | 100 (76 interviews, 24 stand-alone mental health/QoL surveys) |
| Age | 50-87 (median age 56.0, mean age 58.4 years) |
| Age at diagnosis | 24-79 years (median age 47 years, mean age 47.2 years, SD 10.5 years). |
| Years since diagnosis | 1-32 years (median 10 years, mean 11.4 years, SD 7.8 years) |
| Ethnicity and sexuality | White MSM 53 (gay men 50, bisexual men 3) White heterosexual men 8 White heterosexual women 8 White bisexual women 1 Black African heterosexual men Black African heterosexual women 17 Black African women of unknown sexual orientation 1 |
| Employment status | Full or part-time paid employment: 28 Retired: 20 Not in paid work 52 |
| Partnership status | 67% single (46 MSM and white heterosexuals, 21 black African participants) 33% partnered (25 white, 9 black African) |
| Parenthood | 52 (97% of black African, 82% of white heterosexual, and 17% of MSM participants) |
| Grandparenthood | 1 MSM, 60% Black Africans, 31% white heterosexuals |
| Living arrangements | Living alone 59 (65% of white heterosexual, 59% of white MSM, and 57% of black African heterosexual participants) Living with a partner 20 Living with one or more children 15% |
| Annual income | £0-120,000 (median £10,400, mean £20,430, SD £24,240) Less than £10,000 per annum: 48% (76% of women) |

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|--|--|
| | <p>and 41% of men; 83% of Black African and 35% of White participants)</p> <p>Less than £31,000: 80</p> |
| <p>Receiving one or more welfare benefits (Disability Living Allowance; Employment and Support Allowance, including Incapacity Allowance; Housing Benefit)</p> | <p>Overall sample: 55%</p> <p>Women 78%</p> <p>Men 47%</p> <p>Black Africans 73%</p> <p>White heterosexuals 53%</p> <p>MSM 45%</p> |

TABLE 2
Strategies for improving mental health and wellbeing

| <i>III. Shifting focus</i> | |
|--|--|
| Strategy | Sub-theme |
| <i>1. Making comparisons</i> | <ul style="list-style-type: none"> *generalised others *personal contacts *“normal ageing” *other medical conditions |
| <i>2. Volunteering</i> | <ul style="list-style-type: none"> *focus/purpose *shifting focus to wider world *contributing *reciprocating |
| <i>3. Accentuating the positive</i> | <ul style="list-style-type: none"> *value of current circumstances, abilities, relationships, and roles *‘living in the moment’ *‘simple things’ |
| <i>4. Minimizing the role of HIV medications</i> | <ul style="list-style-type: none"> *embedding medications in routines *treating medications like ‘any other pills’ |
| <i>IV. Securing external support</i> | |
| Strategy | Sub-theme |
| <i>1. Accessing support from mental health professionals</i> | <ul style="list-style-type: none"> *managing/talking through repercussions of HIV diagnosis *supplementing support from friends/family/partners |
| <i>2. Accessing support from HIV organizations</i> | <ul style="list-style-type: none"> *practical help and guidance therapeutic value of meeting and learning from other PLWH *belonging, membership and social solidarity *opportunities for comparative work *exposure to ‘living examples’ of ageing well with HIV |
| <i>3. Avoiding HIV support groups</i> | <ul style="list-style-type: none"> *precluding ‘endless focus’ on HIV |