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A model of caregiver paediatric HIV disclosure decision-making

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Abstract

Many of the over 3 million HIV-positive children will only be told of their status as adolescents. Knowing one's status may increase treatment adherence, reduce onward HIV transmission, increase trust in caregivers, and maximise available support. Yet deciding whether, what, how, and when to tell HIV-positive children about their condition, is challenging for caregivers. We systematically review HIV disclosure theories before presenting a process model of caregiver paediatric HIV disclosure decision-making. The model, consisting of both a pre-intention and a post-intention stage, integrates individual and contextual determinants. It aims to be situationally-specific, broadly applicable, and consistent with the empirical literature. Research and practice implications are discussed.

Keywords

paediatric disclosure; HIV; caregiver; decision-making; model

Introduction

There are 3.2 million children living with HIV, with 91% in sub-Saharan Africa (UNAIDS, 2014). The majority of these children will have acquired HIV perinatally. Children's awareness of their HIV positive status may enhance treatment adherence and engagement with care, reduce onward HIV transmission, increase child trust in caregivers, reduce child confusion, and maximise support (Krauss, 2013). There is also the potential, however, for detrimental effects for the child, for example, increased levels of distress, difficulties in HIV adjustment and reduced well-being. Paediatric HIV disclosure, therefore, presents challenges to caregivers concerning what is in the child's best interest, when and how to disclose, and how to support the child after disclosure.

Paediatric HIV disclosure may be full (telling the child that they have a serious illness and the illness is HIV) or partial (telling the child that they have an illness without naming it as

HIV) (Krauss, 2013) and may occur as a single event or over time. The World Health Organization (WHO) states that children should be aware of the name of their condition by aged 12, with younger children informed of their status incrementally in preparation for full disclosure (WHO, 2011). Disclosure often occurs at a later age in resource-limited contexts than in resource-rich environments (Pinzon-Iregui, Beck-Sague, & Malow, 2013) but similar reasons for disclosure and non-disclosure have been elicited in different regions. A recent systematic review found no differences in psychological outcomes between children who did and did not know their HIV status (Krauss, 2013).

Paediatric HIV disclosure differs from HIV disclosure in other contexts. Firstly, if the discloser is the biological mother and the child is perinatally infected, she will have transmitted the virus to the child, and emotions such as guilt or shame may be elicited. Secondly, the recipient is a child, whose level of understanding and emotional maturity will be important for the discloser to consider. Thirdly, the child is being told about *his/her* status rather than that of the person disclosing. Finally, the parental relationship between discloser and disclosed differentiates paediatric disclosure from most HIV disclosure situations.

There have been recent systematic reviews of factors associated with, or reasons given for, paediatric HIV disclosure (Pinzon-Iregui et al., 2013; Vreeman, Gramelspacher, Gisore, Scanlon, & Nyandiko, 2013). It is unclear if existing explanatory *theories* of HIV-disclosure decision-making are applicable to caregiver disclosure decision-making context, however. We, therefore, carried out a systematic review of HIV disclosure theories to assess their relevance to paediatric HIV disclosure.

Methods

Studies were included if they focused on HIV disclosure, and presented a new or tested an existing theory of HIV disclosure decision-making. Studies were retrieved from Pubmed/Medline, PsycINFO and Web of Science using combinations of the terms, “HIV disclosure”, “model” and “theory” in the title/abstract (on 11th February 2015 by the first author). Titles/abstracts were subsequently screened for relevance. Relevant articles were retrieved in full text and assessed for eligibility.

Results

Forty eight titles/abstracts remained after duplicates were removed. Thirty of these articles were excluded at the screening stage. Full text versions of the remaining 18 articles were obtained. After applying inclusion criteria, 12 articles remained (see figure 1). Inter-rater reliability between the first author and a second researcher was good ($\kappa=0.73$).

The 12 articles referred to 10 distinct theories (see Table 1). Five theories applied to any HIV-positive person disclosing, four to HIV-positive men (two to MSM) and one to caregivers. Six of the theories related to disclosing to any individual, three to sexual partners and one to HIV-positive children.

