

# AIDS and Behavior

## HIV disclosure anxiety: A systematic review and theoretical synthesis

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# **HIV disclosure anxiety: A systematic review and theoretical synthesis**

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Running Head: A cognitive model of HIV disclosure anxiety

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## HIV disclosure anxiety: A systematic review and theoretical synthesis

### Abstract

HIV disclosure can help people living with HIV to access social support, enhance antiretroviral adherence, facilitate engagement in care and reduce unprotected sex. Given interpersonal risks associated with HIV disclosure, however, anxiety about sharing one's status is common. To investigate anxiety about HIV disclosure in HIV-positive populations, we conducted a systematic review of qualitative and quantitative studies, with 119 studies included. The review demonstrated that perceived interpersonal risks are associated with HIV disclosure and outlined evidence of associations with anxiety, fear and worry. We present a new cognitive model of HIV disclosure anxiety adapted from clinical theories of health and social anxiety, consistent with evidence from the review. The model attempts to explain the development and maintenance of anxiety in individuals whose functioning is *most* affected by concerns about sharing their status. Implications for helping people living with HIV struggling with significant levels of anxiety about HIV disclosure are discussed.

**Key words: HIV disclosure; anxiety; fear; cognitive; model**

## Introduction

1  
2  
3 HIV disclosure (sharing one's HIV positive status with others) has a number of potentially  
4  
5 positive consequences. HIV partner disclosure can reduce levels of unprotected sexual  
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7 activity, partly through greater condom negotiation and use<sup>1-3</sup>, and facilitate partner HIV  
8  
9 testing<sup>1</sup>. Sharing one's status to partners or others can improve engagement in care<sup>1,4</sup>, and  
10  
11 help in the initiation of and adherence to antiretroviral treatment (ART)<sup>5</sup>, through the  
12  
13 availability of disclosure-specific support or the reduced need to hide medication from  
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15 others<sup>6</sup>. There may also be psychological benefits to status sharing. Well-being may be  
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17 enhanced (although evidence is equivocal<sup>7</sup>) through increased social support<sup>8</sup>, the  
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19 development of more helpful cognitive appraisal of HIV-related stressors and enhanced self-  
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21 esteem<sup>9,10</sup>. HIV disclosure may reduce anxiety levels, although again, evidence is  
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23 equivocal<sup>1,7</sup>.

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31 Given the potential individual and public health benefits associated with HIV disclosure, the  
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33 process of sharing one's status with others could be thought of as a helpful health behaviour.  
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35 HIV disclosure, however, exposes the person living with HIV (PLHIV) to potential rejection  
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37 and discrimination. This is the case whether HIV disclosure is direct (the PLHIV telling  
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39 others about their status), indirect (somebody else revealing the PLHIV's status to others), or  
40  
41 guessed (others concluding that the PLHIV is HIV-positive)<sup>11</sup>. In addition, once one's status  
42  
43 is shared with a particular individual, it cannot be *unshared*. Given the interpersonal risks  
44  
45 associated with HIV disclosure, *anxiety* about sharing one's status is likely to be the norm,  
46  
47 generally serving to inhibit HIV disclosure. Concerns about other people knowing one's HIV  
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49 status may be heightened to the extent that very little or no HIV disclosure takes place. This  
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51 can contribute to feelings of social isolation<sup>12</sup>. There may be some situations, however, when  
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53 anxiety is influential in motivating disclosure rather than non-disclosure (e.g., when the  
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55 PLHIV is concerned about others finding out about one's status from a third party).  
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1 Some models of health behaviour recognise the importance of anxiety. The Self-Regulatory  
2 Model of Illness Behaviour<sup>13</sup> suggests that fear and anxiety (amongst other emotional and  
3  
4 cognitive factors) influences coping with health threats. Fear is also included in the Protection  
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6 Motivation Theory<sup>14</sup> as a factor that influences behavioural intentions and health behaviour.  
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10 To investigate the nature of anxiety about HIV disclosure in HIV-positive populations, we  
11  
12 conducted a systematic review. As rates of HIV disclosure (and potentially the nature of HIV  
13  
14 disclosure anxiety) differ according to context (e.g., the characteristics of the person living  
15  
16 with HIV, the disclosure recipient, route of infection, whether disclosure is direct, indirect or  
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18 guessed, and the time since diagnosis<sup>11,15,16</sup>), our review adopted an inclusive approach to  
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20 study eligibility.  
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## 26 **Method**

### 27 *Study eligibility criteria*

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31 Studies were included in the review if they:

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34 1. Were empirical, reporting primary data;
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37 2. Included HIV-positive participants;
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40 3. Reported or measured anxiety, worry or fear about HIV disclosure or one's HIV  
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42 status being shared;
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45 4. Referred to the PLHIV sharing their HIV status with others, others sharing the  
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47 PLHIV's status with third parties, or others guessing the PLHIV's status;
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50 5. Assessed the association between anxiety/worry/fear about sharing one's HIV status  
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52 and any outcome, or cited disclosure anxiety/worry/fear as a reason for non-disclosure  
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54 or any other outcome.  
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### ***Sources of information and search strategy***

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3 Studies published in peer-reviewed journals were retrieved from the electronic databases  
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5 Pubmed/Medline and PsychINFO. There was no date restriction. The searches were  
6  
7 conducted using combinations of the following terms: ‘anxiety’, ‘fear’, ‘worry’ and ‘HIV  
8  
9 disclosure’ in either the title or abstract. The searches were conducted on 2<sup>nd</sup> January 2015.  
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### ***Data collection and abstraction***

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17 The first author carried out the initial searches. All duplications were removed. The first  
18  
19 author screened the remaining titles and abstracts for eligibility. A random sample of 20% of  
20  
21 the articles at this stage was independently rated by both the first author and a second  
22  
23 reviewer (an undergraduate psychology student). Inter-rater reliability was calculated using  
24  
25 Cohen’s Kappa. The value for Cohen’s Kappa was 0.78,  $p < 0.01$ , suggesting a good level of  
26  
27 inter-rater reliability. Articles considered relevant were retrieved in full text. These articles  
28  
29 were then assessed for eligibility by both reviewers. Exclusions were reported, with reasons  
30  
31 given.  
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37 Data was extracted for the following study characteristics (by the undergraduate psychology  
38  
39 student, verified by the first author): authors; date of publication; location; design;  
40  
41 methodology; nature of the sample including sex and age; nature of disclosure recipient; and  
42  
43 findings relating to HIV disclosure anxiety.  
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### ***Results***

48  
49 After duplicates were removed, there were 426 articles. 159 articles were screened in as  
50  
51 potentially eligible. 119 of these articles were subsequently considered eligible for the  
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53 review. Most commonly articles were rejected as they did not report on anxiety *about HIV*  
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55 *disclosure*.  
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Figure 1 summarises the review process.

**Figure 1 here**

Study characteristics are summarised in Table I.

**Table I here**

### ***Study characteristics***

Fifty one of the studies took place in Africa, with a further 39 studies in North America.

Fifteen studies took place in Asia, with 8 in Europe, 4 in South America and 2 in Australasia.

There were three intervention studies<sup>17-19</sup>. The remainder of the studies were cross sectional.

The most commonly used method to capture data was qualitative interviews (64 studies).

Surveys were used in 43 studies, with focus groups in 18 studies. The other approaches used were self-report questionnaires (8 studies) and participant observations (3 studies). Fifteen of the studies used more than one method.

### ***Participants and disclosure recipients***

Sample sizes ranged from four to 775 (median sample size 52, IQR 26-164). Most commonly (59 studies), participants did not belong to a specific subgroup of HIV-positive individuals.

Twenty three studies were based on parent samples. Other studies sampled ethnic minority groups (eight studies), individuals taking ART (six studies), adolescents (five studies), and

MSM (three studies). The remainder (15 studies) sampled from diverse populations (e.g.,

intervention participants, sex workers and prisoners). Seventy seven of the studies sampled

both males and females, 32 accessed female only samples, and ten studies sampled males

only. The disclosure recipient was not specified in 77 of the studies. HIV disclosure to one's

partner was the focus of 24 studies. Other studies focused on disclosure to children (nine

1 studies), family and friends (five studies), work colleagues (three studies) and dentists (one  
2 study).

### 3 4 5 *Qualitative and survey findings*

6  
7 The most commonly reported reason for non-disclosure or disclosure anxiety theme was the  
8 fear of discrimination or stigmatising responses from others (58 studies). Anxiety about  
9 rejection and abandonment (e.g., divorce from partner) was also reported frequently (54  
10 studies) with the specific fear of partner violence cited in 18 studies. Anxiety about  
11 secondary/indirect disclosure (disclosure recipients sharing one's status with others) was  
12 commonly reported (17 studies), as was the concern about causing stress, worry and burden  
13 to others if they were disclosed to (15 studies). There were a range of other disclosure anxiety  
14 themes reported, including the fear of being blamed, worries about being isolated, anxiety  
15 about feeling guilty and ashamed, and concerns about losing one's job.

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Anxiety about HIV disclosure was reported to be a barrier to ART initiation or adherence in  
14 studies, and to engagement in care for oneself or one's child in eight studies. HIV  
disclosure anxiety was given as a reason for being isolated or lacking social support in five  
studies and was mentioned as a barrier to safer sex (e.g., condom use) in three studies.

