



## How older people living with HIV narrate their quality of life: Tensions with quantitative approaches to quality-of-life research

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### ABSTRACT

This article draws on life-history interviews with older (aged 50+) people living with HIV in England to uncover the interpretive practices in which they engaged as they evaluated their own quality of life (QoL). Our paper highlights the distinctive insights that biographical and narrative approaches can bring to QoL research. While accounts of subjectively 'poor' QoL were relatively straightforward and unequivocally phrased, accounts of subjectively 'good' and 'OK' QoL were produced using complex interpretive and evaluative practices. These practices involved biographical reflection and contextualization, with participants weighing up and comparing their current lives' 'pros' and 'cons', their own lives with the lives of others, and their present lives with lives they had imagined having at the time of interview. Thus, 'good' and 'OK' QoL were constructed using practical, relational, and interpretive work – features of QoL analytically unavailable in quantitative data gathered through standardised measures (including our own survey data collected from these same participants). Our findings underscore the uneasy fit between QoL's quantitative measurement and its subjective understandings and evaluations, on the one hand, and the interpretive work that goes into achieving these understandings and evaluations, on the other.

### 1. Background

Effective antiretroviral medications now allow people living with HIV (PLWH), if diagnosed at early stages (Croxford et al., 2020), to expect a normal life span (Nakagawa, May et al., 2013). Yet these medications do not guarantee a good quality of life (QoL), given PLWH's disproportionately numerous comorbidities (e.g., Lerner et al., 2020; Falutz, 2020; Collins & Armstrong, 2020) and such social stressors as HIV-related stigma, concerns over disclosure, social isolation, and uncertain futures (Ghiasvand et al., 2020; Rosenfeld, Ridge, & Von Lob, 2014). This gap between extended life expectancy and QoL in the HIV context has led many researchers (see e.g., Andersson et al., 2020; Safreed-Harmon, Anderson, Azzopardi-Muscat, Behrens, & Monforte, 2019; Guaraldi et al., 2019; Harris, Rabkin, & El-Sadr, 2018; Lazarus et al., 2016; Pozniak, 2014; Zeluf-Andersson et al., 2019) to consider how to improve the QoL of PLWH in an era of effective viral suppression and increased longevity.

As with most research into QoL, including health-related QoL (HRQoL), in other populations (Lysaker et al., 2005), research into

PLWH's QoL is overwhelmingly quantitative (see e.g., Fredriksen-Goldsen et al., 2015), generally relying on such surveys as the WHO-QOL HIV-BREF (see e.g., Cho et al., 2019; Kteily-Hawa et al., 2019) or seeking to devise similar instruments designed to measure QoL and/or identify factors that might increase it (see e.g., Brown et al., 2018; Webster, 2019). Other scholars apply quantitative measures to narrative accounts of living with HIV (see e.g., Macapagal et al., 2012) to identify pre-selected factors linked to QoL in previous research. Yet, while widely seen as a valuable means of collecting data from sizeable populations to provide a cross-sectional assessment of QoL, predict treatment success (Haraldstad 2019, 2642), compare key factors across populations, identify disparities, and inform health treatment and policy, quantitative studies of QoL are subject to a range of critiques.

First, despite its exponential growth since the 1970s, there is still no consensus in QoL research on how to define and measure QoL (Haraldstad 2019, 2643), nor has consensus emerged 'about whether quality of life can or should be measured (Moons et al., 2006, 892). Critics have noted that QoL researchers privilege issues of measurement over

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conceptual clarification, use QoL, health status, and functional status interchangeably (and use instruments designed to measure health status to measure health-related QoL – see [Andresen & Meyers, 2000](#)), and conflate QoL's indicators with their determinants. The lack of conceptual clarity in the field has given rise to such problematic practices as measuring QoL against idealised, normativised standards of health and functionality; giving more weight to 'limitations and impediments, without considering positive elements that contribute to quality of life' ([Moons et al., 2006, 896](#)) ('of concern to the disability community, who worry that the public does not understand how valuable life can be for people with disabilities' – [Ubel, Loewenstein, & Jepson, 2003, 599](#)); and developing and applying QoL measurements without due attention to cultural and age-related differences. These and other weaknesses (e.g., focusing on health-related QoL to such an extent as to 'substantially overestimate the impact of health-related factors' or 'seriously undervalue the effect of nonmedical phenomena' ([Moons et al., 2006, 896](#)), and eliding how subjective QoL changes over time 'as a function of health alterations' and shifting priorities - [Moons et al., 2006, 895](#)) shape current debates over QoL research.

However, less attention has been paid to the broader consequences of approaching QoL as a standardised measure rather than as a complex, subjective, evolving construction to which analytical access can only be gained *via* close attention to narrative accounts. To those concerned with these wider consequences, the very structure of quantitative surveys necessarily elides the depth and complexity of the work involved in defining and assessing one's own QoL – work that can only be captured by more narrative approaches. As [Duggan and Dijkers \(1999: 180\)](#) write, participants completing quantitative surveys and questionnaires.

- (1) have to adjust to the researcher's logico-deductive framework; (2) are required to use words or phrases that are foreign to them; (3) are expected to express complex opinions and feelings in numbers ordered along a unidimensional scale; and (4) are required to make complex judgments in a compressed period of time.

