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Theoretical Models of Parental HIV Disclosure: A Critical Review

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Abstract

This review critically examined three major theoretical models related to parental HIV disclosure (i.e., the Four-Phase Model, the Disclosure Decision Making Model, and the Disclosure Process Model), and the existing studies that could provide empirical support to these models or their components. For each model, we briefly reviewed its theoretical background, described its components and or mechanisms, and discussed its strengths and limitations. The existing empirical studies supported most theoretical components in these models. However, hypotheses related to the mechanisms proposed in the models have not yet tested due to a lack of empirical evidence. This review also synthesized alternative theoretical perspectives and new issues in disclosure research and clinical practice that may challenge the existing models. The current review underscores the importance of including components related to social and cultural contexts in theoretical frameworks, and calls for more adequately designed empirical studies in order to test and refine existing theories and to develop new ones.

Keywords

Parental HIV infection; HIV disclosure; Parental HIV disclosure; Literature review; Theoretical model

Over the past decade, new medical innovations and increasing availability of highly active antiretroviral therapy (HAART) have improved the health and longevity of HIV-positive parents, which means they may be more likely to raise their children for many years after the initial diagnosis (Enger et al., 1996; World Health Organization, 2011). For HIV-positive parents or other caregivers, telling children their parents' HIV positive status ("parental HIV disclosure") becomes an increasingly important issue in terms of caregivers' mental health, children's health, parenting and custody plan, and family relationship (Antle, Wells, Goldie, DeMatteo, & King, 2001; Kennedy et al., 2010; Rotheram-Borus, Draimin, Reid, & Murphy, 1997; Shaffer et al., 2001). However, disclosing HIV status to children (infected and/or uninfected) is a complex psychosocial challenge for the caregivers due to potential stigma and shame associated with HIV infection (Chaudoir, Fisher, & Simoni, 2011; Thorne, Newell, & Peckham, 2000). Existing research also suggests that some caregivers did not disclose parental HIV positive serostatus to children because they did not know how to do so (Corona et al., 2006).

Although there is a growing interest in parental HIV disclosure among researchers and health care providers, the theoretical frameworks of parental HIV disclosure are limited and the majority of existing empirical studies have not been conducted within a theoretical framework of HIV disclosure (Qiao, Li, & Stanton, 2011). Therefore, the aims of this review

are to critically review the existing theoretical models related to parental HIV disclosure and to make a contribution to developing theoretical framework that can guide further empirical studies and interventions in this area. Due to the lack of theoretical frameworks specifically designed for parental HIV disclosure, we will also review major theoretical frameworks for general HIV disclosure. Similarly, although we will focus on empirical studies about disclosing parental HIV status to children, we will also review studies related to disclosing HIV diagnosis to other social and familial contacts (e.g., sexual partners, family members, and friends). There may be substantial overlap in the theoretical components of differing models of disclosure, so the findings of empirical studies could provide support for more than one theoretical framework.

The four-phase model

In 1969, Kubler-Ross proposed a framework for understanding the feelings and concerns of patients facing terminal illness, describing a series of stages through which the patients with terminal illness may process (Kubler-Ross, 1969). This framework reflects the perspectives and coping mechanism of dying people and their families. Employing the similar approach, Tasker developed the Four-Phase Model (FPM) as guidance on disclosing parental HIV status to children and/or disclosing HIV status to infected children (Tasker, 1992). The FPM depicts disclosure process as a continuum: secrecy phase, exploratory phase, readiness phase, and disclosure phase (See Table 1). This model does not suggest that all families should automatically start at the secrecy stage, but outlines experiences and challenges of families at different time points with focuses on the role of health professionals, parent-professional relationship, and parent-to-parent (or other adult) relationship.

It is notable that Tasker's model was developed before the introduction of HAART which has made it possible for HIV positive persons to live longer and healthier (Egger et al., 1997). In the context where such advanced therapies are available and HIV has changed from fatal disease to a chronic one, we need to be cautious to study HIV disclosure by applying such a model of disclosing terminal illness. However, the applicability of the FPM in the context of HAART has been supported by findings from both research and field practice. A number of qualitative studies indicate that HIV-positive parents request help and guidance from health care providers or other professionals in disclosing HIV status to children (Nam et al., 2009; Nostlinger et al., 2004; Thomas, Nyamathi, & Swaminathan, 2009; Rwemisisi, Wolff, Coutinho, Grosskurth, & Whitworth, 2008; Wiener, Battles, & Heilman, 1998). Successful support required that parents not feel coerced into disclosing to children before they were adequately prepared to do so (Dematteo et al., 2002).

