

PARENTAL HIV DISCLOSURE: SCOPING LITERATURE REVIEW WITH A LENS ON INFORMATION BEHAVIOR

Abstract

Many children have been and continue to be impacted by parents living with HIV/AIDS and disclosure of parental positive HIV/AIDS status to their children has multiple benefits. Research has been done on the prevalence and influencing factors of parental HIV disclosure however many identified gaps in research have not yet been fulfilled. The application of an information behavior theoretical framework may enable an opportunity to fulfill such research gaps. This is a scoping literature review that aims to align previously identified research findings about parental HIV disclosure to opportunities that may benefit from the application of information behavior theory and answer the questions: 1) What research has been done about parental HIV disclosure? 2) How has information theory been applied to research about parental HIV/AIDS disclosure?

Introduction

Many children have been and continue to be impacted by parents living with HIV/AIDS. The disclosure of parental positive HIV/AIDS status to their children has multiple benefits, including the ability to better support these children. "Disclosure, or self-disclosure, is a process in which personal information is verbally communicated to another person" (Qiao et al., 2013, p.1). UNICEF (2024) estimates that as of 2023, roughly 14.1 million children under the age of 18 had lost one or both parents to AIDS-related causes. Additionally, understanding the benefits to the parental disclosure of HIV status to children has become more important as HIV treatment has improved. As treatment has improved, HIV-positive parents have an improved prognosis and are living longer (Madiba, 2013; Nostlinger et al., 2004; Sun et al., 2021). And, as the prognosis of HIV has improved, more people living with HIV (PLH) are becoming parents (Cyrus et al., 2023; Nostlinger et al., 2004). To best support PLH, along with their families and children, it is necessary that we understand how to encourage parental disclosure, which has been shown to have numerous benefits.

The study of information behavior began over 50 years ago. The research was originally limited to interaction with formal information and systems but has become more broadly defined over the last several decades (Bawden & Robinson, 2022). Information behavior is defined as "the totality of human behavior in relation to the sources and channels of information, including both active and passive information-seeking and its use" (Wilson, 1999, p. 249). The act of disclosure is encompassed by current definitions of information behavior. Disclosure is defined by the Cambridge English Dictionary as "the act of making something known or the fact that is made known" (n.d.) and by The Britannica Dictionary as "something (such as information) that is made known or revealed (n.d., Definition 2).

Prevalence of parental HIV disclosure to children remains low or unknown beyond a significant range and variations between high income vs. resource-limited countries were also significant

(Qiao & Stanton, 2013; Sun et al., 2021). To better understand how to encourage parental disclosure of positive HIV/AIDS status to children, research has been done on the prevalence and influencing factors of such disclosure. However, this research has also identified gaps in research that have not yet been fulfilled. A scoping literature review aims to identify the types of research on a topic and gaps in current research being performed (Williams, 2023). This is a scoping literature review that aims to align previously identified and new research findings to opportunities that may benefit from the application of information behavior theory through answering two research questions: 1) What research has been done about parental HIV disclosure? 2) How has information theory been applied to research about parental HIV/AIDS disclosure?

Methodology

Literature to support this research of parental HIV disclosure was found through a variety of peer-reviewed journals and accessed through Dominican University's databases. Keywords used to find relevant literature included: parental HIV disclosure (+ benefits, + barriers), HIV disclosure literature review and HIV disclosure intervention. Journals leveraged were academic journals focused on interdisciplinary AIDS research, public health and social sciences. Eleven research articles in total were included in the data set.

Results

Summary of Data Set

This literature review surveyed a representative sampling of peer-reviewed research articles about parental HIV disclosure to children. The studies varied in research method and data collection. In addition to showing agreement about the benefit of parental disclosure benefit, the studies surveyed for this literature review also consistently described the need for population-specific interventions to encourage parental disclosure, due to differing culture and social contexts (Cyrus et. al, 2023; Madiba, 2013; Qiao & Stanton, 2013). The studies surveyed took place between 2002 through 2023 and in fact, parental HIV disclosure research was not considered until the early 1990's (Trask, p. x, 1992).

Ten of the articles surveyed for this literature were original research studies. Of those ten studies, four were qualitative studies (Corona et. al, 2006; Kennedy, 2010; Lightfoot et. al, 2023; Madiba, 2013) and ranged from 26 to 274 participants. Four studies were mixed-methods studies (Cyrus et. al, 2023; Dematteo, 2002; Goodman et al, 2021; Nostlinger et. al, 2004) and ranged from 105 participants to 628 participants. Two studies were randomized controlled trials (RCT) (Da et. al, 2024; Sun et. al, 2021) and consisted of 80 and 791 participants. Of the ten research studies surveyed in this literature review, all but one were done without a theoretical framework. One qualitative study was based on Family Systems and Communication theory (Kennedy, 2010). While the qualitative studies provided more detailed findings, the study size was small, and all studies had less than 1,000 participants.

Sociodemographic data of study participants collected as part of the ten original research studies surveyed for this literature varied greatly and many studies did not track any sociographic factors. The absence and differing application of sociodemographic factors in these studies limits the ability to correlate sociodemographic factors to parental disclosure prevalence rates.