In contrast, the biographical approach (comprising e.g., life history, life review, narrative, and reminiscence, all of which 'reach for meaning and accounts in individual biographies' provided through first-hand accounts – [Bornat, 2008, 343](#)) gives participants 'the opportunity and time to review and reflect on their lives and the quality of their lives' ([Duggan & Dijkers, 1999: 180](#)), describe these in their own words, and raise their own topics and concerns. Moreover, while quantitative instruments treat QoL as a measure of general wellbeing whose meaning is taken as analytically 'read', the biographical approach places 'the primary responsibility of conferring 'meaning'' on 'the subject, not the interviewer' ([Duggan & Dijkers, 1999, 180](#)).

Thus, the biographical approach to QoL frames the construct as a complex, situated concern whose meaning and evaluation require ongoing interpretive work. To scholars conducting narrative research, this work takes the form of a narrative's 'how' dimension (the constructive process, or how the story is told) and 'what' dimension (the story's substantive focus) ([Marvasti & Gubrium, 2020; Gubrium & Holstein, 2009](#)). Both dimensions are especially relevant for studies of health and QoL, whose construction by researchers, epidemiologists, and policy makers as 'objective measures' often elides their complexity as emergent and subjective constructs involving narrative, interpretive, evaluative, and biographical work ([Phoenix, Smith et al., 2010; Randall & Kenyon, 2004](#)). This work, and the content on which participants draw when constructing, discussing and evaluating their QoL in biographical context, are analytically unavailable in quantitative studies of QoL, including those shaped by preliminary investigations garnering subjective understandings of QoL (see e.g. [Bristowe et al., 2020](#)), and studies using 'patient reported outcomes' which, while 'measur[ing] patients' perceptions of their own health' ([Kall et al., 2020, 2](#)), use surveys or questionnaires solely comprised of set questions with closed, pre-selected options as answers.

Narrative approaches have become important, if contested ([Thomas, 2010](#)), modes of investigating chronic health conditions ([Caddick et al., 2015; Frank, 2013; Charmaz, 2002; Ezzy, 2000; Korhonen et al., 2020](#)), providing access to how individuals variously understand and construct (e.g. [Faircloth et al., 2004; Rosenfeld, 2006](#)), and manage ([Townsend et al., 2006; Zinn, 2005](#)) their experiences of illness, (re)constructions of self ([Charmaz, 1991](#)), and recovery approaches ([Ridge & Ziebland, 2006](#)). Research into HIV narratives have uncovered a range of factors that shape the lived experience of HIV diagnosis, social relations and relationships ([Rosenfeld & Anderson, 2018](#)), and disclosure ([Rosenfeld, Ridge, Catalan, & Delpech, 2016](#)), and ageing with HIV. These findings include the enduring impacts of having lived through the AIDS epidemic in younger years, with memories of the epidemic before effective medications shaping experiences of living with HIV in later years and in the HAART era ([Catalan, Ridge, Cheshire, Hedge, & Rosenfeld, 2020; Hal-kitis, 2013](#)). PLWH's narratives clearly show not only the endurance of HIV-related stigma despite medical developments, but this stigma's intersection with others: for example, for OPLWH, the intersection of ageism with HIV-related stigma ([Emlet, 2006](#)), and, for PLWH across age groups, the 'stigmatization of less-than-perfect adherence to antiretroviral therapy' ([Bernays et al., 2017](#)). Narrative research is especially useful for uncovering artful practices that PLWH devise and use to manage these and other challenges (see e.g. [Rosenfeld, Catalan, & Ridge, 2018b](#)). Yet, although narrative approaches can illuminate gaps between QoL as quantitative measure, and QoL as the product of situated interpretation and evaluation, they remain under-used in studies of QoL.

This article examines narratives pertaining to QoL produced by older (aged 50+) PLWH (OPWLH) in the context of life-history interviews conducted as part of a multi-method study (see Sample and Methods, below, for more detail). We use these data in the absence of similar research that explicitly asked participants to define, consider, and evaluate their own QoL as they narrated and reflected on their life histories. Our goal is not to privilege qualitative over quantitative studies of QoL, or to attribute to narrative accounts 'properties of transparency and validity that other forms of data do not possess' ([Thomas, 2010, 648](#)). We aim instead to highlight the distinctive insights that narrative accounts of QoL can provide, both on substantive and processual levels, and to consider the extent to which current quantitative research captures – or fails to capture – QoL's complexities. Rather than approaching QoL as a measurable entity whose meaning and contours are already established, we scrutinise how these participants arrived at characterizations of their own QoL (QoL as narrative process), and which aspects of their own and others' lives they cite, describe, and evaluate to arrive at their characterisation of their own QoL (QoL as narrative content).