Disclosure determinants and evidence

The theories commonly included individual cognitive determinants. Disclosure outcome expectancies and perceived disclosure risks and benefits were often cited (J. Bird, 2009; J. D. Bird & Voisin, 2011; Gaskins et al., 2012; Jemmott et al., 2014; Rutledge, 2007; Semple, Patterson, Shaw, Pedlow, & Grant, 1999; Serovich, 2001). Other individual factors included self-efficacy (Gaskins et al., 2012; Jemmott et al., 2014; Semple et al., 1999), approach/avoidance goals (Chaudoir, Fisher, & Simoni, 2011), normative beliefs (J. D. Bird & Voisin, 2011; Jemmott et al., 2014), HIV knowledge (Gaskins et al., 2012), privacy/responsibility beliefs (J. D. Bird & Voisin, 2011; Rutledge, 2007) and disclosure intention (Jemmott et al., 2014). Contextual and relational factors including partner factors, sexual setting, sexual risk behaviour (J. D. Bird & Voisin, 2011; Rutledge, 2007) and social network elements (Derlega, Winstead, Greene, Serovich, & Elwood, 2004) were sometimes cited. Finally, cultural/societal factors, including stigma (J. D. Bird & Voisin, 2011; Derlega et al., 2004), cultural identity and cultural values (Iwelunmor, Sofolahan-Oladeinde, & Airhihenbuwa, 2014) appeared in some theories.

Evidence (mostly from the US) was often derived from inductive qualitative studies (J. D. Bird & Voisin, 2011; Gaskins et al., 2012; Iwelunmor et al., 2014; Rutledge, 2009). Quantitative studies found support for some or all of the individual theory components (Gaskins et al., 2012; Jemmott et al., 2014; Semple et al., 1999; Serovich, Lim, & Mason, 2008).

Discussion

Theories of HIV disclosure decision-making had a number of overlapping features. There were many aspects that were rarely included, however. Only one theory (Rutledge, 2007) discussed post-intentional processes and affect (e.g., mood, guilt, shame) was generally absent. Disclosure recipient factors (e.g., prompts to disclose, level of recipient understanding and health) were rarely mentioned. Social and professional disclosure support was not emphasised, and the relationship between individual and contextual factors were usually not explored. The impact of descriptive norms (beliefs about the disclosure practice of others) was not cited. Expected outcomes of *not* disclosing and the impact of competing demands were not included. The individual's values and their previous experience of HIV-related loss and HIV communication rarely featured, although the latter was an aspect of one model (Chaudoir et al., 2011). These factors may all be important with paediatric HIV disclosure. Finally, the only theoretical study that focused on paediatric HIV disclosure (Jemmott et al., 2014), appeared to incorrectly specify the model that it intended to test (e.g., omitting the *importance* of behavioural beliefs as part of the attitudes construct), measured key constructs in a limited way (e.g., using a single question for perceived behavioural control), tested a theory that only focused on individual determinants and did not outline post-intentional processes.

A new model of paediatric HIV disclosure

Given the limitations of existing theories in relation to caregiver paediatric HIV disclosure decision-making, we present a new integrative model (figure 2) with the aims of (a)

specifying the salient variables in understanding disclosure practices; (b) delineating the sequences as the disclosure process unfolds; and (c) explaining the relationship between factors.

The model is most relevant to children (aged 16 years) who are perinatally infected as caregivers will often know the child's status before the child. Where evidence exists in relation to the model this appears in Table 2.

Pre-Intention Phase: Distal factors

Child factors—The child's age may influence (a) disclosure attitudes, both affective elements (e.g., disclosure anxiety) and cognitive elements (e.g., expectations of disclosure consequences) and (b) normative beliefs about when disclosure should occur. For example, as children progress to adolescence, caregivers may become concerned about unprotected sexual activity if the child does not know their status, hoping that disclosure will minimise onward transmission risk. Compromised cognitive functioning in some young people with perinatally acquired HIV (Laughton, Cornell, Boivin, & Van Rie, 2013) may moderate the effect of age, delaying the decision to disclose. Older children may be more likely to ask questions about their medication or condition, suggesting disclosure readiness and leading to concerns about the child learning their status from others. This may, in turn, influence attitudes towards non-disclosure. We suggest that child ill-health and medication use is associated with pro-disclosure attitudes often due to concerns about adherence difficulties. Finally, we argue that the route of infection is influential, with caregivers of perinatally-infected children concerned about being asked questions about transmission that may invoke guilt and shame.