Of the ten original research studies surveyed for this literature review, one study took place in the USA (Corona et. al, 2006), one study took place in Canada (Dematteo, 2002), one study in Europe (Nostlinger et. al, 2004), two studies in Asia (Da et. al, 2024; Sun et. al, 2021), three in Africa (Cyrus et. al, 2023; Lightfoot et. al, 2023; Madiba, 2013) and two did not identify where the research took place (Goodman et al, 2021; Kennedy, 2010). A systematic review of global literature was also included in this literature review (Qiao & Stanton, 2013). This review surveyed 38 articles about parental HIV disclosure published in English-language journals before 2011 and included 26 studies that took place in the USA, 5 in Europe, 4 in Africa, 4 in Asia and 2 in Canada. While varied in location, the applicability of findings from one research study to a different population may be limited due to social and cultural differences.

The Benefit of Parental HIV/AIDS Disclosure to Children

Numerous benefits to parental disclosure of positive HIV/AIDS status to their children have been identified and there is much consistency to the benefits of disclosure found in the research.

“Growing evidence that parental HIV disclosure to children is beneficial and that it increases mutual support with the nuclear family” (Sun et al., 2021, p. 1). In the literature surveyed for this literature review, six research articles identified benefits of parental HIV status disclosure to children. Of the six research studies, five identified access to greater support as one benefit of disclosure (Cyrus et al., 2023; Goodrum et al., 2021; Kennedy, 2010; Madiba, 2013; Sun et al., 2021) and four research studies identified reduced stress, anxiety, and/or depression as a benefit of disclosure (Goodrum et al., 2021; Kennedy, 2010; Madiba, 2013; Sun et al., 2021). Three of the six research studies identified improvement to the parent’s treatment adherence as a benefit of disclosure (Cyrus et al., 2023; Madiba, 2013; Sun et al., 2021); three research studies identified better communication within the family as a benefit (Cyrus et al., 2023; Goodman et al., 2021; Kennedy, 2010) and three research studies identified an improvement in the quality of family relationships as a benefit to parental disclosure (Cyrus et al., 2023; Goodman et al., 2021; Kennedy, 2010). Despite variations in research methods and populations studied, the benefits of parental disclosure of HIV/AIDS status to children are generally consistent.

Barriers of Parental HIV/AIDS Disclosure to Children

Of the research surveyed for this review, there was consistency in barriers noted or identified to parental HIV/AIDS disclosure to children. The most common barrier noted to parental disclosure was fear of negative reactions from either the children, the community, or both (Cyrus et al., 2023; Lightfoot et al., 2023; Madiba, 2013; Sun et al., 2021). Negative reactions identified included anticipation of stigma, discrimination and/or disrespect. “Parents who felt shame, embarrassment, or fear of judgement related to their own HIV status expressed unwillingness to disclose their status to their children” (Cyrus et al., 2023, p. 7). Another consistently noted barrier was fear about the child’s age and related ability to understand information about HIV/AIDS and its significance (Lightfoot et al., 2023; Madiba, 2013; Sun et al., 2021; Science Letter, 2006). Research participants described concerns about their children understanding HIV and/or sex generally and a fear that their children would not be able to maintain confidentiality due to not understanding the significance of the information. “While the higher-level theme was the child’s maturity level to understand what living with HIV means, parents were also concerned that a child might be too young to understand confidentiality or how to “keep secrets” (Cyrus et al., 2023, p. 7). Related, a need for more support and knowledge about how to disclose was identified as a barrier to disclosure (Madiba, 2013). Other barriers identified in research

were fears about the reaction of children to the disclosure such as causing the children worry (Lightfoot et al., 2023; Madiba, 2013; Sun et al., 2021) and a feeling that HIV status deserved protection and was not their children's business (Madiba, 2013; Sun et al., 2021). Despite variations in research methods and populations studied, the barriers to parental HIV/AIDS disclosure to children depict many similarities.

Interventions to Increase Parental Disclosure

A few studies surveyed discussed interventions intended to encourage HIV/AIDS parental disclosure to children. These studies explored interventions to mitigate barriers to disclosure such as providing supportive services to parents about and through the disclosure process (Corona et al., 2006; Cyrus et al., 2023; Da et al., 2024). Most studies cited the need for interventions to be population-specific to encourage parental disclosure (Cyrus et al., 2023; Da et al., 2024; Madiba, 2013; Qiao & Stanton, 2013). One study correlated this need to the impact of differing culture and social contexts on interventions (Madiba, 2013). While the identification of effective interventions was considered needed based on the benefits of disclosure, overall, there was more focus on the need for interventions rather than on actual interventions.