## 2. Sample and methods

This article draws on 74 life-history interviews with men who have sex with men (MSM) and black African and white heterosexual men and women, aged 50+ and living with HIV in England (we have elected not to share our primary data), gathered in 2011–2013 as part of a two-year study into the mental health, QoL and social support of PLWH aged 50+, living in England (see [Rosenfeld & Anderson, 2018; Rosenfeld et al., 2016](#)). With continuous guidance from a community advisory board comprised of PLWH, we conducted three focus groups with OPLWH, then gathered life-history interviews with 76 OPLWH living or securing HIV services in the London area (we excluded two interviews from qualitative analysis due to technical issues but included their completed surveys in the survey data set). Each interviewee, and 24 other OPLWH, completed a survey combining the World Health Organisation's WHOQOL-HIV BREF, which measures self-rated QoL using six domains (physical, psychological, level of independence, social relations, environment, and spirituality and religion) and an overall score; the 13-item [Royle and Lincoln \(2008\)](#) Everyday Memory Questionnaire; and two questions on depression taken from the Bournemouth questionnaire ([Bolton & Humphreys, 2002](#)).

We recruited participants through community-based HIV organisations, two London-based HIV outpatient clinics, and one mental health clinic serving a high number of PLWH to secure a representative sample of recently- and longer-term diagnosed (living with an HIV diagnosis for 1–9 or for 10 or more years, respectively) MSM, Black African heterosexual men and women, and White heterosexual men and women. We secured ethical approvals through the NHS-REC and our host university. We excluded OPLWH diagnosed less than 12 months prior to participation and those who were suffering from severe mental strain such that would make participation in the study harmful to their wellbeing.

Of the total sample (73 men and 27 women), 70 were White (of whom 53 were MSM, eight were heterosexual men, eight were heterosexual women, and one was a bisexual woman), 29 (12 men and 17 women) were Black African heterosexuals, and one was a Black African woman of unknown sexual orientation. The sample was aged 50–87 (median age 56 years, mean age 58.4 years, standard deviation 6.9 years). Years since diagnosis ranged from 1 to 32 (median 10 years, mean 11.4 years).

At interview, a post-doctoral researcher trained in qualitative methods asked participants about their daily lives, personal histories, personal, romantic, and family relationships, history with HIV, social relations and support, ageing with HIV, and hopes and concerns for the future. We also asked participants if they had heard of the term ‘quality of life’ and to tell us what they thought it meant and what they thought their QoL was. In this way, we allowed participants to discuss their QoL on their own terms, and elicited sometimes lengthy accounts and evaluations of QoL, factors affecting it, and how they worked to achieve good or ‘OK’ QoL.

Interviews were professionally transcribed *ad verbatim* and fully anonymised before being subjected to thematic analysis (Attride-Stirling, 2001; Boyatzis, 1998), beginning with close, line-by-line readings of individual transcripts by two members of the team (the project's Lead Investigator, and a Co-Investigator) with the strongest expertise and experience in qualitative analysis. This process generated open codes which were then refined to produce closed codes (Charmaz, 2014) reflecting the nuances and range of themes within the dataset as a whole. Our coding was attentive both to initial themes (social support, mental health, and QoL) around which we had organised the research and to such emergent themes as parenthood, uncertainty, concerns for the future, and romantic relations. We created an NVivo folder for each code and populated each folder with relevant interview data, analysing data contained within specific folders when exploring specific themes (i.e., stigma, diagnosis, ageing) and conducting a constant comparison analysis (Glaser & Strauss, 1967), comparing similar segments of data to identify themes that reflected variations and patterns within the data set, then uncovering and documenting relationships between specific themes. This generated an understanding of how, for example, participants' disclosure practices were rooted in intersecting stigmas (HIV stigma, ageism, racism), fears of rejection and isolation, and subjective understandings of ageing and the life course (see e.g., Rosenfeld et al., 2016). While data on QoL informed many of our other publications, for this article, we subjected the data contained in the QoL NVivo folder to further analysis, identifying and comparing accounts of QoL. This uncovered distinct differences in the narrative structure of accounts of ‘poor’, ‘good’, and ‘OK’ QoL, and clear subjective criteria for good QoL. This, in turn, led us to explore the interpretive work in which participants engaged to evaluate their own QoL as, in their own words, ‘good’, poor, or ‘OK’.

We refer to participants by participant number, age by decade, ethnicity, and sexuality (men who have sex with men as MSM [all MSM in our sample were White]; Black African heterosexual men and women as BAM and BAF, respectively; White heterosexual men and women as WHM and WHF, respectively), and as recently (RD) or longer-term (LTD) diagnosed.

### 3. Findings

#### 3.1. Factors related to QoL: quantitative and subjective ‘measures’

Our first finding was that, except for income, factors associated with participants' QoL as determined by the WHO-QOL HIVBREF (partnership status, income, work status, and being in receipt of benefits - see Catalan, Tuffrey, Ridge, & Rosenfeld, 2017 for more detail<sup>1</sup>) differed from those that participants associated with QoL at interview. Both in response to specific questions regarding their own QoL and in the course of describing their lives post-diagnosis, and regardless of how they judged their QoL at the time of interview, participants listed and discussed one or more of the following as criteria for good QoL (see Table 1): finances; good physical and mental health; functional abilities and independence; financial security; social relationships and social support; and having a balanced life, clear structure to their lives, and clear sense of purpose. These criteria often overlapped within the same account, as when P49 (RD MSM, 50s) said ‘for me, a good quality of life would be being reasonably financially secure, having good health, and having a good, calm existence’. Moreover, when asked to define what QoL meant to them, few participants did so without mentioning or discussing their own lives, either to exemplify their understand of what QoL meant, or to develop and consider their understanding of QoL for themselves.