### 66 *Quantitative findings*

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A range of statistical associations with anxiety about HIV disclosure were reported in eight  
studies. Most commonly, associations with psychological variables were assessed. 'HIV  
disclosure concerns' was related to higher levels of general anxiety in two studies<sup>20,21</sup>. One  
study found a statistically significant relationship between 'HIV disclosure concerns' and  
depression<sup>21</sup>, but a different study failed to find this association<sup>20</sup>. The latter study also failed  
to find an association between 'HIV disclosure concerns' and life satisfaction but did find an  
association with reduced social support<sup>20</sup>. 'HIV disclosure concerns' were associated with



1 higher levels of HIV stigma in two studies<sup>21,22</sup>, and were associated with negative self-image,  
2 greater disengagement coping, less time since diagnosis, less primary control engagement and  
3 lower self-esteem in one study<sup>21</sup>.  
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8 In relation to demographic and clinical variables, ‘HIV disclosure concerns’ was greater in  
9 females compared to males in one study<sup>23</sup>, and in heterosexual compared with  
10 homosexual/bisexual participants in three studies<sup>23-25</sup>. ‘HIV disclosure concerns’ were greater  
11 in individuals without an AIDS diagnosis in two studies<sup>24,25</sup>, and greater in those with lower  
12 CD4 counts, no HIV-related hospitalisations, no partner, and of younger age in one study<sup>25</sup>.  
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## 21 **Discussion**

22 The review suggests that anxiety about disclosing one’s HIV status is highly prevalent across  
23 region and population. Fears about rejection and discrimination from others appear  
24 ubiquitous. More generally, anxiety seemed to focus on the possibility of negative effects for  
25 the individual living with HIV in the context of interpersonal relationships. There were also,  
26 however, frequently reported concerns about the effect on others of sharing one’s HIV status.  
27  
28 There is some evidence from qualitative studies included in the review that negative  
29 consequences of anxiety about HIV disclosure, in terms of reduced ART adherence, poor  
30 engagement in care, and isolation, may occur. Importantly, participants themselves often  
31 cited fears about HIV disclosure as a reason for such negative outcomes. No quantitative  
32 studies examined these relationships.  
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52 The review was limited by the fact that most of the studies were qualitative in nature. In  
53 addition, the few quantitative studies were cross sectional with only a limited range of  
54 correlates examined. Hence, it was not possible to quantify the extent to which HIV  
55 disclosure anxiety is related to other psychological and behavioural factors or to examine the  
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1 causes and consequences of HIV disclosure anxiety from the studies. Further, the majority of  
2 studies did not specify to whom the person living with HIV was disclosing. This is important  
3 as disclosure anxiety may differ depending on the recipient.  
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### 6 7 8 ***Models of HIV disclosure*** 9

10  
11 There is a long tradition of developing models of HIV disclosure separate from models of the  
12 disclosure of other health conditions<sup>26</sup>. This may reflect specific issues associated with HIV  
13 (e.g., HIV stigma) and the fact that HIV disclosure may facilitate reductions in onward  
14 transmission. Given the likely importance of anxiety about disclosing one's HIV status, it is  
15 surprising that explanatory models of HIV disclosure have rarely included anxiety as a  
16 central construct. A recent systematic review of HIV disclosure models<sup>27</sup> found that  
17 individual cognitive determinants of HIV disclosure were commonly cited in models (e.g.,  
18 self-efficacy and perceived disclosure risks and benefits), but affect, including anxiety, was  
19 not. Indeed, neither the presence of anxiety *nor how it is develops and can be maintained* has  
20 been included in HIV disclosure theories. Not all disclosure decisions are likely to be  
21 influenced by anxiety but our systematic review suggestions that anxiety about HIV  
22 disclosure is common and may have important consequences. We suggest that *high* and  
23 *persistent* levels of anxiety about disclosure may have an impact on an individual's quality of  
24 life and potentially their social and occupational functioning.  
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46 A new theoretical model of HIV disclosure anxiety (rather than of disclosure *behaviour*) may  
47 help to direct clinicians towards interventions that help to support people with HIV with  
48 significant levels of anxiety and preoccupation about sharing their status with others. This  
49 may be particularly important where anxiety about HIV disclosure is having a large impact  
50 on the individual's psychological and relational functioning and their engagement with care.  
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### *Aims of our model*

1  
2 We present a new model of HIV disclosure anxiety that draws upon existing cognitive  
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4 models of anxiety disorders to explain how high levels of anxiety about sharing one's status  
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6 with others develops and can be maintained. The approach of drawing on theoretical models  
7  
8 relating to affect rather than of health behaviour is novel in the HIV context. For example, the  
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10 Health Belief Model<sup>28</sup> was the most commonly used model used in a recent review of  
11  
12 psychological correlates of HIV testing<sup>29</sup>, and the Information Motivation Behavioural Skills  
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14 Model<sup>30</sup> (based on the Theory of Planned Behaviour<sup>31</sup>) has guided much recent research on  
15  
16 antiretroviral adherence. Such models primarily outline *cognitive* determinants of *behaviour*.  
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18 It may be, however, that *affect* is another important determinant of many HIV-related  
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20 behaviours. For example, consistent relationships between fear of HIV and HIV testing on  
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22 the one hand and HIV testing itself on the other hand, have been reported<sup>29</sup>. It may also be  
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24 that affect (particularly anxious affect) plays a key role in driving many HIV disclosure  
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26 decisions. Of greater relevance for our model, however, is the possibility that high levels of  
27  
28 anxiety about disclosure affects individuals' quality of life and their social and occupational  
29  
30 functioning (through processes such as avoidance leading to social isolation).

31  
32 Existing cognitive models of anxiety disorders emphasise cognitive and behavioural factors  
33  
34 that *maintain* anxiety and minimise quality of life. Models of *social* anxiety<sup>32</sup> are particularly  
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36 relevant as HIV disclosure is a social phenomenon. Models of *health* anxiety<sup>33</sup> are also  
37  
38 relevant given the nature of the condition and the context of care and treatment. Such  
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40 cognitive models attempt to integrate cognitive, affective and behavioural factors and have  
41  
42 clear treatment implications. Existing cognitive models of anxiety disorders cannot be applied  
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44 in their entirety, however. There are specific characteristics associated with HIV that require  
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46 an HIV-specific model, including the extent of HIV stigma, and the infectious nature of the  
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48 condition. In addition, models of social anxiety<sup>32</sup> have self-focused attention at their core,  
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whereas our systematic review suggests that it is the fear of the response of others which is central to HIV disclosure anxiety. Models of health anxiety<sup>33</sup> also suggest that self-directed interpretations (of symptoms) are key rather than interpersonal factors.

Our model is designed to apply to individuals who have high levels of anxiety about HIV disclosure (e.g. a persistent fear of disclosure, with intense anxiety about one's status being known) that has a *significant* impact on their functioning (e.g., significant interference with their normal routine, occupational/academic functioning, or social activities or relationships). This may be manifested in individuals being preoccupied with thoughts about not telling others that they are HIV-positive (direct disclosure), or about avoiding people finding out that they are HIV positive (indirect or guessed disclosure). The model is intended to apply to situations where the PLHIV fears their HIV-positive status will be shared (i.e., where they are motivated to avoid disclosure) or to situations where they want to or feel they have to disclose but are anxious about doing so (i.e., where to some extent the PLHIV is motivated to disclose). That is, anxiety is only likely to characterise situations where there is a level of motivation to *either* disclose or to avoid disclosure.

Our model attempts to explain why some individuals are more affected by anxiety about sharing their status than others and why some situations are more anxiety-provoking than others, despite the ubiquitous nature of HIV disclosure anxiety. We argue, however, that levels of HIV disclosure anxiety are on a continuum both between people and within people (depending on the disclosure recipient and over time). At lower levels of anxiety about HIV disclosure, this may not interfere with decisions about sharing one's status and may have a minimal impact on quality of life. The model aims to be consistent with existing evidence about HIV disclosure anxiety and HIV disclosure rates.

## *A model of HIV disclosure anxiety*

The model is outlined in Figure 2.

**Figure 2 here**

Evidence in relation to the model is presented in Table II.

**Table II here**

### *HIV core beliefs/HIV stigma and conditional assumptions*

We suggest that internalised HIV stigma<sup>34</sup> (endorsing negative beliefs and feelings about HIV about oneself as an HIV-positive person) is a key distal determinant of HIV disclosure anxiety. Indeed, a relationship between HIV stigma and HIV disclosure concerns has been shown<sup>21,22</sup>, and there is evidence of an association between HIV stigma and reduced levels of HIV disclosure<sup>8,12</sup>. Feelings of shame, perhaps based on actual experiences of discrimination after previous disclosure<sup>12</sup> (enacted stigma<sup>34</sup>) or difficulties in adjusting to an HIV-positive diagnosis, are argued to predispose individuals to HIV disclosure anxiety. Indeed, feelings of shame have been reported to inhibit HIV disclosure<sup>35</sup>, and conversely self-compassion has been associated with HIV disclosure<sup>36</sup>. Negative beliefs about HIV (e.g., “People who are HIV-positive will have a short life expectancy”) are likely to contribute to internalised stigma. Illness beliefs are included as important determinants of health behaviour in many theoretical models<sup>13</sup> and have shown to be related to depression in HIV-positive individuals<sup>37</sup>. There may be broader core beliefs about illness (e.g., “people who are ill are to blame”) and the self (e.g., “I am not a strong person”) that impact upon HIV core beliefs.