Although the FPM was proposed almost two decades ago, the model has rarely been directly employed to guide HIV disclosure interventions, with only one such intervention on disclosing HIV diagnosis to infected youth in Puerto Rico (Blasini et al., 2004). Guided by the FPM, this intervention included a series of training for health care providers, and education sessions and follow-up support for families and infected children. The components of the intervention emphasized respecting and sharing different feelings and experiences, engaging parents and youth in a partnership based on confidence and trust with professionals, and building support group cohesion and emotional support among participants (Blasini et al., 2004). The evaluation study of this intervention indicated that 85% of infected children and 97% of caregivers thought disclosure had positive effects. Nearly 60% of infected children improved their adherence to therapy after disclosure (Blasini et al., 2004).

There are several issues that we need to be addressed in applying the FPM in parental HIV disclosure intervention. First, we need to consider potential conflicts between parents and

tensions between parents and other family members (e.g., co-caregivers) due to different parenting and coping styles, which may influence the process of disclosure to children, particularly in a collectivistic culture context (Dematteo et al., 2002; Nam et al., 2009; Palin et al., 2009). Second, HIV-positive parents in different settings may have different expectations for professionals. A study in Canada indicated that most parents living with HIV did not want professionals directly involved in disclosure to children, although nearly half discussed disclosure with professionals (Dematteo et al., 2002). A study in Zimbabwe showed that 56% of parents preferred including a health care worker in their disclosure process (DeBaets, Sifovo, Parsons, & Pazvakavambwa, 2008). Third, this model was mainly designed as “a process model” that can be used to guide health professionals and families with HIV-positive members during the process of disclosing parental HIV infection to children. It did not identify the factors influencing decision-making of disclosure. Therefore, the model may not be particularly useful in predicting disclosure/non-disclosure.

The disclosure decision making model

Some theoretical models of HIV disclosure have been developed to enhance our understanding of decision-making of disclosure by speculating why, how and when HIV-positive individuals will disclose their status (Chaudoir et al., 2011). These models were developed through several theoretical perspectives which included social influence theory, disease progression theory and consequence theory (Ontario HIV Treatment Network Rapid Response Service, 2010) (See Table 2).

Some existing decision-making models with different perspectives incorporated different factors as antecedents to disclosure/non-disclosure of HIV status. Several models investigated specific factors influencing disclosure/non-disclosure in different close relationships (Derlega, Winstead, Greene, Serovich, & Elwood, 2004), particularly different sexual relationship (Bairan et al., 2007). Some models identified factors related to stigma and explored how these factors might affect disclosure decisions (Bird & Voisin, 2010). Some models posited a number of individual cognitive or motivational factors as predictors of disclosure (i.e. egosystem motivations, concerned with protecting and inflating desired self-images, and ecosystem motivations, concerned with contributing or supporting others) (Garcia & Crocker, 2008). Theoretical/conceptual components of these models have contributed to the formulation of some general and comprehensive disclosure decision-making models (Greene, Derlega, & Mathews, 2006; Omarzu, 2000). One of such models is the Disclosure Decision Making Model (DDMM) proposed by Omarzu (Greene et al., 2006; Omarzu, 2000).

The DDMM depicts three stages of decision-making leading to different types and levels of disclosure (Figure 1). One of the key features of the DDMM is the individual's expectation and calculation for potential benefits and risks of disclosure, assuming that individuals will make ultimate decision of disclosure/non-disclosure based on a careful analysis of anticipated outcomes (Greene et al., 2006). Empirical studies have identified specific perceived benefits and risks of parental HIV disclosure for both parents and children. For HIV-positive parents, the perceived benefits included relief from the stress caused by maintaining secrecy, relief from worrying about the children's awareness of parental HIV status from other channels, and support from children (Dane, 2002; LCS Associates, 1994; Pilowsky, Sohler, & Susser, 2000; Rwemisisi et al., 2008; Thomas et al., 2009). The perceived risks included facing children's emotional reactions (e.g., rejection), disclosing other related family secrets (e.g., drug use), and children's disclosing parental HIV infection outside of the family (secondary disclosure) (Nam et al., 2009; Nostlinger et al., 2004; Palin et al., 2009; Pilowsky et al., 2000).