As Table 1 shows, participants provided the same criteria for good QoL regardless of whether they deemed their own QoL to be poor, good, or ‘OK’. But these accounts also contain two key differences. *First*, and especially when compared to accounts of good and ‘OK’ QoL, accounts of poor QoL contained few if any subtleties or qualifications: participants did not state that their QoL was, for example, ‘kind of poor’ or ‘somewhat poor’, but, rather, that it was poor in absolute terms. Participants who declared their QoL to be poor displayed both a clear understanding of why this was the case, as in ‘it's not a good life, because now that I'm retired, I should have money’ (P63, as above), or ‘I should have a good life, but I don't, because I'm isolated and I'm on my own’ (P34, as above), and an expectation that their characterizations of their QoL as poor, and the reasons why their QoL was poor, would be readily understood by the interviewer, without further explication. In contrast, accounts of good and ‘OK’ QoL were phrased in more layered and complex terms (e.g., ‘I suppose [QoL] means that I'm sort of content with my life, which I suppose I am, yes’ - P70, as above), and, indeed, ranged from ‘good’ (e.g., ‘I have a good life. I have a fulfilled life, nice friends, lucky to be a dad’ - P44, as above) to ‘OK, I guess’ (as in ‘it's patchy. I live for other people, mostly’ - P72, RD MSM, 70s).

*Secondly*, while participants did not, overall, engage in processes of evaluation prior to characterising their QoL as poor, those who declared their QoL good or ‘OK’ did so after engaging in a relatively lengthy narrative process of evaluation. This process consisted of comparing the positive and negative aspects of their own lives, their own lives with the lives of other people, and/or their current lives to those they had imagined having. Here, having previously provided fairly clear criteria for good QoL, as above, participants engaged in lengthy narrative and interpretive work as they assessed whether their current lives met these criteria and, if so, to what degree and with what mitigating circumstances.

#### 3.2. Good and ‘OK’ QoL as narrative work

**Balancing the ‘pros’ and ‘cons’:** Participants who considered their QoL to be good or ‘OK’ compared their lives ‘pros’ and ‘cons’ to arrive at an evaluation of their QoL, or to explain to the interviewer how they had done so. Some explained that despite threats to their QoL, their QoL

<sup>1</sup> Survey data (n = 100 surveys) were subjected to univariate and multivariate analysis using SPSS. Because this was a cross-sectional investigation, it was not possible to establish the direction of statistical association.

'could be worse'. P14 (LTD MSM, 50s) knew that his life 'could be different, better, but I also know that it could be worse'. His life would be better, he said, 'if I had a friend who was still living', 'if I were HIV negative' and 'for a lot of things - if some of the neighbours were not so obnoxious or whatever', characterizing these difficulties as factors that 'you cannot change'. 'But', he continued, his life 'could be worse because I could have become HIV positive when I was living alone - this would have been terrible, I think'. Similarly, P23 (RD MSM, 50s), described his QoL as 'not bad; it could be better', explaining 'I'm not up all the time but I'm not down all the time. I can manage it, basically. I'm not always depressed, I might get depressed, I worry about the future probably more than I should. That's probably the main thing'. Here, P23 'manages' his depression and worries about the future to produce a mental state of variable 'ups' and 'downs'; that his 'downs' are balanced by his 'ups' makes his life both 'not bad' and capable of being 'better'.

These participants invoked biographically specific features of their own lives (in P14's case, the death of his friends, his own HIV status, and his unpleasant neighbours, and in P23's case, his tendency towards depression and anxiety) as narrative anchors for evaluating their own QoL. But they also went on to describe aspects of their lives that balanced, mediated, or partially compensated for these challenges (in P14's case, having acquired HIV while living with others who provided some comfort, and in P23's case, that his depression and anxiety were manageable and thus permitted periods of positive mental health) to narratively produce lives that 'could be worse' – in short, as having 'OK' QoL.

Thus, in these and similar accounts of good and 'OK' QoL, participants engaged in an evaluative process structured along the narrative lines of 'on the one hand, but on the other hand ...', as when P24 (RD MSM, 50s)

stated 'I would like to have a few more friends, and a lot more energy, but my physical environment and the friends that I do have are very good'. P74 (RD MSM, 50s), who defined QoL as 'How you manage day to day, week to week, month to month', listed his life's positive aspects ('I feel well supported. I manage day to day'), then described a more variable QoL ('good and bad days'), gave examples of 'bad days' ('times when I think, oh, this is rubbish'), finishing his account by explaining that 'all in all', his life was a good one, as he was able to 'get around and do what I can', albeit with significant difficulty. This account is almost identical in form to that provided by P75 (RD MSM, 50s), who characterised evaluating his own QoL as 'tricky' given what he called his life's 'pros and cons', ultimately concluding that, 'on a scale of ten, I'm at about six':

The quality of my life overall is OK. I've got a good job - big plus. I've got a nice home, not perfect, a bit on the small side, boiler not working right, toilet doesn't flush, I get one flush every two hours – I could go on about stuff like that, but it's all there. I've got my independence; I've got my own front door ... All that is really, really good, and even having all that negative stuff, because I can have them on my own, which is what I want, that improves the quality of my life. So, I would say it's not perfect, but whose life is?