Caregiver factors—The caregiver's previous disclosure experience will affect proximal disclosure determinants. Previous communication with the child about his or her condition may influence attitudes towards disclosure and enhance confidence in future disclosure. Caregiver disclosure to the child may be more likely if the caregiver's own previous disclosure outcomes have been positive and if they are open about their status. Caregiver HIV status is suggested to affect disclosure, with HIV-positive caregivers less likely to disclose due to feeling guilty or ashamed. HIV stigma, particularly fears of HIV discrimination, may be a barrier to disclosure. HIV stigma may have reduced in recent years, and may be lower in resource rich versus resource-limited contexts, consistent with evidence of variations in disclosure rates over time (Butler et al., 2009) and between contexts (Pinzon-Iregui et al., 2013). We suggest that lower levels of stigma are associated with positive disclosure attitudes and less negative feelings about disclosure. HIV-related loss may be associated with increased disclosure through enhancing negative attitudes towards non-disclosure. Low mood, affecting self-efficacy (Bandura, 1998), may adversely affect disclosure intentions. Finally, values such as honesty, trust in relationships, family openness, protection of children, being close to others and being in control may be important, with these higher order goals influencing moral normative disclosure beliefs (Ewart, 1991; Gillard & Roark, 2013).

Contextual factors—Contextual factors may influence proximal disclosure determinants and disclosure barriers and resources. Limited material resources (e.g., employment, finances, and health information) may influence the control that individuals perceive over the disclosure process. The symbolic context (Skovdal, Campbell, Nhongo, Nyamukapa, & Gregson, 2011) includes gender representations, stigma and community values. In communities where women are not empowered, biological mothers who want to disclose to their children may not have the authority to do so as paternal aunts and grandmothers being seen as more appropriate individuals to disclose (De Baets, Sifovo, Parsons, & Pazvakavambwa, 2008). The increasing normalisation of HIV/AIDS in previously stigmatizing contexts (Campbell et al., 2012) may affect the caregiver disclosure decision-making process. Community values about children, for example that it is their right to take control over their own health and the recognition of HIV-infected children's social worth (Campbell et al., 2012), may increase caregivers' confidence and freedom to disclose. The relational context (e.g., caregiver relationships with child, partner, family, friends and healthcare system) may affect caregiver confidence about being able to manage disclosure consequences. Greater social support could provide resources for the caregiver during disclosure and increase disclosure self-efficacy. Having more than one caregiver can either facilitate or obstruct disclosure (Ewart, 1991). For example, different individuals may have different perspectives on disclosure, or could be mutually supportive through the disclosure process. Caregivers' relationships with health care providers can be experienced as either supportive, or as eliciting pressure to disclose (Mawn, 2012). Both effects may influence normative disclosure beliefs.

Pre-Intention Phase: Proximal factors

Caregiver attitudes towards disclosure and non-disclosure—We propose that caregiver attitudes towards disclosure are important disclosure determinants. Attitudes consist of affective elements (e.g., anxiety) and cognitive elements (outcome expectancies of disclosing or not disclosing as well as their perceived salience). The confidence, accessibility and clarity of caregiver attitudes will influence disclosure intention. In addition, disclosure attitudes that are intrinsically motivated (e.g., value-driven) may be more likely to result in stronger disclosure intentions than extrinsically motivated attitudes (e.g., driven by social pressure) (Deci & Ryan, 2000). Attitudinal beliefs may or may not be rational (Ajzen, 2011). Attitudes towards a specific behaviour may conflict with each other, resulting in emotionally discomfiting ambivalence. For example, a caregiver may have a pro-disclosure attitude (believing that the child can understand an HIV diagnosis) alongside an anti-disclosure attitude (fearing that disclosure will result in their being blamed).

We argue that anxiety is particularly important to caregiver paediatric HIV disclosure, given the uncertainty and potential aversive nature of disclosure consequences. Our model draws on cognitive-behavioural models of anxiety disorders (Salkovskis, 2003), which suggest that processes such as cognitive and behavioural avoidance, rumination and catastrophic thinking maintain anxiety. Anxiety may delay disclosure (e.g., if the caregiver anticipates aversive consequences of disclosure) or prompt disclosure (e.g., if they anticipate aversive consequences of non-disclosure).