Our model states that several contextual aspects are likely to influence the extent to which internalised HIV stigma is experienced and negative HIV core beliefs are endorsed. We use distinctions offered by Skovdal and colleagues<sup>38</sup>. Aspects of the *symbolic context* (e.g., community values, community HIV stigma, gender and sexuality representations) may impact upon internalised HIV stigma and HIV disclosure anxiety. Indeed, greater HIV

1 disclosure concerns been reported in women<sup>23</sup>, and heterosexual participants<sup>23-25</sup>. The  
2 *material context* may be relevant, consistent with evidence that greater disclosure fear is  
3 reported in those with no income<sup>39</sup>. Finally, *the relational context* is likely to influence  
4 internalised HIV stigma and HIV disclosure anxiety. For example, the HIV status of one's  
5 partner and family members, their beliefs about HIV and HIV disclosure, and the quality of  
6 these relationships (e.g., the level of perceived trust), may influence internalised HIV stigma  
7 and HIV disclosure anxiety.  
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Cognitive models of depression<sup>41</sup> suggest that core beliefs produce conditional assumptions  
or rules that protect against distress and are activated in specific situations. For example, a  
belief that HIV is shameful may lead the individual to believe that they must hide their status  
from others to avoid being devastated by rejection (e.g., "If I hide my status, then I will be  
safe"). Such rules for living can, however, be unhelpful if they form a barrier to personally  
important goals (e.g., accessing support). Our model, therefore, includes the construct of  
conditional disclosure assumptions, arising from internalised HIV stigma.

### *Trigger event*

We argue that HIV disclosure anxiety is heightened by specific events or situations which are  
interpreted in the light of negative core HIV beliefs and conditional assumptions about HIV  
disclosure. Indeed, our review suggested that HIV disclosure anxiety is present in particular  
contexts (e.g., taking ART medication in social situations, attending clinic, sexual situations)  
where HIV disclosure is thought to be required or wanted (direct disclosure), or where there  
might be a concern that one's status will be revealed involuntarily or guessed (indirect or  
guessed disclosure). For example with the latter situation, individuals may be concerned that  
their antiretroviral use or their visits to clinic will be observed by others and that their status  
will, therefore, be inferred. An HIV diagnosis is likely to be an initial trigger to HIV

1 disclosure anxiety but subsequently episodes of disclosure anxiety may be prompted by  
2 different determinants.  
3

4  
5 Within sexual relationships, a sense of responsibility to one's partner and/or a concern about  
6 onward HIV transmission may trigger anxiety about disclosing, with a normative belief that  
7 one *should* share one's status. This may occur in new relationships or when there is  
8 increasing depth within relationships. Within friendships, a desire for closeness may trigger a  
9 perceived need to disclose. Such situations may trigger disclosure approach goals (e.g.,  
10 sharing one's status to enhance relationship quality) or disclosure avoidance goals (e.g.,  
11 hiding one's status to avoid rejection and reduce potential relationship conflict)<sup>42</sup>.  
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### 23 *Threat interpretation and HIV disclosure anxiety*

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27 A sense of threat (usually interpersonal in nature) is central to HIV disclosure anxiety. Our  
28 model uses a quasi-mathematical equation taken from a cognitive-behavioural model of  
29 health anxiety<sup>33</sup> to describe this threat interpretation: the probability of a negative outcome  
30 multiplied by the awfulness of the outcome, divided by coping plus rescue factors.  
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38 Greater anxiety will occur if the *probability* of negative outcomes (e.g., rejection from others)  
39 is predicted to be high. The greater the extent to which these outcomes are judged as *awful*,  
40 the more that anxiety is a likely outcome. Although these two synergistic components of  
41 perceived threat have not been separated in the HIV disclosure literature, it is likely that fears  
42 about discrimination/stigma, rejection, the effect on others and violence from studies  
43 included in the systematic review, are heightened by both perceptions of the likelihood and  
44 awfulness of the anticipated outcome. These perceptions may be experienced in the form of  
45 negative automatic thoughts or anxiety-laden images. *Coping* factors refer to the confidence  
46 in being able and prepared to face the anxiety of both sharing one's HIV status and the  
47 outcome of HIV disclosure (and to cope with this anxiety). This may or may not be related to  
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1 one's *actual* ability to manage anxiety in the feared situation or to disclose effectively.

2 Perceived coping ability (related to the concept of self-efficacy) is likely to predict the extent  
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4 to which an individual is motivated to face and persist in challenging situations related to  
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6 status sharing. *Rescue* refers to the perceived ability of others to minimise the individual's  
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8 anxiety about disclosing and to provide helpful support.  
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12 Previous disclosure experiences (and how these are appraised) are likely to influence all of  
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14 the elements of the threat equation. Some theorists have, indeed, specified a role for previous  
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16 disclosure experiences in making subsequent disclosure decisions<sup>42</sup> and there is evidence that  
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18 negative disclosure experiences inhibit future HIV disclosure<sup>12</sup>. One of the consequences of  
19  
20 not sharing one's HIV status is that there is no opportunity for the person living with HIV to  
21  
22 learn that others' responses to HIV disclosure may be benign or supportive (or that they  
23  
24 themselves can tolerate negative responses). As a result there may be an ongoing fear about  
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26 disclosing, with less social support available if the individual chooses to share their status in  
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28 the future<sup>12</sup>.  
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36 Contextual factors will influence the extent to which the situation is perceived as threatening.

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38 *Relational* factors are argued to be particularly important. There is evidence that women  
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40 living with HIV often disclose their status to family members first and then to partners,  
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42 whereas men are more likely to disclose to partners first<sup>39</sup>. There is also evidence that  
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44 married individuals are more likely to disclose to partners, whereas non-married individuals  
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46 tend to share their status with their family<sup>39</sup>. Finally, the quality of intimate relationships is  
47  
48 associated with partner disclosure occurrence<sup>40</sup>. These patterns of disclosure may signal  
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50 differing levels of anxiety by characteristics of the discloser and their assessment of  
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52 interpersonal threat associated with the disclosure recipient. Given the perceived threat  
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54 associated with HIV disclosure, it is unsurprising that ambivalence about whether/when to  
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1 disclose is experienced. Indeed, one study reports the fear of abandonment weighing against  
2 the need for support and the desire to raise risk awareness in HIV disclosure decisions<sup>43</sup>.  
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### 5 *Maintaining factors*

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9 Central to our model is the role of maintaining processes. It is these thoughts, feelings and  
10 behaviours that potentially maximise the negative impact of HIV disclosure anxiety and turn  
11 normative anxiety into something more problematic for the individual.  
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### 15 Behavioural factors

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19 The most powerful anxiety maintenance process is *avoidance* of situations that provoke  
20 anxiety (situations where one's status may be shared or inferred). The individual may, for  
21 example, avoid telling others about being HIV-positive and as a result may use condoms in  
22 sexual relationships rather than disclosing, only take medication when alone, and avoid  
23 sexual relationships completely to avoid sharing one's status<sup>44</sup>. It is important to note that  
24 avoidance is a self-protective strategy that is helpful in the short term (as it reduces anxiety).  
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27 Avoidance, however, reinforces threat interpretations as the individual fails to disconfirm  
28 anxious predictions and they remain alert to future threats<sup>33</sup>. We include avoidance in our  
29 model to signal situations where widespread avoidance of disclosure anxiety-provoking  
30 situations is part of a maintaining cycle that has a negative impact on individual functioning  
31 (given the effects of, for example, ongoing anxiety and reduced social support).  
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48 Closely associated with avoidance is the use of *safety seeking behaviours*<sup>32</sup>. These are  
49 behaviours intended to prevent or minimise feared negative outcomes that may involve  
50 entering the feared situation but using subtle avoidance. Evidence from the systematic review  
51 includes reports of the hiding of bottle feeding<sup>45</sup> and making excuses for bottle feeding<sup>45</sup>. Other  
52 examples of safety seeking behaviours might include only disclosing to other known HIV-  
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1 positive people, attempting to assess the potential recipient's HIV attitudes before deciding  
2 whether to disclose, or presenting a plausible alternative account for medication use<sup>12</sup>. Again,  
3 these strategies are not inherently unhelpful but they can become so if they play a part in a  
4 cycle that maintains perceived threat and this has a significant impact on functioning.  
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### 10 Cognitive factors

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12 Cognitive factors maintaining disclosure anxiety may include preoccupation with thoughts  
13 about disclosing or others finding out about one's HIV status, negative rumination and self-  
14 focused attention in social situations where one's HIV status is not known. There may be  
15 attentional biases, with a focus on attending to negative talk about people with HIV, as well  
16 as scanning for information about HIV and other people's views about the condition. We  
17 suggest these factors based on the clinical anxiety literature<sup>32,33</sup>. They have not been  
18 investigated, to our knowledge, in HIV-positive populations.  
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### 31 Affective and Physiological factors

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35 There is evidence that HIV disclosure concerns are positively associated with general levels  
36 of anxiety<sup>20,21</sup>. High levels of general anxiety are likely to maintain beliefs about  
37 interpersonal threat relating to specific disclosure situations. We also propose that HIV  
38 disclosure anxiety is characterised by increased arousal (e.g., sweating, feeling hot) in  
39 situations where disclosure of one's status is possible or required. This aversive nature of  
40 these symptoms and the desire to use avoidance to manage them serves to maintain anxiety,  
41 similar to processes occurring in social anxiety<sup>32</sup>.  
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### 53 ***Summary and conclusions***