Some participants explicitly described this process of weighing up 'pros and cons', and of granting more significance and weight to certain factors than to others, as a conscious effort to focus on factors that produced a sense of living a good life. P32 (LTD MSM, 50s) described two ways of approaching his current life and its quality: negatively comparing it to what his life could have been and what he would have preferred it to be (which, he said, would result in 'madness'), and focusing on his life's positive features ('a little life', a loving partner, a home, a sex life) which,

**Table 1**  
Narrative accounts of poor and of good and 'OK' QoL.

Criterion for good QoL	Poor QoL	Good/OK QoL
<b>Finances</b>	No, it's not a good life, because now that I'm retired, I should have money. I have to plan my life. I need shoes, I need clothes. It's cold now. I need electricity, heating, everything. I get to plan nothing. I can't. You see? (P63, RD BAM, 60s). It's not a happy life. It's a different life to what I had ... You're not paid enough to survive on benefits (P22, RD MSM, 50s). No, no, obviously mine is not good at the moment. For as long as I remain out of employment, I cannot have my own finances. I have to be looked after, and I have to buy things from the suggested shops, I cannot go to my own shops and buy what I want. I'm confined to certain areas. So that disqualifies me from the kind of quality life (P83, RD BAF, 50s).	P51 (RD MSM, 50s): Quality of life to me used to be about just houses but it's not about money. I mean money wise I have more than enough money to have a life I like. If I had more money what would I do? I'd just do exactly the same, but instead of spending £50 at the pub on a Friday night I'd spend £150, the drink would be more, but the enjoyment factor would be just be the same. Money doesn't necessarily make you happy, I know that, but enough money gives you freedom, and my quality of life is to have enough money to say no, but real quality of life is the ability to say no I don't want to do that, and I have the finances to live with the consequences of that.
<b>Physical and mental health</b>	[My QoL] is poor. I'm not happy. I'm depressed. I don't sleep well, I've got this pain in my legs now, numbness in my legs, the pain in my back, oh, that's making my life poor. How am I going to live that quality of life with this? (P66, LTD BAM, 50s). Quality of life? I ain't got much ... I'm one of these people, I'm either high or low. I don't fluctuate. So, i.e. going on holiday, that was a high, I go to my friends, I do anything and everything, but it still doesn't take my depression away. It's still there, it doesn't matter what I do (P47, LTD WHF, 60s). Interviewer: Is it a good life?	Considerably I think it is [a good life], yes, because I have a stable relationship and I don't have any worries about my health (P57, RD BAM, 50s). It means a range of things because quality of life depends upon, one, how healthy you are. Apart from the [deep vein thrombosis], I'm healthy. I'm hoping once I've had the surgery, I shall be back to that again. But in terms of HIV, actually, yes, I'm well and healthy, so that's one factor (P81, RD MSM, 70s). I'm happy, I can eat what I want, and then do everything for myself, so I think I have the quality of life I need, yes (P21, LTD BAF, 50s).
<b>Functional abilities and independence</b>	No. I would say yes, but with the other condition, it just makes it a bit frustrating. Because I can't do things I should be able to do (P52, RD BAF, 50s).	
<b>Social relations and support</b>	No, definitely not happy. I should have a good life, but I don't, because I'm isolated and I'm on my own. I don't mean having a partner, but on your own as in friends and things like that. Sometimes I feel absolutely wretched in my head and I have to go out. Then I see a neighbour, and I'm quite good at putting a smile on so they don't see that (P34, RD MSM, 60s).	I have a good life. I have a fulfilled life, nice friends, lucky to be a dad, I think - as a gay man, to be a dad, I am pretty lucky. I have family that I'm not overly close to but close enough to, in my mind; I have a son who I'm incredibly close to; have a partner who I love dearly, and I know loves me. I have a nice circle of friends. So, in terms of my quality of life, it's really good. I have a job I like. What more could I really ask, other than not to be HIV? (P44, RD MSM, 50s).
<b>Balanced life/sense of purpose</b>	Interviewer: So quality of life is a bit of an issue as well. It is, yes, I think because I haven't got enough structure, which I find very hard now, and a routine, and I'm hoping I can pull it around in the next two or three weeks, and I want to try and get back into the gym. That's a big thing for me, to get a bit of routine, because when I do that, I do feel lifted. But it's hard again because you sort of think, well, why should I bother about it? I'm not motivated, I'm not seeing anybody (P33, LTD MSM, 50s).	Yes, I know what quality of life is. How you value your life. I value my life very much, because I still consider myself, I have a long way to go, so I know quality of life. I know why I am living. I am living for a purpose (P78, LTD BAM, 50s).



in aggregate, 'negate' the bad stuff' in his current life (being on benefits, being unemployable, and having 'lost everything'). P32 frames these actions (remembering what he had wanted his life to have been, weighing each factor's significance for his QoL, avoiding 'dwelling' on his life's negative aspects, and mining his life for the 'good bits') as an effort: these are actions that he 'tries' to do:

If I think about how I would like my life to have been, and I try not to because that's bad karma, therein lies madness. If I think how things could've been, I would swap them in an instant. I do not want to be a man who is 52 on benefits, who looks through the papers, who looks at people who are f\*\*\*ing less qualified than he will ever be mentally and who cannot get a job, who lost everything. But, *and the but negates everything before*, I have something I've always wanted. I have a little life. I have a bloke who loves me, who fights with me every day. I have a home. Yes, we have holes in the carpet. I chose to save up for flooring, which is very hard. Yes, I have a sex life. Yes, I have a different life to one I would have ever thought of but *I try and get the good bits out of the bits that I've got* and I try not to dwell on the bad stuff *because the bad stuff is so big* (emphasis added).