Commonly reported caregiver-anticipated outcomes of disclosure/non-disclosure may be (a) health or non-health related (b) self, child or socially focused. Negative anticipated consequences for the *caregiver* may include concerns about the child asking how they became infected and then blaming them. Negative anticipated disclosure consequences for the *child* include being discriminated against if they disclose to others, concerns that they may harm themselves, and poor comprehension of disclosure information. Positive anticipated outcomes of disclosure include on-going sexual abstinence, improved ART adherence, the child knowing themselves better, and better engagement with a helping social network. Positive anticipated outcomes of non-disclosure include protecting one's child and reducing the likelihood of discrimination towards the family. Negative anticipated outcomes of non-disclosure include regret about the child learning their status from others.

Caregiver normative beliefs—Caregiver normative beliefs about disclosure are likely to influence disclosure intentions. Social norms/perceived social pressure to disclose may exist. Indeed, instances of caregivers feeling pressured by health professionals to disclose have been reported (Mawn, 2012). Other normative beliefs include moral norms. For example, a carer may believe that it is a child's *right* to know their status (Chew, Beng, & Mun, 2012; Wiener, Battles, Heilman, Sigelman, & Pizzo, 1996) and the caregiver's *duty* to disclose. Finally, beliefs about the disclosure practices (descriptive norms) of other caregivers (Fishbein, 2010) may affect disclosure intentions. Normative disclosure beliefs could differ in resource-rich and resource-limited contexts, consistent with the evidence of differing disclosure rates (Pinzon-Iregui et al., 2013).

Caregiver self-efficacy—Caregiver self-efficacy to disclose and to cope with disclosure consequences is likely to affect intentions and disclosure planning. Some studies have reported caregivers being concerned about what to tell children about HIV, not being able to answer post-disclosure child questions and not knowing how to deal with a child who reacts negatively to being disclosed to (Madiba, 2012).

Intention—We argue that caregiver paediatric HIV disclosure is largely intention-driven, although unplanned disclosure does occur (John-Stewart et al., 2013). The intention to disclose different levels of information about HIV to a child is context-specific and fluctuates due to changes in distal determinants (e.g., caregiver mood) and proximal determinants (e.g., self-efficacy). We suggest that the intention to disclose leads to disclosure planning, moderated by disclosure barriers and resources.

Post Intentional Phase

Action and coping planning—The extent and specificity of disclosure plans (action planning) whilst overcoming barriers to and managing disclosure consequences (coping planning) will affect disclosure likelihood (Gollwitzer, 1999). In resource-rich contexts with greater institutional support, a gradual joint (health care worker and caregiver) planned process of increasing levels of disclosure over time may occur. This could involve rehearsing disclosure plans (Blasini et al., 2004a). In resource-limited contexts there may be less action planning prior to disclosure, although planning to reduce negative disclosure consequences,

for example, preparing food, offering gifts, and ensuring that the child feels loved, has been reported (Vaz, Eng, Maman, Tshikandu, & Behets, 2010).

Barriers and resources—We suggest that the relationships between forming an intention to disclose and disclosure planning and between disclosure planning and disclosure, are moderated by disclosure barriers and resources. Disclosure-specific support, both instrumental (e.g., suggestions of what to say) and emotional (e.g., being available to listen to expressions of disclosure anxiety) (Wills, 1991) from professionals or one's social network is one potential resource. A greater extent of competing demands may reduce the likelihood of disclosure. The extent of competing demands may differentiate resource-limited from resource-rich contexts, consistent with differing global disclosure rates.

Disclosure event—Paediatric HIV disclosure varies by who discloses, the content and process of communication, and the affect elicited during communication. The discloser may be either a caregiver or health care worker (John-Stewart et al., 2013). Full disclosure may be paired with messages about the possibility of prejudice from others and with instructions not to disclose to others (Dorrell & Katz, 2014; Murphy, 2002). Children often perceive HIV disclosure as a one-off event (Vaz et al., 2010), with neither preparatory nor follow-up discussion. Caregivers may view disclosure in a similar way (Chew et al., 2012), although there are also reports of caregivers describing disclosure as a process, with full disclosure preceded by partial disclosure (Vreeman et al., 2013). A range of emotions are experienced by children during disclosure events, for example, sadness, worry, isolation and relief (Dorrell & Katz, 2014; Vaz et al., 2010).