Parents living with HIV often consider children's interests in their decision-making about disclosing their HIV status to children. They may perceive that disclosure might educate children, and ensure children to be prepared for parental incapacity or death (Pilowsky et al., 2000; Schrimshaw & Siegel, 2002; Vallerand, Hough, Pittiglio, & Marvicsin, 2005; Wiener et al., 1998). The perceived risks accompanying disclosure may include children's emotional reaction, the potential stigma children might encounter, children's developmental and behavioral problems, and decline in the quality of the parent-child relationship (e.g., losing respect from children) (Murphy, Steers, & DelloStritto, 2001; Nostlinger et al., 2004; Palin et al., 2009; Pilowsky et al., 2000).

The DDMM does not merely identify perceived benefits and risks as determinants to disclosure/non-disclosure; it also emphasizes that the perceived benefits and risks may mediate the relationship between the characteristics of individuals and environment (e.g., disclosers, disclose targets and contexts) and the disclosure process (e.g., cope, content and approach). In the context of parental HIV disclosure, this notion can be tested with two hypotheses. First, individual and environmental variables (e.g., demographic variables of parents and children, family relationship, community norms) are associated with perceived benefits and risks of disclosure. Second, perceived benefits and risks of disclosure are related to characteristics of disclosure.

Supporting the first hypothesis, existing studies have suggested that children's age might influence parental assessment of the potential benefits and risks. For example, most HIV positive parents might perceive little benefit from disclosure to their young children because these children might not be sufficiently mature to understand the diagnosis (Schrimshaw & Siegel, 2002; Tompkins, 2007; Vallerand et al., 2005). Parents with school-age children might worry about the risks of secondary disclosure and stigma and ostracism against children from their peers in schools (Corona et al., 2006; Thomas et al., 2009; Tompkins, 2007; Vallerand et al., 2005). For adolescent children, parents living with HIV might consider the benefits and risks of disclosure from the perspective of protecting children from HIV infection (Dane, 2002; Nam et al., 2009; Schrimshaw & Siegel, 2002; Vallerand et al., 2005).

Supporting the second hypothesis, some empirical studies have indicated that parents' perceived risks of disclosure influenced disclosure approaches to children (Kirshenbaum & Nevid, 2002; Murphy, Roberts, & Hoffman, 2002; Schrimshaw & Siegel, 2002). For example, HIV-positive parents often explicitly requested children not to tell others about parental HIV infection when they perceived a high risk of HIV-related stigmatization and discrimination in their communities (Kirshenbaum & Nevid, 2002; Murphy et al., 2002; Schrimshaw & Siegel, 2002). However, few studies have directly investigated how the perceptions of benefits and risks of disclosure influenced the processes of disclosure.

The DDMM proposes that disclosure is a consequence of rational analysis about anticipated benefits and risks of the disclosure. The emphasis on analysis of individual cognitive process may risk ignoring influences from others and the social environment, such as peer norms, social network and cultural contexts. In addition, HIV disclosure is a gradual process of interaction between disclosers and targets rather than an event at one time point (Hawk, 2007; Murphy, 2008). The targets' reactions to the disclosure and outcomes of the disclosure may also influence decision-making for future disclosure. These two complementary components should be considered in future applications of the DDMM.

The disclosure process model

In order to understand the comprehensive process of disclosure, Chaoudoir and colleagues developed the Disclosure Process Model (DPM). This model was originally designed for

disclosure studies among people living with a stigmatized condition (Chaudoir & Fisher, 2010). Subsequently it was modified for HIV disclosure in a literature review of HIV disclosure (Chaudoir et al., 2011). We present the later version here (Figure 2).

