“‘Life-Coursing’ and Accounts for Decisions to Disclose HIV to Parents and Children: Findings from the HIV and Later Life Study

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HIV and Later Life
www.keele.ac.uk/hall
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The Hall Study


Pilot study of social support, MH and QoL of PLWH aged 50+ in the UK

Purposive sample reflecting population of older people with HIV in the UK for ethnicity, sexual preference, sex, & time since acquisition

Recruited through 3 clinics, and several HIV organisations, in London

17 stakeholder interviews

3 focus groups (23 participants), 76 life-history interviews, and 100 surveys with OPLWH

Age range 50-87 (94% were 50-70)
PARTICIPANTS BY GENDER, ETHNICITY AND SEXUAL ORIENTATION

- White Gay Men (50)
- Black African Heterosexual Women (17)
- Black African Women of unknown sexual orientation (1)
- Black African Heterosexual Men (12)
- White Heterosexual Women (8)
- White Bisexual Women (1)
- White Heterosexual Men (8)
- White Bisexual Men (3)
‘LIFECOURSING’

‘Using the typified life course as an interpretive resource for human actions and states’ (Rosenfeld & Gallagher 2002)

Here, actors draw on ‘the’ life course to ‘develop images of growth, progress, or decline through time as guidelines for understanding or as standards for comparison’ (Holstein & Gubrium 2007, 343).
CRITERIA FOR DISCLOSURE

1) Knowledge of HIV
2) Relevance
3) ‘Dramaturgical skill’
4) Likelihood of emotional distress
<table>
<thead>
<tr>
<th>ASSUMPTIONS ABOUT OLDER PARENTS</th>
<th>CONSEQUENCES FOR DISCLOSURE OF HIV</th>
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<tbody>
<tr>
<td>Social worlds shrinking</td>
<td>Reliant on out of date information re: HIV</td>
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<tr>
<td>Disengaged/disengaging</td>
<td>Unlikely to encounter new information about HIV</td>
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<td>Impervious to new developments</td>
<td>Thus more likely to hold stigmatized beliefs</td>
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<tr>
<td>Abilities have peaked/may be waning</td>
<td>And to be distressed by disclosure</td>
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<tr>
<td>Assumptions About Children</td>
<td>Consequences for Disclosure of HIV</td>
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<td><em>Tabula rasae</em></td>
<td>Unexposed to early messages/realities</td>
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<tr>
<td>Expanding worlds</td>
<td>Knowledge of HIV unpredictable and fragmented</td>
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<tr>
<td>Awareness of others increasing</td>
<td>Will encounter information about HIV</td>
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<tr>
<td>Becoming more competent with age</td>
<td>Vulnerable to stigmatized messages</td>
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<td>Likely to be confused/distressed by disclosure</td>
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DISCLOSURE
DECISION-MAKING
OLDER PARENTS

Relevance of HIV: Low

Knowledge of HIV: Limited and out-dated

‘What do you think it would mean to your mum if you turn round and told her? That you’re going to die an early death from AIDS; that’s what she would probably anticipate’ (P49, RD MSM, 50s)
‘She’s an 83-year-old little old lady with everything from diabetes to osteoporosis, via angina, and why should I inflict that on her? What good would it possibly do? I wouldn’t want to impose that information on her. It wouldn’t be fair. That’s how I see it. It doesn’t make the slightest benefit for me. It doesn’t make any benefit for her. It would only worry her sick’ (P24, LTD MSM, 50s)
Relevance of HIV: High

Closeness

Relational longevity

Filial obligation

‘They’ll know eventually’

Knowledge of HIV: Limited but varied & unpredictable
‘There is a kind of plus in disclosing to the family because as you grow older you get weaker and you need someone to give you medicine. If they find out that you have to take that medicine, and you didn’t tell them about it, they will be cross with you, why didn’t you tell them, ‘I didn’t know I had to give you that medicine’ - and there will be a clash between you and them. Unless you think 100% that you are going to be healthy throughout, I think you have to tell one or two around you’ (BAFG#9, LTD BAF)
TIMING DISCLOSURE TO CHILDREN
I. ONLY DISCLOSE WHEN ‘MATURE ENOUGH TO UNDERSTAND’

Understand what?
‘I told the elder one. I want them to grow up. If the person is small when you tell them, maybe he won’t know what you are saying. But the other one, I sat him down and told him about it’ (P21, LTD BAF, 50s).
‘They are still so young that maybe they would say something to their close friends, and I don’t need that. It hasn’t been much of a problem to tell them how I got it, or why, but I just don’t want the people around to know, and that’s why I just choose not to tell them’ (P42, RD WHM, 60s).
‘If before, you disclosed it and you told your children why you have it, you’re okay. But if you have never told them, and then they come to know that you’re HIV, a lot of people think, HIV people were like sleeping with men. It puts you in a corner’ (P10, LTD BAF, 50s)
III. DISCLOSE WHEN DISCLOSURE IS LEAST DISRUPTIVE TO CHILD

‘I live with three [of my children]. I see them every day. One is at uni, one is at college, and one is doing her year eleven this year … All my children know except my girl … I broke the news to the two boys, because they go for testing and they’ve got the education about HIV. But the girl, it’s a tricky situation. Now, she’s in year eleven, she’s writing her GCSE. For me to tell her, I feel I might disturb her education … I was thinking of telling her this year, but I think once she finishes her exams’ (P82, RD BAF, 50s).
IV. DISCLOSE BEFORE CHILD
‘FIGURES IT OUT’

‘They know I take tablets because they see me taking them, but they don’t know what it’s for. And it’ll be a year or two before I broach the subject with them and they see me quite healthy so there’s no reason for them to think any, anything else.

IV  Why would you need to tell them, do you think?
Because they will start asking at some stage, “Why are you taking those tablets?”’ (P56, RD MSM, 50s)
'On the other hand, also it’s becoming a threat to me. These younger kids, they can Google the name of your tablets. And at times, the way she asks, you think, does she know something? So it’s a bit of a heartache to me sometimes’ (P82, RD BAF, 50s)
Age is not just a characteristic of those making disclosure decisions

Is also a resource for those making disclosure decisions, *via* lifecoursing
Lifecoursing as A Comparative Process

When lifecoursing, age does not appear as a static object

Rather, it represents where you are on an upward/downward trajectory

And where you are going
THE LIFEAGE OF MAN.

STAGES OF MAN'S LIFE FROM THE CRADLE TO THE GRAVE.

Until the first fire, there are no laws. A Child is amiable. In all jovial and cheerful.

At ten he must look like a bird and fly. A Child is amiable. In all jovial and cheerful.

At twenty love must With bull-like strength. At forty, strength. Strength falls at sixty. At sixty years old, youth at sixty years old, youth.

At sixty years old, youth at sixty years old, youth.

At seventy years old, youth at sixty years old, youth.

At eighty years old, youth at sixty years old, youth.

The old king has seen much
Much seen hides upon life, youth at sixty years old, youth.

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THE HALL TEAM

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