Research implications

We have specified where relationships in the model are consistent with current evidence (table 2). Much of the evidence comes from cross-sectional studies, however, many factors have not been systematically investigated (e.g., disclosure self-efficacy), and most of the disclosure attitudes specified have only been elicited in qualitative studies. There is a need to develop valid and reliable measures of constructs for key relationships to be tested. We predict, for example, that interventions enhancing caregiver pro-disclosure attitudes, normative beliefs to disclose and disclosure self-efficacy will increase disclosure intentions, disclosure planning, and disclosure itself.

Practice implications

Our model suggests that professionals could assess previous caregiver HIV disclosure experiences, disclosure attitudes, normative beliefs, self-efficacy, and disclosure barriers and resources in attempting to help caregivers to decide whether and how to disclose to a particular child at a specific time. To increase disclosure rates, caregiver satisfaction with the disclosure process and positive child outcomes, there may be a role for modelling to increase self-efficacy (Bandura, 1998; Gillard & Roark, 2013), motivational interviewing to sensitively address ambivalence (Miller & Rollnick, 2009), and health system interventions to enhance support. Some paediatric HIV disclosure interventions have been developed (Blasini et al., 2004b; Boon-Yasidhi et al., 2013; Cantrell, Patel, Mandrell, & Grissom, 2013;

Nicastro et al., 2013; O'Malley et al., 2015), although with limited grounding in theory and an absence of comprehensive evaluation.

Conclusion

With large numbers of children living with HIV, paediatric HIV disclosure is an important psychological and public health concern, requiring a new conceptual framework. There is now increasing empirical work to inform such a framework. This article describes a process model that explicates the factors that may influence caregiver disclosure decision-making.

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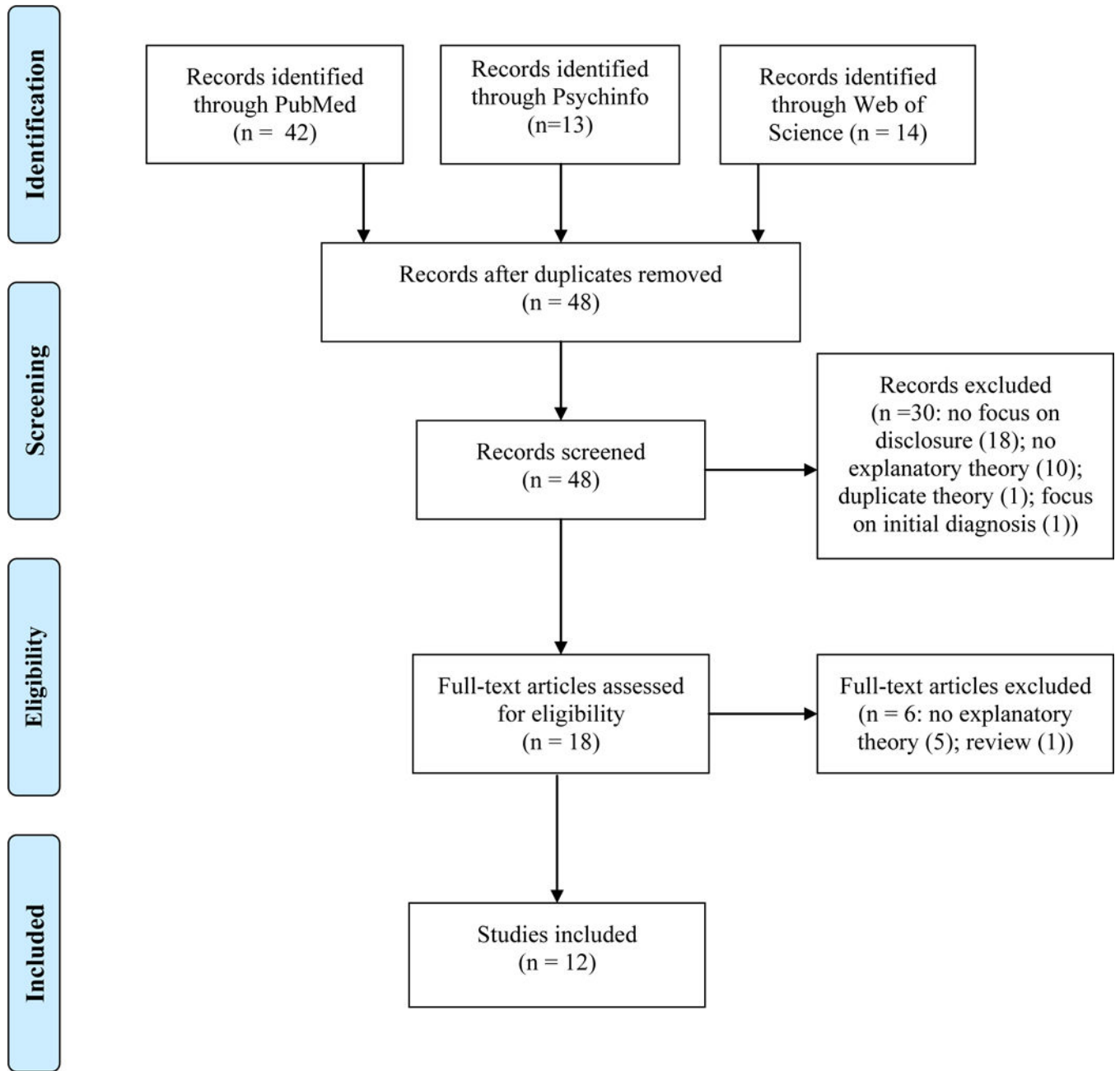