**'The lives of others':** Participants also compared their own QoL to the QoL they knew or imagined other people had. Participants sometimes spoke in general terms, as when P8 (RD MSM, 50s) said 'even people I know, everyone's a bit messed up, nothing's perfect. I've got this problem, that problem, but people have got their own, sometimes worse'. Yet, participants more often listed specific aspects of their own and others' lives that they considered pivotal to good QoL (for example, independence, financial stability, and personal relationships) before stating that their own QoL was comparatively better than was other people's. For example, P10 (LTD BAF, 50s), deemed her QoL 'OK, compared to other people', linking her own QoL to her ability to live independently, which others could not necessarily do: 'It's good. I can survive, I can eat, I can walk; I can do anything'. P42 (RD WHM, 60s), declared his QoL 'good' after contrasting his life with that of people he pitied for their lack of enthusiasm for their work and unhappy marriages – neither of which he shared at the time of interview, although his wife had 'cheated on' him before their divorce:

I feel very sorry for people that are not looking forward to going to work every Monday, and just looking forward to Friday, and hate every day they go to work. It must be horrible to live like that, and go home to a screaming wife, and things like that. So I have a good quality of life. I have to say that, even if I'm fed up with what my wife did.

Participants also deemed their lives good or 'OK' after comparing them to those of people with other health conditions. P18 (RD BAF, 60s) considered her HIV 'a normal thing' and herself 'a normal person', saying 'I'm growing old but I'm much better than those people who have other sicknesses. I don't feel any pain in my body now. I'm just a normal person'. Here, some participants pointed to what they perceived to be the relative lack of effective cancer treatments as a reason for their QoL being better than that of people living with cancer, given that PLWH in the United Kingdom had free and ready access to effective HIV medications. As P5 (RD WHF, 50s) explained, 'it's easier to have HIV than it is to have cancer, because at least there's treatments. Because we've got drugs, we can get help. Cancer patients, sometimes there's no help'. Thus P57 (RD BAM, 50s), who had deemed his QoL good because of his 'stable relationship' and lack of 'worries about my health' (see Table 1), described himself as

just like anybody suffering from any other ailment, cancer or anything. There are differences because they're different medical conditions. If you have any medical condition, it's just you have to manage it. You have to understand there are some things you can't do. Diabetes, there's some things you can't do, HIV also. So that's part of life.

Thus, participants' evaluation of their QoL as good or 'OK' was the result of interpretive work in which they engaged during the interview. However, both in response to specific questions about QoL and while producing longer accounts of living and ageing with HIV, several participants also described struggling to achieve 'good' or 'OK' QoL in the context of their everyday lives (a theme we have explored elsewhere – see Rosenfeld et al., 2018) and struggling to interpret their QoL as 'good' or 'OK'. Here, 'good' and 'OK' QoL were the often tenuous and fragile products of ongoing practical, relational, and interpretive work.

### 3.3. QoL as struggle

Some participants described their 'good' or 'OK' QoL as being undermined by concerns (e.g., for the future), as when P23 (see above) stated that he worried about the future more than he 'should'. P60 (LTD MSM, 60s) described his QoL as 'getting worse, currently' due to increasing pain levels, 'which means I take more and more morphine', saying that he worried that 'if I take much more morphine, I won't be able to drive, which will then isolate me. I won't be able to get to do some of the things I now currently do'. When asked to define QoL, P54 (RD MSM, 60s), answered, 'Well, for me, I still want to get around, I think being confined to the house would drive me crazy. I think that would tip me, I'm sure it would, after a while, although you might get used to it. I love getting out, I love walking. If I could stay how I am for a number of years, I'd think myself very lucky'. Thus, although these participants could, at the time of interview, maintain their independence (a key subjective criterion for good QoL) as they defined it (driving, 'getting out'), they also struggled with the spectre of threats to independence with increasing frailty over time.

Other accounts invoked the struggle of interpreting their QoL as falling on the positive side of a tenuous line between good and poor QoL. For some, this line represented concrete challenges, as when P80 (RD WHF, 50s), who considered herself 'sort of content with my life', cited 'not having as much money' as 'the thing that I am most concerned about, probably, in terms of the quality of my life'. Now divorced, P80 was struggling financially, 'because when I took on my flat, I took it on as being married, and obviously I don't have any extra income'. Here, P80's 'OK' QoL was contingent on external factors over which she had little, if any, control. For P75 (RD MSM, 50s), the line between good and poor QoL was that between contributing to society and taking from it without reciprocating: 'That's an important aspect of quality of life', he explained, 'maintaining that independence, maintaining my dignity, maintaining my place in society, as a net contributor, not a net – well, I don't want to use the word scrounger, I really don't mean it like that – I want to be on the credit rather the debit side, and I still am. So, yes, it's all right'. Similarly, P45 (RD WHM, 50s) described struggling to balance his 'logical' assessment of his own assets (moderately good health, work, interests, and the ability to pursue activities, which he sees as essential for good QoL, and which lead him to consider his own QoL as 'not that bad') with the emotional impact of his 'disastrous' lack of friendship and other relationships, which override his 'logical' assessment.