The DPM is composed of three main interrelated components: decision-making, disclosure event, and outcomes (See Table 3). The decision-making process affects the disclosure event in both the content of the disclosure and reaction of the targets. The disclosure event affects the outcomes of disclosure through three mediating processes: alleviation of inhibition, social support, and changes in social information. Change in social information refers to a situation after disclosure in which disclosure targets have new information about disclosers and disclosers are aware of the fact that the targets have obtained the updated information (Chaudoir & Fisher, 2010). Being open about HIV positive status may make disclosers more likely to engage in behaviors that they previously avoided for the purpose of hiding their serostatus (e.g., taking antiretroviral medications in public). Finally, the outcomes of disclosure may influence future disclosure decision-making through a “feedback loop” (Chaudoir et al., 2011).

Since the DPM and the DDMM share an emphasis on calculation of perceived benefits and risks of disclosure during the decision-making process, empirical evidence that supports the DDMM also support the DPM. We will not repeat the overlapping evidence but focus on studies regarding the disclosure event and outcome process. Studies investigating the disclosure event suggest that unplanned and indirect disclosure were common in the practice of parental HIV disclosure (Dematteo et al., 2002; Kennedy et al., 2010; Murphy, Roberts, & Hoffman, 2003; Vallerand et al., 2005; Woodring, Cancelli, Ponterotto, & Keitel, 2005). Children who were informed about parental HIV status often reacted emotionally and negative reactions were common, particularly in the setting of indirect and unplanned disclosures (Dematteo et al., 2002; Vallerand et al., 2005).

The outcomes of disclosure can be examined at three levels in the DPM: individual level, dyadic level and social level. Existing empirical studies about parental HIV disclosure have investigated the impacts of disclosure in terms of the individual level and the dyadic level. Although the results are mixed, studies suggest that parental HIV disclosure to children might be associated with better adherence to clinic appointments (Mellins et al., 2008), lower anxiety and depression (Armistead et al., 1999), and higher social support for parents living with HIV (Murphy et al., 2001).

As for the dyadic level, existing quantitative studies show mixed results regarding the short-term effect of disclosure of parental HIV on children. Some studies indicate that disclosure was associated with lower emotional and social functioning (Xu, Wu, Rou, Duan, & Wang, 2010), more externalizing symptoms (Palin et al., 2009), and higher depression score (Mellins et al., 2008) among children. However, other surveys suggest that disclosure was not significantly related to children’s negative psychological outcomes (Armistead, Klein, Forehand, & Wiersen, 1997; Armistead, Tannenbaum, Forehand, Morse, & Morse, 2001; Kirshenbaum & Nevid, 2002; Mellins et al., 2008). Studies focusing on long-term effects indicate that most children, particularly younger children, adequately adjusted to parental HIV disclosure over time even after an initial negative emotional reaction (Lee & Rotheram-Borus, 2002; Murphy, Marelich, & Amaro, 2009; D. A. Murphy, Marelich, & Hoffman, 2002; Nöstlinger, Bartoli, Gordillo, Roberfroid, & Colebunders, 2006). As for the relationship between the discloser and disclosure target, HIV-positive parents who had disclosed to children reported having stronger parent-child relationship (Dane, 2002; Murphy et al., 2009; Schrimshaw & Siegel, 2002; Vallerand et al., 2005) and higher family cohesion (Wiener, Battles, & Heilman, 1998). In addition, disclosing HIV status to infected

children was associated with better medication adherence among children (Bikaako-Kajura et al., 2006; Blasini et al., 2004).

The DPM also proposes potential effects of individual disclosure at the social level in terms of increasing education about HIV, reducing HIV-related stigma, facilitating discussion of HIV and promoting HIV-risk reduction behaviors such as HIV counseling and testing (Chaudoir et al., 2011). A series of studies about Magic Johnson's public announcement of his HIV positive status confirmed the social outcomes of individual disclosure (Cohn, Miller, Yamaguchi, & Douglas, 1992; Ehde, Holm, & Robbins, 1995; Kalichman & Hunter, 1992).