Figure 1.
Study search process

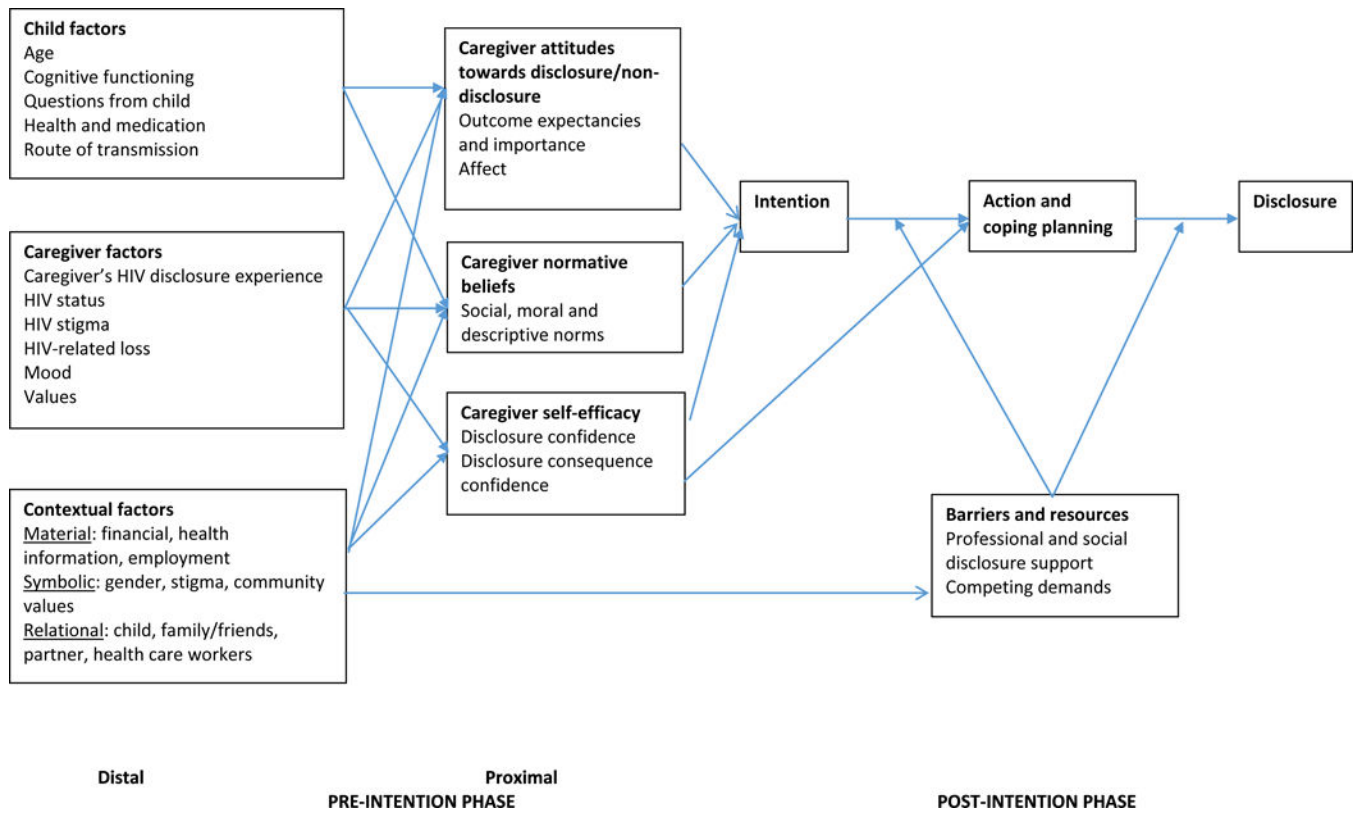


Figure 2.
Caregiver HIV Paediatric Disclosure Decision-Making Model

Table 1

Articles included from review of HIV disclosure theories.

Author	Theory	Study sample	Disclosure recipient	Disclosure determinants	Author-derived evidence
Bird et al. (I. Bird, 2009; J. D. Bird & Voisin, 2011)	Author-derived (inductive) theory	HIV+ African American MSM	Casual sexual partners	Stigma influences disclosure decision-making antecedents (perceived risks, privacy/responsibility beliefs, partner factors, sexual setting and sexual risk behavior).	Qualitative study (n=20) using grounded theory. US (Bird, 2009).
Chaudoir et al. (Chaudoir, Fisher, & Simoni, 2011)	Disclosure Process Model	Any HIV+	Any	Disclosure decision influenced by approach and avoidance goals (which are influenced by previous disclosure outcomes).	N/A
Derlega et al. (Derlega, Winstead, Greene, Serovich, & Elwood, 2004)	Model of HIV-Disclosure Decision-Making	Any HIV+	Any	Cultural attitudes and contextual factors influence reasons for and against disclosure.	Quantitative study (n=145), US. Reasons for disclosure consistent with model.
Gaskins et al. (Gaskins et al., 2012)	Author-derived (inductive) theory	Rural African American Men	Any	HIV knowledge, benefits and risks, social demographics, context and barriers/facilitators influence disclosure decisions. Disclosure efficacy subsequently influences disclosure.	Qualitative study (n=40) using grounded theory. US.
Iwelunmor et al. (Iwelunmor, Sofolahan-Oladeinde, & Airihinbuwa, 2014)	PEN-3 cultural model	HIV+ men	Any	Cultural empowerment, relationships and expectations and cultural identity influence disclosure.	Qualitative study (n=27). South Africa. Male identity, family and community factors cited as reasons for disclosure/non-disclosure.