Now, because I've got health in most senses, sort of, job and work and like I've got, I'm sort of ... that's fine. I don't necessarily enjoy the work, but at least I've got a job, which many people haven't got, at least in my situation. I still have interests and activities I can do. I'm quite lucky. I live in a nice place and I can do stuff, I can actually go out. *And those are really important aspects of my life*. The two other aspects, which you'd term as, sort of, friends and relationships, it's a total disaster. *And that tends to colour my view of life* perhaps more than it should, given that. *I've got three things that are really quite good and two things that are bad. But I find myself focusing on the two things that are bad* [laughs]. ... As I probably said in the questionnaire, I probably feel quite dissatisfied with my life *at just an emotional level, and yet logically* I can see that it's not that bad. But *emotionally it feels that way*, because I feel as if I'm on my own in life, to a large extent. I think that's the problem (emphasis added).

#### 4. Discussion

Our aim was to highlight the distinctive insights that narrative accounts of QoL can provide, both on substantive and processual levels, in the HIV context, without privileging qualitative over quantitative studies. We now consider how our analysis of participants' QoL narratives uncovered patterns, variations, and tensions of direct relevance for studies of QoL among PLWH.

*First*, although participants' own criteria for good QoL did not neatly match factors that correlated with good QoL in our survey data, participants did cite several of these factors when discussing their QoL. However, in their narratives, these factors derived their meaning from their relation to other factors, e.g., concerns for the future, how successfully participants managed their lives overall, and how they framed and granted meaning to factors shaping their lives. Put another way, while participants' criteria for good QoL could be listed discretely, as we did in [Table 1](#), participants did not invoke or apply them as isolated, individual factors but, rather, treated them as interrelated, weighing up the significance of specific features of their lives (independence, relationships, life purpose) against each other to arrive at an assessment of their QoL as 'good' or 'OK'. That this necessarily involved complex narrative work points to the potential limits of measuring QoL through pre-selected, discrete questions (about e.g., in P45's case, explored above, health, financial resources, employment, and the ability to pursue activities). While these factors might correlate to good QoL in survey data, they may also appear, in narrative data, to be moderated or even outweighed by other concerns, as when, in P45's case, two concerns (poor friendships and relationships) outweighed four other 'really important aspects' of his life (health, work, interests, and activities).

*Second*, participants' accounts of poor QoL differed in narrative structure from those of good and 'OK' QoL. Accounts of poor QoL were relatively short, declarative, and supplied with little or no voiced evaluation or comparison. Declaring their QoL to be poor in unequivocal terms, without engaging in the complex narrative work explored above, suggests that participants who deemed their QoL poor imagined that the interviewer would readily understand the reasons they gave for their QoL being poor. In contrast, participants who declared their QoL to be good or 'OK' did so after often relatively lengthy comparison and narrative evaluation, as above. This suggests that, for many participants with self-professed good and 'OK' QoL, these characterizations were neither straightforward nor easily understandable by the interviewer.

*Finally*, good and 'OK' QoL emerged as the product of complex narrative and interpretive work. While they had provided criteria for good QoL, participants narratively demonstrated – and often explicitly described – the challenges of applying these criteria to their own lives. Again, this evaluation involved, *inter alia*, deciding which aspects of their own (and others') lives were relevant to evaluating their own QoL (narrative substance), and how much weight to give them in comparison to other dimensions of these lives (narrative process); remembering their past, considering their present, and imagining their future, comparing these, and assigning meaning to their similarities and differences; making comparisons (i.e. comparing their current lives' negative and positive aspects, their past, present, and imagined future lives, as above, and their own lives with the lives of others); and deciding how 'good' they could reasonably expect their QoL to be (again, often through the comparative work noted above), as when P75 said 'it's not perfect, but whose life is?'

The various activities in which participants engaged in the process of evaluating their own QoL may tell us as much about what QoL is as does participants' eventual characterization of their own QoL. We suggest that the time it took for participants to arrive at their evaluations of their own QoL as 'good' or 'OK', and their re-engagement with subjectively relevant factors at different points in the interview/narrative, are significant aspects of QoL's subjective meaning. In these narratives of good and 'OK' QoL, QoL appeared not as a straightforward, easily measurable quality, but as a complex, biographically grounded one that took time and effort to evoke and describe.

These differences in the types of findings that qualitative and quantitative methods provide, even within the same sample, raise questions about purely quantitative measures' capacity to capture QoL as the product of complex and challenging interpretive activities, and as a subjective assessment that may vary over time and in relation to the context in which it is conducted (e.g., quantitative surveys, narrative life-history reviews, daily life). As with all narratives, accounts, and stories, the narratives analysed here are 'interactive and contextual achievement [s]' ([Andersen, 2015](#), 669), shaped by the relations, interactions, and chosen themes that structure the interview and wider discourses that inform its *foci* and sensitivities (see e.g., [Mazanderani & Papparini, 2015](#)). The meanings that participants attributed to features of their lives, and their attributed significance to each other and to their QoL, largely took their form and content from the point in the interview, narrative, and life review in which assessments were made: participants re-engaged themes and concerns, and considered their QoL in relation to biographical milestones and concerns, that they had previously discussed, and in response to the interviewer's requests to define QoL and to consider the quality of their own lives as people living and ageing with HIV. These explicit questions, and the biographical details that participants were encouraged to provide, acted as a background to which they could refer as they worked to make sense of and evaluate their own QoL and make it sensible to the interviewer.