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56 We present a novel cognitive model of HIV disclosure anxiety that attempts to both explain  
57 the nature of high level of anxiety about sharing one's HIV-positive status and to suggest  
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1 avenues for therapeutic intervention. Our model is the first HIV disclosure model that we are  
2 aware of to focus on the role of anxiety and factors that maintain HIV disclosure threat  
3 responses. The model is based on robust clinical models of anxiety disorders, adapted for the  
4 specific context of HIV disclosure. Our model differs from health anxiety models<sup>33</sup> in having  
5 the interpretation of future interpersonal situations at its core versus the interpretation of  
6 one's own symptoms. It also highlights a specific role for (a) deeper level cognitions about  
7 the self in relation to the condition (e.g., internalised HIV stigma beliefs) (b) context,  
8 compared with health anxiety models. Our model differs from social anxiety models<sup>32</sup> as it  
9 does not have self-focussed attention at its core, and instead highlights both a specific role for  
10 context, and provides more detail on the threat interpretation/feared prediction.  
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27 There is evidence for some aspects of the model (e.g., the relationship between HIV stigma  
28 and HIV disclosure anxiety, and catastrophic beliefs concerning HIV disclosure outcome).  
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30 Many components of the model, however, remain to be investigated (and there is an absence  
31 of standardised measures of HIV disclosure anxiety or its determinants that will facilitate  
32 model testing). For example, there have not been any attempts to separate out the different  
33 elements of threat interpretation to investigate whether the model accurately describes and  
34 predicts disclosure anxiety. Although there are not current measures of these beliefs, they  
35 could be operationalised and measured reliably and validly in the future. Another limitation  
36 is that the model does not attempt to explain post-disclosure outcomes. Future research  
37 should attempt to operationalise key elements of the model (e.g., HIV disclosure anxiety,  
38 disclosure conditional assumptions, threat interpretations, and disclosure avoidance) so that  
39 relationships suggested by the model can be tested. In addition, the model would benefit from  
40 studies examining the prevalence of disclosure anxiety-related impact on quality of life and  
41 functioning in different HIV-positive populations.  
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Our model has clear clinical implications. In particular, we suggest that the existence of HIV disclosure anxiety should be normalised and the maintenance components of the model should be focused on in interventions where individuals are most affected by HIV disclosure anxiety and are motivated to consider sharing their status (threat interpretations, avoidance, safety-seeking behaviours, rumination, and attentional focus). Many of the cognitive-behavioural strategies used in treating health anxiety and social anxiety could be relevant for working with individuals who are most anxious about sharing their status. Such techniques could involve developing ways to challenge anxiogenic cognitions (e.g., cognitive restructuring and behavioural experiments), graded exposure to feared situations with the withdrawal of safety-seeking behaviours, teaching disclosure communication skills to enhance perceptions of coping, exploring different explanations for disclosure anxiety (Theory A versus Theory B), and accessing HIV disclosure support. In addition, motivational interviewing could be used to address disclosure ambivalence. The goals of such an intervention might be to help the individual to understand what maintains their high levels of anxiety, and to enable them to manage anxiety such that they can make a considered decision about how to respond to threat interpretations. This may help to break the HIV disclosure anxiety maintaining cycle, reducing both the preoccupation with HIV disclosure and disabling levels of anxiety. This may enable the sharing of one's status *in situations where the individual wants to disclose*, or the management of anxiety in situations where one's status is not known and there is no motivation to disclose.

We argue that developing a new theory-based intervention to minimise significant levels of HIV disclosure anxiety, is warranted, given the limited evidence of existing effective interventions to reduce anxiety about HIV disclosure from the systematic review<sup>17-19</sup>. It is interesting to note that the most promising of the interventions included in the review<sup>17</sup> used some of the components that we suggest might be beneficial.

## Compliance with Ethical Standards

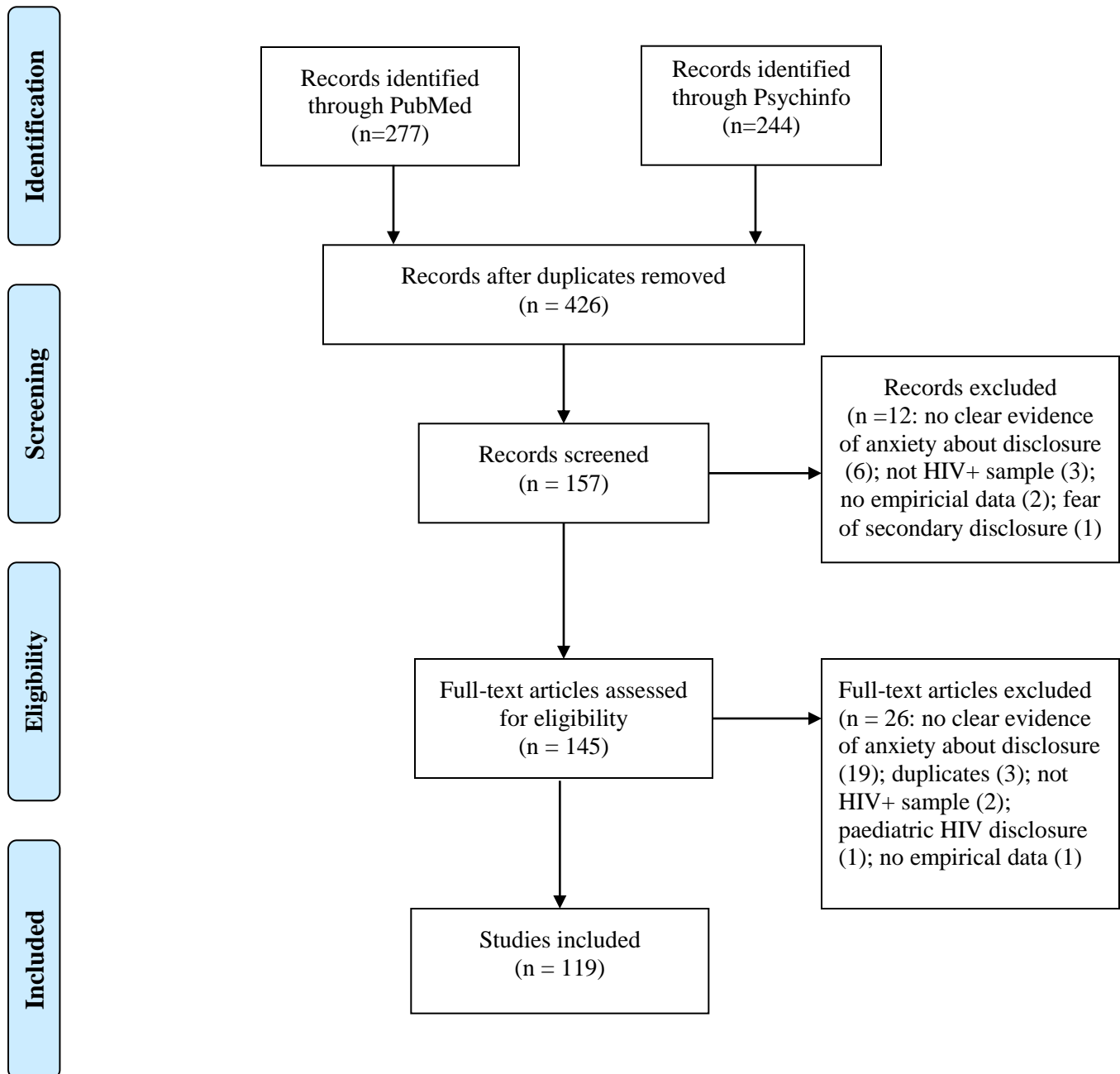
Ethical approval: This article does not contain any studies with human participants performed by any of the authors.

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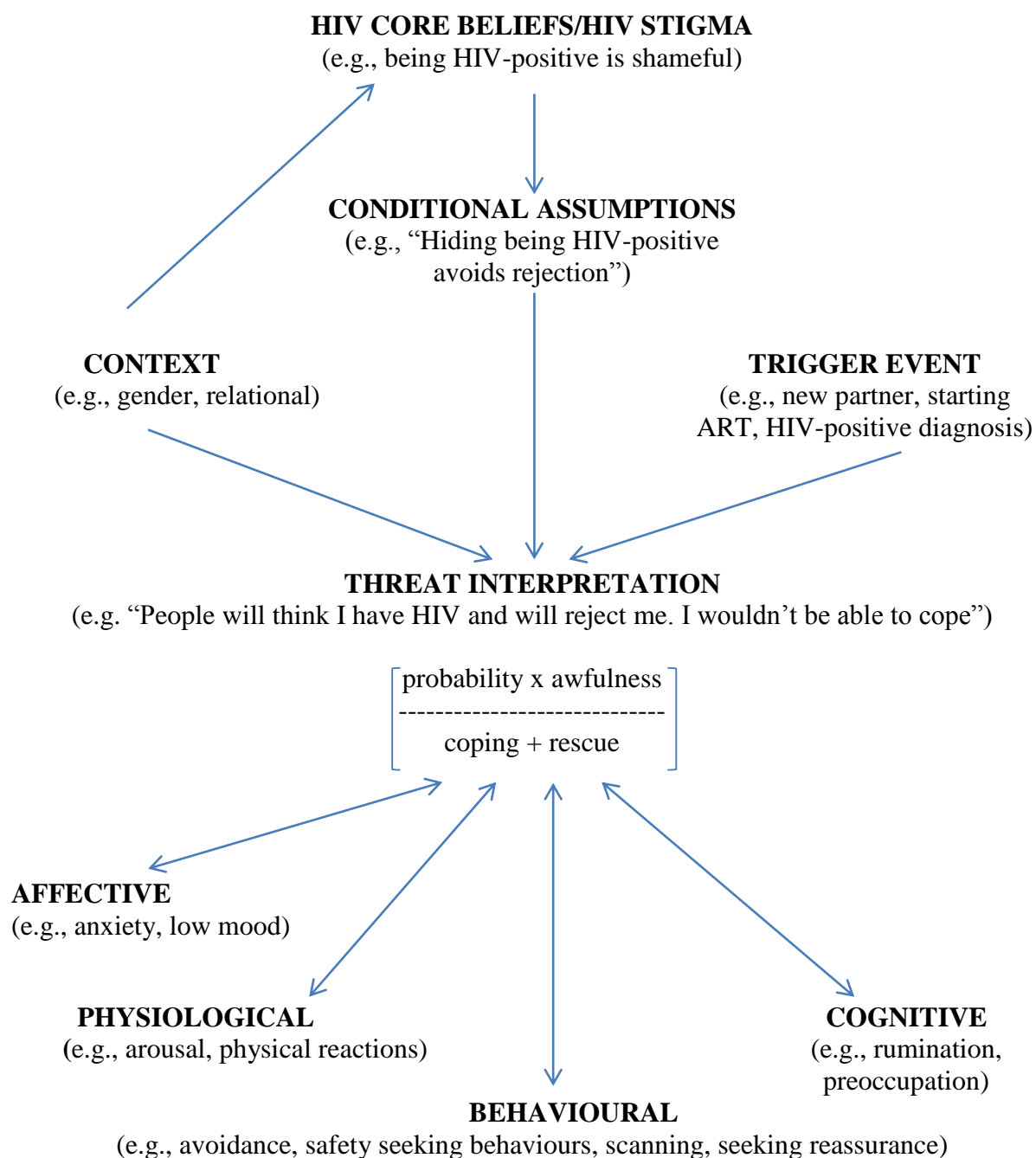
**Figure 1: Study search process**

