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Abstract

Human Immunodeficiency Virus (HIV) is a disease that is associated with risky sexual behaviors, injection drug use, and poverty. Due to this correlation to behaviors that are generally judged and criticized, a negative level of stigma in society may result due to personal beliefs and values, as well as misconception and lack of knowledge. The three types of stigma are perceived, experienced, and internalized. Each of these types elicits negative psychosocial and behavioral effects on the targeted individuals. Although children and adolescents who contract HIV parinatally from their mothers did not obtain HIV from the risky behaviors that commonly cause the stigma, it still may have harmful consequences on these young persons. Disclosure of HIV status to children and adolescent is important in order to maintain treatment adherence and enhance understanding of their disease, however the potential stigma surrounding HIV can complicate the disclosure process and the subsequent disease management period.

Keywords

stigma, HIV disclosure, children, adolescents

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Abstract

Human Immunodeficiency Virus (HIV) is a disease that is associated with risky sexual behaviors, injection drug use, and poverty. Due to this correlation to behaviors that are generally judged and criticized, a negative level of stigma in society may result due to personal beliefs and values, as well as misconceptions and lack of knowledge. The three types of stigma are perceived, experienced, and internalized. Each of these types elicits negative psychosocial and behavioral effects on the targeted individuals. Although children and adolescents who contract HIV perinatally from their mothers did not obtain HIV from the risky behaviors that commonly cause the stigma, it still may have harmful consequences on these young persons. Disclosure of HIV status to children and adolescents is important in order to maintain treatment adherence and enhance understanding of their disease, however the potential stigma surrounding HIV can complicate the disclosure process and the subsequent disease management period.

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Human Immunodeficiency Virus (HIV) is a human RNA retrovirus that destroys specific blood cells, CD4+ T cells, which are needed to help the body fight disease. If left untreated or mismanaged, HIV can lead to Acquired Immune Deficiency Syndrome (AIDS), resulting in severe immune system damage. (Libman & Makadon, 2007) Approximately 33.4 million people in the world are currently infected with HIV, including 2.2 million under the age of 15 (Ferris, Burau, Schweitzer, Mihale, Murray, Preda, Ross, & Kline, 2007). In the United States specifically, the population group aged 13-29 is the largest HIV positive age group (35%) in the aggregate in comparison to the other age groups of 30-39, 40-49, and over 50 years old ("HIV/AIDS," 2010). Globally, approximately 90% of HIV transmissions in children are perinatally-induced through pregnancy, labor or delivery, or breastfeeding (Patton et al., 2009).

After highly active antiretroviral therapy (HAART) became available in 1996, mortality rates in HIV positive children and adolescents dramatically declined. As a result, the mean age of death in perinatally infected children has doubled from nine years old to over eighteen years. (Hazra, Siberry, & Mofenson, 2010) This use of HAART and the subsequent increase in life expectancy causes more children and adolescents to grow to an age where disclosure of their HIV status is inevitable (Ferris et al., 2007). Most of these individuals who are perinatally infected

learn about their HIV status between the ages of 9 to 12 years old (De Luria, 2010). Although these young people contracted the disease from their mothers, they may experience the stigmas associated with HIV, which can result in negative psychosocial, health, and physical effects. This is due to the particular stigma that people associate with HIV since it is related to sexual behavior and substance abuse, which are both criticized by the majority of society. (Wright, Naar-King, Lam, Templin, & Frey, 2007) This can be detrimental to a child or adolescent, especially since the attitudes towards HIV/AIDS positive individuals can cause shame, guilt, and the thought that the disease was by the power of God's retribution (Nyblade, 2006).

Stigma

Individuals with HIV typically have histories of negative life experiences such as traumatic events, mental illness, and stigma (Whetten, Reif, Whetten, & Murphy-McMillan, 2008). Stigma is defined as "an desirable or discrediting attribute that an individual possesses, thus reducing the individual's status in the eyes of society (Whetten, Reif, Whetten, & Murphy-McMillan, 2008, p. 535)." People negatively used stigma to establish power and legitimize inequalities such as ones based on gender, sexual orientation, class, race, and ethnicity. Discrimination, which is the negative form of exclusion, distinction, or restriction

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due to a person's characteristics, can result. (Nyblade, 2006) According to a survey done by the Kaiser Family Foundation, thirty percent of participants reported that they were somewhat comfortable around an HIV positive person, and twenty one percent reported that they were not too comfortable or not at all, mainly due to misconceptions about transmission of the disease and its associated stigma (Whetten, Reif, Whetten, & Murphy-McMillan, 2008). According to Vanable, Carey, & Blair, nearly one fourth of Americans are still afraid of direct contact with someone who has HIV, and approximately one third of individuals would actively avoid interacting with HIV positive individuals if they knew their positive HIV status (2006). Also, in a study done in New York, forty one percent of the HIV positive participants experienced others acting negatively toward them after learning their HIV status.

One of the several causes of the negative stigma associated with HIV was rooted early in the epidemic. In the 1980s, there was an intense environment of secrecy and decreased social support among gay men who were acquiring the disease. (Whetten, Reif, Whetten, & Murphy-McMillan, 2008) This resulted in negative stigma rooted on social behavior, not only due to the fear of physically acquiring the disease from someone, but also fear of the symbolic contagion that the person may be associated with if they interact with an HIV positive individual (Campbell, Foulis, Maimane, & Sibiyi, 2005). Stigma associated with HIV includes social rejection, financial security, internalized shame, and social isolation, which are manifested in different types of stigma (Nyblade, 2006).