These interpretations, re-engagements, and biographical relevancies are, again, analytically unavailable through closed surveys, whose structure precludes this cycling through, referring back, etc. Given that participants' thought processes as they consider closed survey questions are typically hidden from researchers, and that closed surveys are not designed to inspire the same biographical life review as did our interview, it is impossible to know if participants engage in the complex, reflexive evaluations and interpretations evident in our data when completing closed surveys. The critical question is whether closed surveys would therefore produce different subjective assessments of QoL, or even if they can do so, given these assessments' often equivocal nature as they played out over the course of the interview.

While we recognise that the value of biographical/narrative and quantitative approaches hinges on the purpose of the investigation being conducted, we also draw attention to the gaps between the findings we generated using each of these methods within the same sample as significant for future QoL studies. The complexities of QoL that emerged in these narrative data suggests that QoL's interpretation and 'measurement' are sufficiently linked to the context in which they occur as to problematise the claims to validity across contexts and cases that many quantitative measures have assumed. While surveys can identify specific challenges faced by PLWH and other groups, they cannot capture their variably perennial or intermittent nature, when and how they arise in respondents' lives, and the active struggles they introduce. Nor can surveys capture how participants struggle to evaluate the significance of various factors to, and arrive at an assessment of, their own QoL.

While living and ageing with HIV introduces distinctive circumstances, concerns, and experiences (e.g., intersections between HIV-related stigma and ageism, premature development of comorbidities - see [Rosenfeld & Anderson, 2018](#); [Rosenfeld, Catalan, & Ridge, 2018a](#); [Emlet, 2006](#)) that shape PLWH's perceived QoL, we suggest that our findings are relevant for younger PLWH and, indeed, for other groups, as they highlight quantitative measures' inability to capture the biographical and interpretive work that narrative approaches are designed to capture – work that reflects the complexities of defining and evaluating QoL itself.

#### 5. Conclusion

While quantitative surveys can measure responses to questions based on previously identified areas of concern, they miss the very processes of interpretation and evaluation that signify the difficulties of defining, evaluating, and achieving QoL among the very populations whose QoL

they seek to establish and improve. Given the substantive insights into what QoL means to people living with HIV (and, by extension, to other groups) that these narrative and interpretive practices and struggles provide, we suggest that researchers working across a range of methods pay close attention to the processes involved in evaluating QoL and consider approaching them as not just the 'how' of data generation, but as data in themselves. This would involve gathering narrative data and subjecting it to open analysis rather than applying pre-selected measurements and thus rendering invisible the interpretive work that, we suggest, constitutes the very nature of QoL as an ongoing process of evaluation, comparison, and the like. The biographical approach would, we suggest, help QoL researchers to avoid some of the criticisms levelled against it which we consider at the outset of this article: conceptually privileging negative over positive elements, and health over other factors, measuring QoL against normalised standards of functionality and health, and applying measurements derived from studies of specific age and/or cultural groups to participants to whom they may not apply in the same ways.

**Limitations:** This article's findings are limited by a number of factors. The first is that these data were collected between 2011 and 2013, well before a new era of optimism over the successes in reducing HIV transmission, largely due to the successes of pre-exposure prophylaxis (PrEP), whereby taking HAART protects against HIV acquisition, and treatment as prevention (TasP), whereby PLWH who are virally suppressed due to adherence to HAART cannot transmit the virus. These developments freed many PLWH from concerns over transmitting their HIV to others, and have caused HIV incidence significantly to decline, including in the United Kingdom (O'Halloran et al., 2019; HIV Lancet 2020). This will have affected how PLWH's HIV-related experiences and concerns, although whether – and if so, how – significantly this change has affected OPLWH's experiences and the narrative work in which they engage as they evaluate their own QoL is yet to be determined. The second limitation relates to the study's sample: because most interviewees lived in London (other interviewees accessed services in London), OPLWH living outside of London were underrepresented, as were those who did not access HIV clinical services and/or HIV organisations. Because we secured a sample that represented the largest groups of PLWH living in England at the time (white MSM, Black African heterosexual men and women, and white heterosexual men and women), OPLWH from other ethnic groups (i.e., of Black Caribbean or Asian origin) were excluded from the sample, as were OPLWH who had been diagnosed for less than 12 months or suffering from significant mental. Thus, as with most research, included into the lives of PLWH, the HALL study did not represent the full range of OPLWH living in England. However, the high proportion of PLWH accessing clinical services, and our representative sampling based on demographic information about PLWH in the United Kingdom available at the time, makes us confident that our findings effectively captured this older population's core concerns and experiences.

#### Declaration of competing interest

The authors declare no conflicts of interest with respect to the research, authorship, and/or publication of this article. The authors received no financial support for the research, authorship, or publication of this article.

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