Three hypotheses can be tested to confirm the mechanism of how disclosure affects various psychosocial or clinical outcomes. First, disclosure can alleviate the psychological stress of inhibition and the psychological stress of inhibition is associated with disclosure outcomes (e.g., treatment adherence). Second, social support mediates the association between disclosure and its outcomes. Third, disclosure may facilitate the improvement of certain outcomes. For example, the discloser may improve treatment adherence after disclosure because the discloser does not need to hide taking medications in front of the disclosure targets. One study provided support for the hypothesis that disclosure can promote treatment adherence through greater social support (Waddell & Messeri, 2006). However, few existing studies have examined whether disclosure could alleviate the psychological stress of inhibition or investigated the potential mechanisms through which the disclosure may affect treatment adherence (Chaudoir et al., 2011).

Besides the mechanism of calculating perceived benefits and risks that is similar to that in the DDMM, the DPM posits an additional mechanism of predicting disclosure, the "feedback loop". The feedback loop emphasizes the interaction between discloser and disclosure target by investigating how reactions to disclosure or disclosure outcomes may affect future disclosure. There was evidence suggesting that social support obtained after disclosure could increase the likelihood of future disclosure (Wouters, Meulemans, & VanRensburg, 2009). More studies are needed to test this new mechanism.

The DPM predicts a comprehensive process of HIV disclosure including decision-making, event, outcome and feedback loop. This model aims to not only explain why disclosure takes place but also examine when and why the disclosure can be beneficial to the discloser and the disclosure targets. However, some of the hypotheses based on this model have not yet been tested by empirical studies. In addition, this model might not be easily generalized to various settings as the model lacks components related to social and cultural contexts.

Synthesis

The current review contributes to the conceptualization of the disclosure practice and the development of appropriate theoretic framework to understand the dynamics and impacts of disclosure by presenting three typical theoretical frameworks of HIV disclosure and empirical evidence that supports these frameworks. Existing empirical studies on parental HIV disclosure or general HIV disclosure have confirmed the applicability and utility of most components of the three theoretical frameworks. However, there are limited studies examining interactions between main components in the frameworks. Therefore it is hard to assess the mechanisms proposed by the framework due to the lack of empirical evidence. The gap between theoretical and empirical studies has underscored the needs of future research on parental HIV disclosure in terms of testing and developing theories that can guide empirical studies and clinical practices.

Consequence theory, central to both the DDMM and the DPM, has been questioned by some researchers, because this theory applies a perspective of “sovereign-self” assuming that self is a rational agent who acts based on the internal workings of the individual mind and thus the act of disclosing is depicted as an process driven by individual rational choice (Baxter & Sahlstein, 2000). An alternative perspective advocated by some scholars is the “social-self” that emphasizes that a self is constructed with and through others (Baxter & Montgomery, 1996; Gergen, 1994; Sampson, 1993). Therefore, the disclosure is an action of the discloser but also is a negotiated process between disclosers and disclosure targets within different social relations in a certain context (Baxter & Sahlstein, 2000). The decision-making process and disclosure practice may extend beyond individuals to families, communities, or other larger social contexts (Petronio, 2000).

Empirical studies have suggested an important role of culture context in the practice of HIV disclosure for several reasons. First of all, HIV disclosure may take on different meanings in different cultural contexts, such as revealing a secret, admitting guilt, or stating a medical fact (Obermeyer, Baijal, & Pegurri, 2011). Second, cultural values may affect decisions on HIV disclosure. In some cultures (e.g., Asia and Hispanic), the values of family may be a barrier to HIV disclosure. HIV-positive individuals might choose not to disclose their status to family members due to intentions to protect family from shame and stigma (Mason, Marks, Simoni, Ruiz, & Richardson, 1995; Yoshioka & Schustack, 2001). Third, reasons for HIV disclosure may vary across cultural backgrounds. For example, one comparative study between American HIV-positive men and Indian HIV-positive men indicated that American men’s reasons for disclosure were relation-focused, whereas for Indians men disclosure was obligatory (Vira, 2004). Finally, different cultural contexts may shape the disclosure patterns. In some areas (e.g., Asia, Middle East), involuntary disclosures have been common (Obermeyer et al.). It was physicians (rather than the HIV-positive individuals) who were thought to have the authority to make a decision on disclosure because they were assumed to know better than patients who were often poor or low-educated (Mobeireek et al., 2008).