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit [www.prisma-statement.org](http://www.prisma-statement.org).



**Figure 2: A Model of HIV Disclosure Anxiety**



**Table I: Disclosure anxiety studies**

Study	Location	Design (cross sectional unless stated)/ Methodology	Sample (all HIV+)	Disclosure recipient	Findings related to HIV disclosure anxiety
<b>Akani &amp; Erhabor (2006)</b>	Nigeria	Survey	187 (82 females), 19-56 years.	Any	Fear of stigmatization, victimization, accusation of infidelity, and secondary disclosure cited as reasons for non-disclosure.
<b>Beauregard &amp; Solomon (2005)</b>	Canada	Qualitative interviews	5 females, 40-48 years.	Family	Fear of disclosure due to stigmatization and uncertainty as to how people would react. Fear of being abandoned by family members, particularly children, due to lack of understanding.
<b>Bhagwanjee et al (2011)</b>	South Africa	Qualitative interviews	19 male mineworkers, 33-57 years.	Any	Fear of being abandoned, causing stress or being treated differently cited as reasons for not disclosing to partners and family. Stigmatisation stated as reason for not disclosing to non-family.
<b>Bohle, Dilger &amp; Groß (2014)</b>	Tanzania	Participant observation, Survey, Qualitative interview	59 females on ART (mean age 39 years).	Any	Fear of discrimination the main reason cited for non-disclosure.
<b>Brackis-Cott, Mellins &amp; Block (2003)</b>	US	Focus groups	12 HIV+ mothers, 30-48 years, (mean 40 years).	Children	All HIV+ mothers had disclosed to their adolescent children, despite anxiety.
<b>Braitstein et al (2011)</b>	Kenya	Survey	Parents of 97 children lost to follow up (45% of who were known to be HIV+). 43% female. Median age of child, 0.6 years.	Any	Most common reason given for not returning to the clinic was disclosure issues or fear of community or family discrimination (related to the mother's own status or the child's).
<b>Brickley et al (2009)</b>	Vietnam	Qualitative interviews and focus groups	Pregnant and postpartum females. 20 in interviews, 14 in focus groups. 19-34 years.	Any	Participants reported avoiding disclosure of their HIV status due to fear of stigma and discrimination, particularly in the wider community.
<b>Buchanan et al (2012)</b>	US	Survey	120 perinatally infected children and adolescents (55 females), aged 8 to 18	Any	Where the caregiver was fully responsible for adherence, there was significant agreement between caregiver and child on the reported barrier to ART adherence "child concerned that others notice medications" ( $k=0.41$ , $p=.008$ ).

			years, mean age 12.8 years, and their parents/ caregivers.		
<b>Busza et al (2013)</b>	Tanzania	Qualitative interviews	14 perinatally infected (5 females), 15-19 years.	Partners	For those that acknowledged sexual feelings, concern about how to tell a potential partner about their status and how they might react.
<b>Bwirire et al (2008)</b>	Malawi	Focus groups	10 antenatal and 6 postnatal females and 9 midwives, aged 20-55 years.	Partner (and community)	Fear of stigma, discrimination, household conflict and divorce on disclosing were reasons cited for loss to follow up in a PMTCT programme.
<b>Catz et al (2012)</b>	US	Qualitative interviews	30 prisoners (9 females), 20-58 years (mean 39 years).	Partners	Fear of rejection cited as biggest deterrent to disclosing HIV status, and a barrier to risk reduction (e.g., condom use).
<b>Chakrapani et al (2010)</b>	India	Survey, focus groups and qualitative interviews	200 in survey (100 males, mean 34 years; 100 females, mean 28.3 years); 58 in focus groups, 31 in Qualitative interviews.	Partners	Fear that disclosure will bring marital discord and family shame was a barrier to condom use.
<b>Chakrapani et al (2009)</b>	India	Focus groups	19 female sex workers, 21-48 years (mean 33 years).	Any	Fear of adverse consequences after disclosure, in particular, stigma and discrimination by family and community, was cited as a barrier to seeking ART.
<b>Chandra et al (2003)</b>	India	Qualitative interviews	68 (33 females), 18-50 years (mean 31 years).	Any (with emphasis on family)	Reasons given for non-disclosure included fear of discrimination.
<b>Chin &amp; Kroesen (1999)</b>	US	Qualitative interviews	9 Asian/Pacific Islander females, 21-51 years (mean 38.8 years).	Any	Disclosure decisions influenced by fears of being stigmatized, concerns about disappointing or burdening others and concerns about discrimination.
<b>Christianson, Lolas &amp; Johansson (2008)</b>	Sweden	Qualitative interviews	10 (5 females), 17-24 years.	Partners	One participant reported that fear of disclosure led them to 'switch off' lust, leading to a lower sex drive so that the need to disclose was avoided.
<b>Cloete et al (2010)</b>	South Africa	Focus groups	83- Males and Females aged 18+ (Demographic info not collected)	Any	Fear of disclosure due to concerns about rejection by family or partners, and loss of job.

<b>Colombini et al (2014)</b>	Kenya	Qualitative interviews	48 females (4 aged 18-24 years, 32 aged 25-34 years, 12 aged 35+ years).	Any	Fear of being discriminated against and being rejected cited as leading to non-disclosure, however this reportedly did not affect ART adherence and motivation to stay healthy.
<b>Conserve &amp; King (2014)</b>	US	Qualitative interviews	21 (16 females), 18+ years, of Haitian decent.	Any	Barriers to disclosure included the fear of being stigmatized and rejected, and also concern that it may cause confidants (usually close family or friends) to worry.
<b>Corona et al (2006)</b>	US	Survey	274 parents (216 female) mean age 35.8 years.	Children	Reasons for non disclosure- worry about emotional consequences of disclosure (67%) and worry that child would tell other people (28%).
<b>Curioso et al (2010)</b>	Peru	Qualitative interviews	31 on ART (3 females), 18+ years.	Any	Fear of disclosure was a barrier to ART adherence: participants discussed having to be secretive with their medication.
<b>Dafarty &amp; Padayatchi (2008)</b>	US	Qualitative interviews	40 with TB co-infection (24 females), 21-47 years (mean 34 years).	Any	Participants reported not adhering to ART due to fears of others seeing them taking the medication or going to collect it from the clinic.
<b>Dageid et al (2012)</b>	South Africa	Qualitative interviews and focus groups	23 males in interviews, aged 22-73 years (median 39 years). 8 males in focus group, aged 22-47 years (median 32 years).	Any	Fear of rejection, isolation, tarnished reputations and perceived stigma given as reasons for non-disclosure. Five participants reported fearing violence following disclosure. Participants feared that loved ones may not be able to cope if they disclosed their HIV diagnosis to them.
<b>Degroote et al (2014)</b>	Belgium	Survey	54 (4 females), 33-51 years (mean 42 years).	Workplace	Fear of social or professional consequences reported as a barrier to disclosure.
<b>Deribe et al (2008)</b>	Ethiopia	Survey	705 (353 females) 166 aged 18-25 years, 358 aged 26-35 years, 181 aged >36 years.	Mainly partner. Also family, friends, church.	Fear of partner reacting negatively cited as reason for non-disclosure (e.g., anger. Rejection/separation, violence, accusations of infidelity, worry)
<b>Deribe et al (2009/2010)</b>	Ethiopia	Survey and Qualitative interviews	706 (353 males, mean 34 years; 353 females, mean 29 years). 11 in-depth interviews (4 males, 7 females).	Partner	Anxiety about worrying partner and revealing unfaithfulness were reasons for non-disclosure (men). Fear of violence, financial hardship, abandonment and being blamed cited as reasons for non-disclosure (women).
<b>Derlaga et al (2002/ 2004)</b>	US	Survey	145 (39 females), Mean age 37 years.	Any	Perceived HIV-related stigma associated with reasons given for non-disclosure included fear of rejection.