Jemmott et al. (Jemmott et al., 2014)	Theory of Planned Behavior	Caregivers	HIV+ children	Behavioural beliefs about disclosure consequences, Subjective normative beliefs and self-efficacy influence intention, which influences disclosure.	Quantitative study (n=100). South Africa. Intention associated with normative beliefs in bivariate and multivariate analysis and with self-efficacy in bivariate analysis.
Rutledge et al. (Rutledge, 2007, 2009)	Author-derived (inductive) theory	HIV+ MSM	Sexual partners	Two disclosure processes: forming a and enacting disclosure policy.	Qualitative study (n=15) using grounded theory. US.
Semple et al. (Semple, Patterson, Shaw, Pedlow, & Grant, 1999)	Social Cognitive Theory	Any HIV+	Sexual partners	Self-efficacy and outcome expectancies drive disclosure.	Quantitative study (n=233). US. Self-efficacy and outcome expectancies associated with disclosure.

Author	Theory	Study sample	Disclosure recipient	Disclosure determinants	Author-derived evidence
Serovich et al. (Serovich, 2001; Serovich, Lim, & Mason, 2008)	Consequence Theory/Revised Consequence Theory	Any HIV+	Any	Anticipated rewards and costs (and disease progression) drive disclosure.	Quantitative studies. 138 MSM (Serovich et al., 2001), 125 women (Serovich et al., 2008). US. Rewards and costs associated with disclosure.
Serovich et al. (Serovich, 2001; Serovich et al., 2008)	Disease Progression Theory	Any HIV+	Any	Disease progression drives disclosure.	Quantitative studies. 138 MSM (Serovich et al., 2001), 125 women (Serovich et al., 2008). US. Disease progression not associated with disclosure.

