



Age and life course location as interpretive resources for decisions regarding disclosure of HIV to parents and children: Findings from the HIV and later life study



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ABSTRACT

Studies of disclosure amongst older people living with HIV (PLWH) are uninformed by critical social-gerontological approaches that can help us to appreciate how older PLWH see and treat age as relevant to disclosure of their HIV status. These approaches include an ethnomethodologically-informed social constructionism that explores how 'the' life course (a cultural framework depicting individuals' movement through predictable developmental stages from birth to death) is used as an interpretive resource for determining self and others' characteristics, capacities, and social circumstances: a process Rosenfeld and Gallagher (2002) termed 'lifecoursing'. Applying this approach to our analysis of 74 life-history interviews and three focus groups with older (aged 50+) people living with HIV in the United Kingdom, we uncover the central role that lifecoursing plays in participants' decision-making surrounding disclosure of their HIV to their children and/or older parents. Analysis of participants' accounts uncovered four criteria for disclosure: the relevance of their HIV to the other, the other's knowledge about HIV, the likelihood of the disclosure causing the other emotional distress, and the other's ability to keep the disclosed confidential. To determine if these criteria were met in relation to specific children and/or elders, participants engaged in lifecoursing, evaluating the other's knowledge of HIV, and capacity to appropriately manage the disclosure, by reference to their age. The use of assumptions about age and life-course location in decision-making regarding disclosure of HIV reflects a more nuanced engagement with age in the disclosure decision-making process than has been captured by previous research into HIV disclosure, including on the part of people aging with HIV.

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Introduction

At the outset of the HIV/AIDS epidemic in the early 1980s, disclosure of HIV status in the West was an almost exclusive

challenge to men who have sex with men (MSM), who were the most affected by the virus. But the diversification of the HIV/AIDS epidemic along lines of sex, sexual orientation, ethnicity, and nationality has introduced the necessary 'information management' of stigmatized identities (Goffman, 1963) to heterosexual men and women across the globe. The HIV population has further diversified along lines of age, as the emergence of successful antiretroviral medications in the mid-1990s changed HIV from a life-threatening to a manageable

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medical condition, and enables people living with HIV (PLWH) to survive into later life (Justice, 2010; Nakagawa, May, & Phillips, 2013; van Sighem, Gras, Reiss, Brinkman, & de Wolf, 2010). This aging of the HIV population, bolstered by rising rates of HIV acquisition at older ages (Cresswell & Fisher, 2013; Greysen et al., 2013; Smith, Kall, Rice, & Delpech, 2011), introduces yet another layer of complexity to stigma management, as increasing numbers of older PLWH now manage the virus's medical, social, and psychological dimensions from the vantage point and social circumstances of older age (as, for example, parents and grandparents and the children of elderly parents). As with younger PLWH (Fair & Albright, 2012; Fernet et al., 2011; Thoth, Tucker, Leahy, & Stewart, 2014), living with HIV had at its centre dilemmas and strategies related to disclosure of HIV status – a process complicated by fear of rejection (Gilbert & Walker, 2010) and/or causing distress to the disclosed-to person (Derlega, Winstead, Greene, Serovich, & Elwood, 2002; Petrak, Doyle, Smith, Skinner, & Hedge, 2001; Rouleau, Côté, & Cara, 2012), and discrimination (Petrak et al., 2001) and even violence (Brown, Serovich, & Kimberly, 2016).

Yet research into disclosure practices amongst older PLWH remains relatively thin, and tends to replicate the tendency of most other studies of disclosure of HIV and of aging with HIV to, in Sankar et al.'s (2011: 1188) words, conceptualise 'age as a demographic variable only' (by, for example, asking such questions as 'does the age of the PLWH and/or the age of the potential recipient of disclosure affect disclosure decisions, practices, and outcomes?'). Thus, while studies of how young or middle-aged parents living with HIV disclose their status to their young children (see e.g. Delaney, Serovich, & Lim, 2008; Liamputtong & Haritavorn, 2014; McDonald, 2013) have uncovered the centrality of their children's age to the decision-making process, the various uses of age and life course location as interpretive frames for decision-making regarding disclosure remain either wholly unconsidered or, at best, under-theorized. This gap in knowledge is exacerbated by the lack of research into disclosure by older PLWH of their HIV status to elderly parents (but see Shehan et al., 2005).