<b>Diagne Gueye et al (2007)</b>	France	Survey	54 mothers	Mainly partner, also family, friends, church	Fear of violence and separation were reasons for cited non-disclosure to partner.
<b>Dinkel (2014)</b>	Germany	Self-report questionnaire	167 MSM, 22-74 years (mean 45 years)	Any	Disclosure concerns subscale of HIV Stigma Scale- associations with: HADS anxiety, $r=0.19$ , $p<0.05$ ; HADS depression, $r=0.14$ , ns; Life Satisfaction (general), $r=-0.1$ , ns; Life Satisfaction (health), $r=0.01$ , ns; Perceived Social Support, $r=-0.17$ , $p<0.05$ .
<b>Doherty et al (2006)</b>	South Africa	Qualitative interviews	40 mothers whom exclusively bottle/breast fed (mean 24 years).	Any	Some participants reported hiding the fact that they bottle feed their baby as they feared others would find out/ think that it was because they are HIV+. Participants also reported making up other excuses to avoid stigma e.g., the baby would not breastfeed/ having other illnesses.
<b>Donahue et al (2012)</b>	Malawi	Qualitative interviews	59 females, 21-36 years.	Any	Fear of involuntary disclosure (and subsequent community stigmatisation) was a barrier to infant HIV testing and care programmes.
<b>Eisenhut et al (2009)</b>	UK	Survey	62 mothers.	Any	A common reason given by mothers for not having their children tested was fear of disclosure to others (56%).
<b>Ekama et al (2012)</b>	Nigeria	Survey	170 pregnant females 65 aged 18-29 years, 89 aged 30-34 years, 16 aged $\geq 35$ years.	Any	Fear of being identified as HIV positive (63.6%) was the most common reason for nonadherence.
<b>Errol et al (2012)</b>	India	Qualitative interviews	13 interviewed (8 males, 3 females, 2 transgender), aged 28-55 years.	Any	Participants reported fearing that neighbours or family would find out about their status or they would be forced to tell them due to home visits by staff from the HIV clinic.
<b>Ezechi et al (2009)</b>	Nigeria	Survey	625 pregnant females. 270 aged 18-29 years, 322 aged 30-39 years, 33 aged 40+ years.	Partner	Fear of rejection, stigma, and possible abuse were cited as reasons for non-disclosure.
<b>Fesko (2001)</b>	US	Qualitative interviews	18 (9 females), 2 aged 23-30 years, 9 aged 31-40 years, 7 aged 41-50 years.	Workplace	Fear of possible consequences such as being fired or rejected by co-workers were cited as reasons for non-disclosure.
<b>Fongkaew et al (2014)</b>	Thailand	Qualitative interviews	30 (13 females), 14-21 years.	Any	Participants feared disclosure as they worried that they may be rejected by their partner or humiliated by their peer group due to stigmatisation and disgust; this reportedly led to non-adherence.

<b>Forsberg (1996)</b>	US	Survey	306 with haemophilia co-infection, mean 19 years).	Partners	Participants feared that their partner would not want to have sex with them after disclosure or that their partner may tell someone else about their status.
<b>Gari, Habte &amp; Markos (2010)</b>	Ethiopia	Survey	384 females attending ART clinics, 18-57 years (mean 29.5 years).	Any	Fear of abandonment, break-up and stigma reported as barriers to disclosure.
<b>Gaskins (2006)</b>	US	Qualitative interviews	20 African American males, 31-54 years.	Any	Concern about rejection and the disclosure recipients telling others were cited as barriers to disclosure.
<b>Gaskins et al (2011)</b>	US	Qualitative interviews	40 African American males, 22-49 years (mean 38 years).	Any	Fear of negative reactions or stigma, and fear of the disclosure recipient telling others were common reasons reported for non-disclosure.
<b>Gielen et al (1997)</b>	US	Qualitative interviews	50 females, 16-45 years.	Any	Reasons quoted for non-disclosure included concerns about rejection, discrimination and violence.
<b>Gillard &amp; Roark (2013)</b>	US	Qualitative interviews and observations	9 African American/Hispanic, 17-19 years.	Any	Participants reported amotivation to disclose due to fear of stigma and negative reactions/consequences, particularly if previous confidants had reacted negatively, e.g., gossiping and rejection.
<b>Gorbach et al (2004)</b>	US	Qualitative interviews	55 MSM (mean 38.5 years).	Partners	Some men reported a fear of being rejected by a prospective partner as a reason that they only disclosed sometimes.
<b>Gray (1999)</b>	US	Survey	80 females, 20-65 years (mean 35.8 years).	Any	Fears related to disclosure and stigma reported more frequently than fears of dying.
<b>Greene et al (2013)</b>	US	Intervention study  Self-report questionnaire	43 African American 18 males, 25 females, 20-64 years (mean 47.3 years).	Any	<p>Brief Disclosure Intervention (BDI). Disclosure anxiety measured by a single item asking participants to rate how anxious they feel before telling someone on a scale of 1-10. Participants also asked to describe how much they worry about telling others their status (rated from 0-5 by two coders reading the transcripts).</p> <p>Controlling for length of time since diagnosis, there was a condition by time interaction (<math>F(1, 21) = 20.54, p &lt; .001, \text{partial } \eta^2 = .49</math>) with a decrease in disclosure anxiety in the intervention group from Time 1 pretest to delayed posttest (pretest <math>M = 4.41, SD = .89</math>; delayed posttest <math>M = 3.76, SD = 1.22</math>).</p> <p>Controlling for length of time since diagnosis, there was a condition by time interaction (<math>F(1, 40) = 3.70, p &lt; .05, \text{partial } \eta^2 = .08</math>) with a decrease in worry in the intervention group from pretest to immediate posttest (pretest <math>M = 3.68, SD = 1.49</math>; immediate posttest <math>M = 2.80, SD = 1.22</math>).</p>

<b>Grodensky et al (2015)</b>	US	Qualitative interviews	15 females, 50+ years (mean 57 years).	Any	Fear of disclosure cited as a barrier to making church connections and reportedly led to isolation.
<b>Hardon et al (2013)</b>	Burkina Faso, Kenya, Malawi & Uganda	Survey	157 (90 female), mean 34.5 years.	Partners	Fear of stigma, troubles being caused in the marriage and divorce cited as barriers to disclosure.
<b>Hays et al (1993)</b>	US	Survey	165 MSM, 24-68 years (mean 39.6 years).	Any	Fear of discrimination or disruptions of relationships were given as reasons for non-disclosure.
<b>Hogwood, Campbell &amp; Butler (2013)</b>	UK	Qualitative interviews	9 (7 females), 13-19 years (mean 16 years).	Any	Participants reported non-disclosure due to fear of rejection and isolation, and also a fear of losing control of the information due to others not maintaining secrecy.
<b>Holmes &amp; Shea (1997)</b>	US	Self-report questionnaire	106 asymptomatic (28 females), mean 37.8 years.	Any	More disclosure worries (as measured by HAT QoL) in heterosexual versus homosexual / bisexual ( $p<0.05$ ) and in females than males ( $p<0.05$ ).
<b>Holmes &amp; Shea (1998)</b>	US	Self-report questionnaire	201 (44 females), mean 37.5 years.	Any	More disclosure worries (as measured by HAT QoL) associated with higher CD4 count ( $p<0.05$ ), non-AIDS diagnosis (versus AIDS)( $p<0.01$ ), no HIV-related hospitalization ( $p<0.01$ ), younger age ( $p<0.05$ ), heterosexual versus gay/bisexual ( $p<0.01$ ), no partner versus partner ( $p<0.05$ ).
<b>Holmes &amp; Shea (1999)</b>	US	Self-report questionnaire	215 (42 females), mean 37.8 years.	Any	More disclosure worries (as measured by HAT QoL) reported in heterosexuals and those with non-AIDS diagnosis (vs. AIDS), $p<0.01$ .
<b>Hsuing &amp; Tsai (2000)</b>	Taiwan	Qualitative interviews	14 males (mean 36 years).	Any	Fear of disclosure was a stressor.
<b>Issiaka et al (2001)</b>	Burkina Faso	Survey	79 females, 18-38 years (mean 24.5 years).	Partner	Most frequently cited reasons for not disclosing to partner were fears of rejection/abandonment and fears of being considered unfaithful.
<b>Johnson (2012)</b>	Nigeria	Survey	331 (164 females), 31 aged 15-24 years, 150 aged 25-34 years, 150 aged 35> years.	Any	Fear of stigmatization resulted in low disclosure outside immediate family (e.g., to colleagues or community).
<b>Kadowa &amp; Nuwaha (2009)</b>	Uganda	Survey	278 (197 females). 139 had not disclosed- Mean age 31 years.	Any	Fear of divorce or violence, discrimination or stigma, rumours/ gossip, and accusations of promiscuity/infidelity cited as reasons for non-disclosure.