Table 2

Evidence for model components.

Phase	Factor	Sub-Factor	Evidence
Pre-intention distal	Child Factors	Age	Disclosure more likely with older than younger children - several studies (Pinzon-Iregui, Beck-Sague, & Malow, 2013; Vreeman, Gramelspacher, Gisore, Scanlon, & Nyandiko, 2013).
		Cognitive functioning	–
		Questions from child	Disclosure associated with questioning from the child - several studies (Pinzon-Iregui et al, 2013; Vreeman et al, 2013).
		Health and medication	Disclosure associated with child ill-health and ART use –several studies (Vreeman et al., 2013).
		Route of transmission	Perinatally-infected children informed of diagnosis later than behaviourally-infected children (Bhattacharya, Dubey, & Sharma, 2011).
	Caregiver Factors	Caregiver’s HIV disclosure experience	Disclosure more likely if caregiver is open about their status - several studies (Vreeman et al., 2013).
		HIV status	Caregivers living with HIV less likely to disclose than those not living with HIV (John-Stewart et al., 2013; Mellins, Kang, Leu, Havens, & Chesney, 2003). HIV-infected biological mothers reported guilt and shame as factors inhibiting disclosure (Kallem, Renner, Ghebremichael, & Paintsil, 2011; Madiba, 2012).
		HIV stigma	–
		HIV-related loss	Death of the child’s father related to earlier disclosure (Kallem et al., 2011).
		Mood	Lower levels of maternal depression associated with greater disclosure (L. Wiener, Mellins, Marhefka, & Battles, 2007).
Contextual Factors	Material	Poverty/financial difficulties associated with less disclosure (L. S. Wiener, Battles, Heilman, Sigelman, & Pizzo, 1996).	
	Symbolic	–	
	Relational	More positive caregiver-child relationships and higher levels of family expressiveness, communication and cohesion associated with more disclosure (Lester et al., 2002; L. S. Wiener et al., 1996)	
Pre-intention proximal	Attitudes	Outcome expectancies/importance of outcomes	Caregiver concerns about: child asking how they became infected/blaming the caregiver - several studies (Vreeman et al, 2013), child and family being discriminated against if they disclose to

Phase	Factor	Sub-Factor	Evidence
			others - several studies (Pinzon-Iregui et al., 2013), child harming themselves (Vaz, Eng, Maman, Tshikandu, & Behets, 2010), child being unable to understand disclosure information - several studies (Vreeman et al., 2013), protecting one's child (Bogart et al., 2008), child being psychologically affected - several studies (Pinzon-Iregui et al, 2013; Vreeman et al, 2013) – all cited as reasons for not disclosing. Caregiver hopes regarding on-going sexual abstinence (Bhattacharya et al., 2011; Chew, Beng, & Mun, 2012; Madiba, 2012), improved ART adherence –several studies (Pinzon-Iregui et al, 2013; Vreeman et al, 2013), child knowing themselves better (Vaz et al., 2011), child protecting themselves and other better –several studies (Pinzon-Iregui et al, 2013; Vreeman et al, 2013), child becoming better engaged with a helping social network (Vreeman et al., 2010), child learning status from caregiver rather than through other sources (Beck-Sague et al., 2015) – all cited as reasons for disclosure.
		Affect	–
	Normative Beliefs	Social norms	–
		Moral norms	Disclosure associated with the belief that it is the child's right to know their status - several studies (Vreeman et al, 2013).
		Descriptive norms	–
	Self-efficacy	Disclosure confidence	Lack of confidence/feeling unprepared for disclosure cited as a reason for non-disclosure - several studies (Vreeman et al, 2013).
		Disclosure consequence confidence	–
Intention	Intention		–
Post-intention	Action and coping planning		–
	Barriers and resources	Professional and social disclosure support	Greater satisfaction with social support related to greater disclosure (L. S. Wiener et al., 1996).
		Competing demands	–

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