Table 1*Intervention Findings of Research*

Author, year	Intervention Insights
Cyrus et al., 2023	<ol style="list-style-type: none">1. Supportive services to deal with process of disclosing can increase disclosure2. Interventions need to be specific to intended audience3. Need for interventions including anticipated stigma from children and community, fear that disclosure will cause distress to children
Da et al., 2024	<ol style="list-style-type: none">1. Need for more comprehensive measures that capture multi-dimensional nature of parental HIV disclosure2. Further research needed to establish if effects translate into actual changes in parental HIV disclosure behavior3. Research gap in comprehensively understanding how to tailor disclosure interventions to address children's different developmental stages and PLH's unique needs
Lightfoot et al., 2023	<ol style="list-style-type: none">1. Understanding the barriers is insufficient for supporting and promoting disclosure2. Understanding how and why can help inform helpful interventions
Madiba, 2013	<ol style="list-style-type: none">1. Studies show most are conducted in well developed countries2. Geographic distribution of existing studies does not reflect the actual HIV epidemics3. Social and cultural contexts for HIV disclosure in developing countries are likely to differ
Nostlinger et al., 2004	<ol style="list-style-type: none">1. Need for integrating a family perspective into psychosocial support of CLWH2. Models of good practice identified in other chronic diseases (cancer) could provide interesting parallels3. Understanding more about the factors that influence disclosure in a family context may allow for developing and adopting a framework to better support PLH
Qiao & Stanton, 2013	<ol style="list-style-type: none">1. Intervention studies are needed to support families as they struggle with issues associated with disclosure. Existing studies suggest a high desire from parents living with HIV to obtain professional guidance and support during the disclosure process due to complexity of parental HIV disclosure to children [42], intervention studies related to parental HIV disclosure to children were limited worldwide.

	<p>2. Future research and interventions regarding parental HIV disclosure to children should consider children's cognitive development level.</p> <p>3. Future research and interventions also need to consider influence of family and community factors on the disclosure and its consequence.</p>
Sun et al., 2021	With assistance from culturally sensitive interventions, rate of parental HIV should be increased, and mental stress levels of parents and children should decrease accordingly

Discussion

There are a variety of limitations in the research surveyed including quantity of studies, size of studies, gaps in data collection and time and location of studies. Studies, limited worldwide, are for the most part conducted in well developed countries (Lightfoot et al., 2023; Madiba, 2013; Mugo et al., 2023; Qiao & Stanton, 2013). While qualitative studies provided more detailed findings about the benefits, barriers and interventions related to parental disclosure, the study sizes were small, and no studies surveyed were more than 1,000 participants. Research focused on interventions to promote disclosure were more limited (Lightfoot et al., 2023; Madiba, 2013; Mugo et al., 2023; Qiao & Stanton, 2013). Research to address interventions that may address barriers related to children's age / development (Da et al., 2024; Qiao & Stanton, 2013) and the fear of stigma and other negative feelings are particularly limited. "While discrimination has been identified as the major obstacle to prevention and care, the silence in many HIV-affected families may now extend the stigma into the next generation, emotionally burdening both HIV-infected caregivers and HIV-affected children" (Nostlinger et al., 2004, p. 647). While varied in location, the applicability of findings from one research study to a different population, may be limited due to social and cultural differences (Madiba, 2013). The studies surveyed for this review took place between 2002 through 2023 and in fact, parental HIV disclosure research was limited prior to 1995 (Dematteo et al., 2002). These limitations provide ample opportunity for additional research.

Conclusion

Several studies surveyed noted a low, worldwide parental disclosure rate (Lightfoot et al., 2023; Madiba, 2013; Mugo et al., 2023, Qiao et al., 2013; Sun et al., 2021). There is a need to continue research about parental HIV/AIDS that can support increased disclosure prevalence rates. This survey of research literature addressing parental HIV disclosure to children presents opportunities to deepen and broaden related research through the use of a theoretical framework. Given the historical and continued scope of impacted people and consistent agreement that disclosure is beneficial to both PLH and their families, consideration of these opportunities is warranted. There is an opportunity to leverage relevant theoretical frameworks to gain new perspectives about parental HIV disclosure to children and interventions to encourage disclosure. Case & Given offer the most encompassing definition of information behavior to include information seeking “as well as the totality of other unintentional or serendipitous behaviors (such as glimpsing or encountering information), as well as purposive behaviors that do not involve seeking, such as actively avoiding information” (p. 6, 2016). Parental HIV disclosure, “the act of parents living with HIV (PLH) telling their children about their HIV diagnosis” (Da et al., 2024), should be understood as an information sharing behavior as it is an act that entails purposeful and intentional sharing or *not* sharing of information. While there are findings that effective interventions to encourage disclosure need to be population-specific (Madiba, 2013; Mugo et al., 2023; Qiao & Stanton, 2013), most studies are narrowly scoped by location, population and study size. The application of an information behavior theoretical framework may enable an opportunity to do more and larger studies to address intervention needs of a greater number of PLH and their families. Pursuing these research opportunities to better understand more aspects of the HIV/AIDS pandemic is important because while infections have decreased over the past 25 years, an estimated 1.3 million individuals worldwide acquired HIV in 2023 (UNICEF, 2024) and there remains no cure or vaccine (“How HIV/AIDS changed the world”, 2020).

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