We argue that this represents a missed opportunity to make use of social-gerontological constructionist approaches that view age and aging in more dynamic ways and that can help us to identify the subjective relevance of age and life course location to disclosure of HIV status in later life. Our analysis of focus groups and life-history interviews that we conducted with older PLWH uncovered significant concerns over HIV stigma and disclosure to sexual and romantic partners, friends, and family (see Rosenfeld et al., 2015). Although participants' sense that age affected how stigma and disclosure affected their own lives as older PLWH was evident in accounts of disclosure to this range of others, it was in accounts of disclosure to parents and children that participants' use of the life course as an interpretive frame for disclosure decisions was most noticeable. As we will show, participants' decisions to disclose to children and/or older parents involve careful consideration of their children's and parents' historical exposure to information about HIV, on the one hand, and of their age and life course location as proxies for both their ability to understand and cope with the disclosed information and their likelihood of learning of their parent's HIV status from others, on the other. These

interlinked assumptions about how others' circumstances, capacities, needs and exposure to new information are distributed across the life course when engaging in decision-making regarding disclosure demonstrate a more complex role of age in disclosure in later life than has been captured by previous research.

Theoretical approach: the life course versus 'lifecoursing'

Dominant thinking about the life course found in wider cultural constructions and in such ahistorically-minded disciplines as developmental psychology depicts aging as a movement through discrete sequential stages of development. This depiction constructs these stages as reflecting innate age-based capacities and characteristics, with middle adulthood positioned, along an 'up' and 'down' hill representing the life course (Hockey & James, 1993), at the apex of human development, capacity/productivity, and integrity/power (Holstein & Gubrium, 2000, 2007; Rosenfeld & Gallagher, 2002).

In contrast to this dominant view of life course stages, transitions, etc. as objective realities impacting individuals as they move across time, critical gerontologists in particular view this model 'of human development as a cultural construction embedded in social interaction and formal institutions (e.g. education and pensions). Yet, as Holstein and Gubrium (2007) have shown, qualitatively-informed scholars who focus on the meanings that individuals and groups attach to 'the' life course vary in the degree to which they problematize the objective 'nature' of developmental stages. Presupposing the actual existence of stages through which individuals move across biographical time, symbolic-interactionist scholars focus on 'how individuals assemble meanings and subjective understandings of everyday realities as they move through various life stations, phases, or stages' (Holstein & Gubrium, 2007, 337). In contrast, an ethnomethodologically-influenced social constructionist approach, which we adopt here, 'concentrates on how the life course itself is constructed and used as an interpretive resource for shaping the meaning of experience in relation to time' (ibid).² As Rosenfeld and Gallagher (2002, 359) wrote, the life course is best conceptualized as an ongoing process of 'lifecoursing', which they define as 'using the typified life course as an interpretive resource for human actions and states'. Actors of varying ages conduct this interpretive work within both formal organizational settings (i.e. education and psychiatry) and less formal settings (i.e. the family and daily interactions) to assess their own and others' capacity to engage in particular actions, including those related to the management of personal and potentially stigmatizing information.

Lifecoursing is an essentially comparative process, with individuals evaluating themselves and others using 'images

² This 'constitutive version of social constructionism' takes its theoretical lead from the works of Schutz (1964) and Garfinkel (1984 [1967]). Schutz and Garfinkel's path-breaking work on the use of 'a stock of knowledge theoretically available to anyone, built up by practical experience, science, and technology as warranted insights' (Schutz, 1964, 120) and interpretive strategies, respectively, to make sense of and reproduce everyday realities underscored the importance of treating social categories, assumptions, and practices as topics for investigation rather than as analytical resources for understanding actors' social worlds.

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