<b>Kerrigan (2006)</b>	Brazil	Qualitative interviews	10 heterosexual females (mean 37 years), 10 heterosexual males (mean 38.5 years) and 10 MSM (Mean 40 years).	Partners	Women: fears related to disclosure were centred on the potential for negative partner reactions including rejection, abandonment and violence;  Heterosexual men: fear of being labelled/ being treated differently;  MSM: Fear of how partner would respond, risk of getting killed mentioned with casual partners.
<b>Kilewo et al (2001)</b>	Tanzania	Survey	288 pregnant females, 18-43 years (mean 27.7 years).	Partner	Fear of stigma, divorce and violence were reasons given for non-disclosure to partners.
<b>Klopper et al (2014)</b>	South Africa	Survey	150 (106 females) Mean 36 years.	Any	Fear of stigmatization, especially among males, cited as a major reason for delayed/non-disclosure.  Fear of stigmatization appeared to be associated with higher level of education. Fear of blame/discrimination appeared to be associated with less disclosure to sexual partner; more fear if no personal income and not married to partner.
<b>Kumar et al (2006)</b>	Barbados	Qualitative Interviews	139 females. 72 aged <25 years, 67 >25 years.	Any	Fear of stigmatization by anyone, and fear of abnormal reaction and possible violence from partner cited as reasons for non-disclosure.
<b>Kyaddondo et al (2013)</b>	Uganda	Focus groups and survey	Focus groups – 16 parents (8 females). Survey - 148 parents (100 females). 32 aged 18- 24 years; 59 aged 25- 34 years; 57 35+ years.	Children	Reasons for non-disclosure to children include fear of being blamed/ judged as being sexually irresponsible, fears of rejection/isolation.
<b>Laryea &amp; Gien (1993)</b>	Canada	Qualitative interviews	25 (6 females), 18-42 years.	Any	Fears of rejection and discrimination were a barrier to disclosure. Fear of secret being shared, and the concern that this may prevent them from getting a job, particularly in small communities.
<b>Lee et al (2013)</b>	Thailand	Focus groups and qualitative interviews	Focus groups - 40; Interviews- 50 (35 female), mean age 37.5 years.	Any	Fear of rejection and disapproval, fear of breaches of privacy, perceived stigma and shame were barriers to disclosure.
<b>Liamputtong et al (2014)</b>	Thailand	Qualitative interviews	26 females. 4 20-30 years, 17 31-40 years, 5 >40 years.	Family and children	Non-disclosure due to fear of stigma, discrimination, blame and rejection. Worries about their partners' well-being, as it would be assumed that they had HIV too. Concern that family members/children would not cope with disclosure.
<b>Lugalla et al</b>	Tanzania	Qualitative	57 (27 females), most 20-	Any	Fear of being rejected and discriminated against were main reasons for non-disclosure in



<b>(2012)</b>		interviews	39 years.		general. Both sexes reported finding it particularly difficult/ were very reluctant to disclose to their fathers. Women less likely to disclose to partners than men due to fear of violence and abandonment.
<b>Madiba &amp; Canti-Sigaqa (2012)</b>	South Africa	Focus groups	50 men aged 28-70	Any	Several people reported that they did not want to attend support groups as they were afraid of exposing themselves and everyone knowing they were HIV+. One participant stated that the other participants in support groups are not trustworthy so he would not want to disclose his status there.
<b>Madiba (2013)</b>	South Africa	Focus groups	26 parents (18 females), 20-60 years.	Children	Fear of disclosure reported due to fear of onward disclosure from child, fear that the child is not mature enough to cope, and anticipated stigma and discrimination.
<b>Maiorana et al (2012)</b>	US	Qualitative interviews	52 who had participated in interventions purposively selected to represent clinics' demographics.	Any	Positive prevention interventions reported to help explore fears of stigma and rejection associated with disclosure.
<b>Maliska et al (2009)</b>	Brazil	Qualitative interviews	13	Family and friends	Fear of disclosure associated with stigma.
<b>Maman et al (2001)</b>	Tanzania	Qualitative interviews	62- 26 female, 36 males. Mean age 28 years. (Only 27 HIV+).	Partners	Women were more anxious about disclosing their positive test results than men, reportedly worrying about blame, abandonment and abuse. HIV+ men reported less disclosure anxiety, describing it as 'like a normal conversation'.
<b>Maman et al (2003)</b>	Tanzania	Survey	245 females, 3 months after testing. Mean age 32 years. (Only 73 HIV+).	Partners	Fear of partner's reaction was the main reason cited for non-disclosure. Particular fear of abandonment and loss of economic support.
<b>Manopaiboon et al (1998)</b>	Thailand	Survey	129 pregnant females, 15-37 years (median 22 years).	Friends and family	Non-disclosure associated with fear of disclosure outcome (e.g., family feeling ashamed).
<b>Mayanja et al (2013)</b>	Uganda	Survey	421 pre-ART (271 females). 318 > 30 years	Any	Fear of disclosure was most common worry before starting antiretroviral therapy.
<b>Mburu et al (2014)</b>	Zambia	Qualitative interviews and focus groups	Focus groups- 53; Interviews- 58 (29 females), mean 16.8 years.	Partners	Fear of abandonment/ rejection (particularly by partners) and stigma were barriers to disclosure.
<b>Musumari (2013)</b>	DRC	Qualitative interviews	38 (24 females), median age 41 years.	Any	Fear of rejection and gossip cited as reasons for non-disclosure. Participants reported interrupting medication out of fear of disclosing status.
<b>Nagikosi et al</b>	Uganda	Qualitative	48 refusing to engage in	Any	Fear of stigma, rejection, blame, exclusion and devaluation were reported as most

<b>(2013)</b>		interviews	HIV care. Aged 15-49 years.		common barriers to entering HIV care. Some also feared losing social support from caretakers if status was disclosed, or feared that it would prevent them from carrying out their own caring obligations for family.
<b>Nam et al (2009)</b>	Botswana	Qualitative interviews	21 parents (12 females), 22-55 years (mean 37 years).	Children	Concern that others may find out about their status and fear of children being stigmatized were reasons cited for non-disclosure.
<b>Newman et al (2007)</b>	Australia	Qualitative interviews	20 (16 females), 22-54 years.	Any	Fear of disclosure and discrimination due to shame associated with HIV were major barriers to treatment uptake.
<b>Okoronkwo et al (2013)</b>	Nigeria	Survey	221 attending ART clinic (126 females). 59 20-29 years, 74 30-39 years, 55 40-49 years.	Any	188 admitted non-adherence. Fear of partner disclosure was a barrier to adherence in 12.7% of females and 21% of males.
<b>Olagbuji et al (2011)</b>	Nigeria	Survey	166 pregnant females on ART , 25-39 years (mean 31.6 years)	Partner	Fear of spread of information, stigmatization and deterioration in relationships were most common reasons for non-disclosure.
<b>Osinde, Kakaire &amp; Kaye (2012)</b>	Uganda	Survey	403 (74% female, 83% on ART). 27.1% 25-29 years.	Partners	Fear of stigma was main reason for non-disclosure. Some participants also reported fearing abuse, abandonment and rejection from partners if they disclosed to them.
<b>Paiva et al (2011)</b>	Brazil	Qualitative interviews	21 adolescents (10 female). 13-20 years.	Partners	Fear of how their partner would react and fear of ending up alone were reasons cited for not disclosing HIV status to partner.
<b>Patel et al (2012)</b>	India	Qualitative interviews	30 (15 females), 15 aged 20-30 years, 9 aged 31-40 years, 6 aged 41-60 years.	Any	Fear of discrimination and fear of family breakdown were cited as barriers to disclosure.
<b>Petrak et al (2001)</b>	UK	Survey	95 (79 males, mean 37.7 years; 16 females, mean 32.6 years)	Any	Most frequently cited reasons for non-disclosure included protecting themselves from others' negative reactions, discrimination, stigma and concerns about confidentiality.
<b>Phaladze et al (2005)</b>	Botswana, Lesotho, South Africa, Swaziland	Survey	743 (453 females) Mean age 34 years.	Any	Disclosure worries (as measured by the HAT-QoL) independently associated with reduced life satisfaction (p< .001).
<b>Pugatch et al</b>	US	Semi-structured	6 (3 females). Aged 16-24	Family	Fear of social stigma relating to HV disclosure was a barrier to ART adherence.

(2002)		interviews	years.		
<b>Rosen &amp; Ketlapile (2010)</b>	South Africa	Survey	260 lost to follow-up.	Any	Fear of disclosure cited as a reason for loss to follow-up.
<b>Rothberg &amp; Van Huyssteen (2008)</b>	South Africa	Survey	28 (21 males, mean 40.5 years; 7 females, mean 38.6 years)	Workplace	Fear of disclosure of HIV status and stigmatisation were reasons cited for late registration onto a HIV treatment programme/ not using any support programmes. Participants also reported fear that employer will not maintain confidentiality.
<b>Rujumba et al (2012)</b>	Uganda	Qualitative interviews	15 pregnant females, aged 18-43 years.	Partners	Non-disclosure due to fear of abandonment, violence and accusation of bringing HIV into the family.
<b>Schlebusch &amp; Vawda (2010)</b>	South Africa	Survey	112 who had attempted suicide (82 females, 30 males), 18-48 years (mean 34.9 years).	Any	54% of participants reported fear of disclosure of their HIV status because of possible victimisation/stigmatisation.
<b>Seid, Wasie &amp; Admassu (2012)</b>	Ethiopia	Survey	360 (191 females), mean 33.4 years.	Partners	Fear of divorce, stigma and discrimination, and physical abuse were main reasons given for non-disclosure.
<b>Sethosa &amp; Peltzer (2005)</b>	South Africa	Qualitative interviews	55 (41 females) recently diagnosed (mean 27.9 years).	Any	Reasons for non-disclosure included fear of negative reactions, discrimination, violence, and concerns about confidentiality.
<b>Siegel, Lekas &amp; Schrimshaw (2005)</b>	US	Qualitative interviews	158 females, mean 36 years.	Partners	Both pre and post ART periods characterized by fears that disclosure would be met with rejection or a breach of confidentiality.
<b>Siu et al (2012)</b>	Uganda	Focus groups and qualitative interviews	20 (10 females), 15-23 years (Median 19 years)	Any	Fear of secondary disclosure, discrimination, rejection and abuse cited as barriers to disclosure.
<b>Smith &amp; Rapkin (1996)</b>	US	Qualitative interviews	224 (30 females). 73 aged 24-35 years, 102 aged 36-45 years, 49 aged 46-56 years.	Any	Fear of disclosure of AIDS cited as a barrier to getting support from friends and family.
<b>Ssali et al (2010)</b>	Uganda	Qualitative interviews	40 (20 females). 10 of each sex > 35 years, 10 of each sex < 35 years old.	Any	Fear of abandonment, particularly in young women disclosing to their partner, a common reason cited for non-disclosure. Fear of upsetting/worrying the disclosure recipient, particularly family members, given as another reason for non-disclosure.