Many issues in clinical practice may challenge the existing theories. How should health professionals deal with the dilemma between respecting HIV-positive’ privacy and protecting people around patients (Seidel, 1996)? How should primary health care providers deal with the conflicts between local social norms and national guidance on HIV disclosure (Datye et al., 2006)? How should we define the boundaries of openness and closeness, public and privacy (Petronio, 2000)? These questions from field practice call for new theoretical explorations related to HIV disclosure.

In conclusion, future theoretical studies need to not only focus on individual factors but also on social, environmental and cultural factors. A theoretical framework should be able to guide the generation of meaningful research hypotheses, guide the assessment and development of specific intervention components, and address issues from clinical practice. Meanwhile, more adequately designed empirical studies are needed to test and refine existing theories and to develop new ones in the areas of HIV disclosure in general and parental HIV disclosure specifically.

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Figure 1.
The Disclosure Decision-Making Model. Adapted from Omarzu (2000).

Figure 2.
Disclosure Processes Model for HIV disclosure. Adapted from Chaudoir et al. (2011).

Table 1

Description of the Four-Phase Model (FPM)

Phases	Behavioral patterns or needs of	
	HIV-positive parents	Professionals
Secrecy phase	<ul style="list-style-type: none"> • feel shock, loneliness, isolation • identify trusted adults to disclose their HIV status • professionals may be the only people with whom they can share feelings 	<ul style="list-style-type: none"> • respect and meet parents' need for confidentiality • create a trusting and safe environment for parents to discuss parental decisions
Exploratory phase	<ul style="list-style-type: none"> • search parent support groups to explore feelings about disclosure to children. • consider talking with children about clinic visits and treatment or offering some explanations about their health conditions. 	<ul style="list-style-type: none"> • recognize that it is parents who make final decision of disclosing to children(when and how) • honestly express their opinions to provide different perspectives
Readiness phase	<ul style="list-style-type: none"> • move closer to disclosing the diagnosis to their children • begin to plan disclosure and discuss strategies of disclosure with professionals, trusted adults and support groups. 	<ul style="list-style-type: none"> • collaborate with parents in planning disclosure • mutual respect for knowledge and skills of both parents and professionals
Disclosure phase	<ul style="list-style-type: none"> • disclose their HIV status to children following a specific plan and with or without presence of professionals 	

Table 2

Selected theoretical perspectives of HIV disclosure

Theory	Perspectives
Social influence theory (Stenger, 1996; Zea, Reisen, Poppen, Bianchi, & Echeverry, 2007)	HIV disclosure is influenced by a number of contextual factors that HIV-positive persons are living with (e.g., social norms, cultural values and beliefs, and experiences of discrimination).
Disease progression theory (Babcock, 1998)	HIV-positive persons will disclose their HIV status when HIV progresses to AIDS and it becomes difficult for them to conceal the symptoms.
Consequence theory (Emlet, 2006, 2008; Serovich, 2001)	There is a linkage between disclosure decision and analysis of anticipated outcomes. Disclosure occurs when the benefits of doing so (obtaining social and emotional support) outweigh the costs (being stigmatized by others).

Table 3

Key components of the Disclosure Process Model (DPM)

Key components	Descriptions
Decision-making	Decision-making of HIV disclosure is influenced by antecedent goals, including approach goals such as pursuing positive outcomes (e.g., stronger relationship, educating others) and avoidance goals such as preventing negative outcomes (e.g., social rejection, relationship conflict).
Disclosure event	The disclosure event is characterized by content of disclosure (e.g., depth, breadth, duration) and reaction of the target.
Outcomes of disclosure	Individual outcomes: psychological (e.g., distress, self-esteem), behavioral (e.g., antiretroviral treatment adherence), and clinical outcomes (e.g., CD4 counts) on disclosers. Dyadic outcomes: well-being of disclosure targets (e.g., psychological and physical well-being of children who were informed their HIV positive serostatus), the well-being of both the discloser and disclosure target (e.g., safer sexual behaviors with sexual partners), and their relationship with each other (e.g., interpersonal liking, intimacy, and trust). Social outcomes: impacts of disclosure event on social and cultural context (e.g. creating awareness of HIV, reducing HIV-related stigma).