<b>Stinson &amp; Myer (2012)</b>	South Africa	Survey	28 females (17 pregnant, 11 postpartum), mean 27 years.	Any	Fear of disclosing HIV status was reported as a barrier for initiating ART during pregnancy. Fear of the confidant having a negative reaction (e.g., abandonment or stigmatisation).
<b>Stutterheim et al (2011)</b>	Netherlands	Qualitative interviews	42 of African and Afro-Caribbean descent, aged 18-70 years.	Any	Fear of stigmatization was most prevalent reason stated for non-disclosure. Sparing others, particularly parents and children, from worry another reason cited for non-disclosure.
<b>Syed et al (2014)</b>	Malaysia	Qualitative interviews	13 (1 female), mean 34.4 years.	Any	Main reason given for non-disclosure was that they did not want to hurt their family's emotions. Fear of stigma and discrimination was also reportedly linked to non-disclosure.
<b>Terry, Jones &amp; Brown (1994)</b>	New Zealand	Survey	57 (4 females). 12 aged 18-29 years, 21 aged 30-39 years, 24 aged 40-59 years.	Dentist	Reasons given by participants for not disclosing their HIV status to their dentist included fear of rejection, discrimination or breach of confidentiality.
<b>Teti et al (2010)</b>	US	Survey, Qualitative interviews	Survey (184 females) Qualitative (18 females), 34- 51 years.	Any	Fear of rejection and retaliation cited as reasons to be cautious about disclosing.
<b>Thanh, Moland &amp; Fylkesnes (2010)</b>	Vietnam	Qualitative interviews, focus groups, participant observation	45 substance users (5 females), 21-45 years.	Any	Fear of rejection and loss of intimacy reportedly made disclosure difficult and was said to be an obstacle to condom use in those recently diagnosed.
<b>Thomas, Nyamathi &amp; Swaminathan (2009)</b>	India	Focus groups	60 mothers, 23- 42 years (mean 30 years).	Children	Mothers reported that they feared disclosure may cause their children to discriminate against them, do badly in school, or tell others.
<b>Titilope et al (2011)</b>	Nigeria	Uncontrolled intervention  Survey	499 (342 females), mean 37.3 years.	Partners	Fear of rejection was most common reason for non-disclosure. Of those who had not yet disclosed their status, 30.7% reported that counselling had helped them overcome the fear of not wanting to disclose, but only 18.8% stated that they were willing to disclose.
<b>Tzemis et al (2013)</b>	Canada	Self-report questionnaire	775 on ART (25% females), 40-52 years (median 45 years).	Any	Disclosure concerns associated with HIV related stigma in both univariable and multivariable analysis (< .001).
<b>Unge et al (2008)</b>	Kenya	Qualitative interviews	26 (17 females), 23-55 years.	Any	Fear of disclosure and its negative repercussions associated with not initiating ART.

<b>Vallerand et al (2005)</b>	US	Qualitative interviews	35 females, aged 27-56 years (mean 38.5 years).	Children	Mothers expressed fears of rejection by their child or other potential negative reactions from their children if they disclosed to them.
<b>Van Devanter et al (2011)</b>	US	Qualitative interviews	26 Black and Latina females, 16-24 years	Partners	Fear of disclosure to new partners associated with risky sex (not using a condom).
<b>Van Nuil et al (2014)</b>	Rwanda	Focus groups	42 on ART , aged 12-21 years (median 17 years).	Partner	One of the most commonly reported HIV-related anxieties was how and when to disclose to a partner.
<b>Vance &amp; Woodley (2005)</b>	US	Qualitative interviews	12 (2 females), 38-50 years, (mean 44.4 years).	Any	Perceived barriers to successful ageing included fear of disclosure and stigma.
<b>Varni et al (2012)</b>	US	Self-report questionnaire	200 (72% male) aged 18-64 years (Mean age 43.17 years old).	Any	The disclosure concerns measure had a significant positive correlation with enacted stigma ( $r = .27, p \leq .01$ ), concern with public attitudes ( $r = .47, p \leq .01$ ), negative self-image ( $r = .46, p \leq .01$ ), disengagement coping ( $r = .37, p \leq .01$ ), depression ( $r = .24, p \leq .01$ ), and anxiety ( $r = .21, p \leq .01$ ). The disclosure concerns measure had a significant negative correlation with time (years) since diagnosis ( $r = -.14, p \leq .05$ ), primary control engagement coping ( $r = -.26, \leq .01$ ), and self-esteem ( $r = -.18, p \leq .05$ ).
<b>Visser et al (2008)</b>	South Africa	Survey	293 recently diagnosed pregnant females (mean 26.5 years).	Any	Fear of abandonment and discrimination weighed against need for support and desire to raise risk awareness in disclosure decisions.
<b>Walker (2012)</b>	US	Qualitative interviews	13 mothers.	Any	Many women reported living in isolation and fearing disclosure.
<b>Ware, Wyatt &amp; Tugenberg (2006)</b>	US	Qualitative interviews	52 (38 male, 14 female), 28 30-40 years, 24 41-51 years.	Any	Fear of disclosure was reported to result in missing medication as the interviewees did not want others to see them taking pills.
<b>Webel (2010)</b>	US	Intervention Self-report questionnaire	89 females (mean 47 years).	Any	Peer based HIV symptom management intervention consisting of 7 two hour sessions, with the content of the sessions based on the Positive Self-Management Program (PSMP). The control group received a symptom management guide book. There was a significant difference found between groups for disclosure worries as measured by the HAT-QoL ( $\chi^2 = 24.67, p < 0.005$ ). However, inspection of the means indicate that there was no significant group x time interaction.
<b>Wolf et al (2014)</b>	Kenya	Qualitative interviews, focus groups	27 (19 females), 15-21 years.	Adults	Fear of status being disclosed to family reportedly affected medication adherence and caused loss-to-follow up. Also, youths' dependent relationships with adults at home and school were reportedly negatively impacted by youths' fear of disclosure caused by HIV-related stigma.

<b>Zhou et al (2013)</b>	China	Qualitative interviews	39 parents (13 females), 28-76 years (mean 42 years).	Children	Fear of being stigmatized, fear of rejection, and fear of increased psychological burden to children were reasons for non-disclosure.
<b>Zukoski, Thorburn &amp; Stroud (2011)</b>	US	Qualitative interviews	16 (7 female). 3 18-34 years, 6 35-49 years, 7 50+ years.	Any, particularly health profs.	Fear of disclosure cited as a barrier to seeking information about HIV.

Model component	Sub-component	Evidence
HIV Core beliefs/HIV stigma		Higher levels of HIV stigma associated with higher levels of HIV disclosure concerns (Varni et al, 2012; Tzemis et al, 2013) and lower rates of HIV disclosure (Hult et al, 2012; various studies reported in Smith et al, 2008).
Conditional assumptions		No evidence.
Context		Greater disclosure concerns in women (Holmes & Shea, 1997) and heterosexual samples (Holmes & Shea, 1997, 1998, 1999). More disclosure fear in those with no income (Klopper et al, 2014). Different patterns of disclosure in males and females, and in marital and non-marital relationships (Klopper et al, 2014). More partner disclosure associated with better relationship quality (Seid et al, 2012).
Trigger event		Various studies report anxiety about HIV disclosure in relation to ART initiation (e.g., Unge et al, 2008), ART adherence (e.g., Curioso et al, 2010), engagement in care (e.g., Nagikosi et al, 2013), and safer sex (Van Devanter et al, 2011).
Threat interpretation		Many examples of perceived threat associated with HIV disclosure. No evidence of hypothesized components of threat interpretation.
Maintaining factors	Behavioural	Hiding of bottle feeding (Doherty et al, 2006), only disclosing to other HIV+ people (Hult et al, 2012), using condoms instead of disclosing (Greenhalgh et al, 2016), avoiding sexual relationships (Greenhalgh et al, 2016), missing ART doses (e.g., Dafarty & Padayatchi, 2008), not initiating ART (e.g., Unge et al, 2008), not attending clinic (e.g., Braitstein et al, 2011), and avoiding the use of condoms (e.g., Catz et al, 2012).
	Cognitive	No evidence
	Affective and Physiological	HIV disclosure concerns associated with anxiety (Dinkel et al, 2014; Varni et al, 2012).

**Table II: Evidence for model components**