Stigma Types

Types of stigma are perceived, experienced, and internalized. Perceived stigma is the fear of how others may react to the individual's HIV status, such as what may happen, what others may think, and how supportive certain groups may be (Whetten, Reif, Whetten, & Murphy-McMillan, 2008; Nyblade, 2006). Experienced stigma is the stigma that an individual witnesses firsthand, which includes denial of health, education, or employment, exclusion from family or the community, verbal or physical abuse, and loss of respect. Internalized stigma is characterized as the individual's personal negative self-image of being unclean, bad, or being punished, that the individual may have. (Nyblade, 2006) These types of stigma increase isolation and shame that may result in fear of access-

ing health services and have psychosocial effects (Wright, Naar-King, Lam, Templin, & Frey, 2007). Stigma in Children and Adolescents

Due to the fact that HIV is associated with promiscuous sex, drug use, and poverty, a large portion of society resists accepting those who are infected. The preexisting stigma is correlated with a marginalized group who were initially the most infected with HIV during the beginning of the epidemic, resulting in the association of HIV with sexual behavior and illegal drug activity, terminal illness, and infected people as being active transmitters of the virus. (Ostrom, Serovich, Lim, & Mason, 2006; Vanable, Carey, Blair, & Littlewood, 2006) Although children and adolescents acquire HIV perinatally from their mothers, the three types of stigma can still occur. This can be contributed to the fact that people often make the link between sex, sin, and immorality, and automatically apply it to all people infected with the disease. (Campbell, Foulis, Maimane, & Sibiyi, 2005) Despite the fact that this population may or may not be involved with such behaviors, they are unfairly stigmatized due to their HIV diagnosis.

Children and adolescents can be more sensitive to this stigma due to their stages in normal human development. Erik Erikson's stages of child and adolescent psychosocial development are industry versus inferiority and identity versus role confusion, respectively. During the childhood stage, the young person is experiencing the virtue of competence, are becoming more aware of themselves as individuals, and developing a level of self-confidence. In addition, children are preoccupied with achieving recognition from family and peers, and can develop feelings of inferiority if their efforts are ridiculed in any way. Adolescents experience the ego quality of fidelity and therefore attempt to discover their role in the world, what society expects from them, and a sense of identity. Since this stage comes before early adulthood, these individuals also focus a lot on the future. (Jenks, 2005) These young patients are not only experiencing typical stressors of growing up, but also additional ones with HIV, and therefore may not have adequate internal coping mechanisms when faced with stigma. Effects of Stigma

Each person experiences the various types of stigma in different ways, especially children and adolescents. Due to their stages of development, lack of knowledge and cognitive understanding, personal resources, et cetera, this population could experience

more dramatic effects. The presence of perinatal HIV infection is associated with all three major child adversities of poor health, economic hardship, and comprising rearing family or caregiver environment. HIV has a direct impact on physical and cognitive development of the child, as well as psychosocial effects such as poverty, parental substance abuse and illness, and increased risk of child neglect, maltreatment, and abandonment (Steele, Nelson, & Cole, 2007). However, due to the limited longitudinal and other forms of evidenced based research, the effects of stigma discussed below are predominantly from research with adults.

Psychosocial effects.

Stigma can affect the psychological and social aspect of a person and his or her life. This includes a sense of shame, fear of rejection, coping difficulties, adjustment difficulties, and anxiety. (Vanable, Carey, Blair, & Littlewood, 2006) In addition, there are increased links with stigma in HIV with posttraumatic stress disorder, depression, as well as decreased disclosure to sexual partner (Whetten, Reif, Whetten, & Murphy-McMillan, 2008). In relation to the stages of development as outlined by Erik Erikson, children and adolescents are trying to determine their own competence and identity both as individuals and in relation to society, and therefore are already predisposed to psychosocial stress.

Changes in health behaviors.

Stigma can create fears or concerns in individuals that can play a large role in disclosure to others, treatment, acquisition of education, and so forth. In the New York study discussed previously, fifty six of these HIV positive individuals had moderate to high levels of concern for stigma if they took their medications due to fear of unintended disclosure in public. These concerns therefore had a negative influence on their treatment adherence. (Whetten, Reif, Whetten, & Murphy-McMillan, 2008) In addition, stigma causes young persons to avoid seeking counseling because they fear that others will see them enter and leave these services (Campbell, Foulis, Maimane, & Sibiyi, 2005). Other health behavior effects include inadequate self-care and risky sexual behaviors (Vanable, Carey, Blair, & Littlewood, 2006).

Disclosure of HIV

Disclosure to Children and Adolescents

Disclosure of an HIV diagnosis to children and adolescents has a variety of positive and negative

impacts on the individual. Favorable effects include increases in medication adherence and responsibility, as well as awareness of why certain medications and other treatments were being used in the past. However, this knowledge can also have damaging repercussions such as adverse psychological consequences, obtaining the diagnosis before he or she is developmentally ready, as well as subsequent disclosure to others that may result in stigmatization and its related effects. (Vreeman et al., 2010) In addition, perinatally infected children and adolescents can experience a high magnitude of distress due to resulting pessimism about their HIV treatment and care, personal future, and health (Lam, Naar-King, & Wright, 2007).

Disclosure to Others

After the child or adolescent has been told his or her HIV status, they are inevitably going to tell others, or others may find out by other means. This can cause positive effects such as engaging the individual in a supportive network and increasing help in his or her care, which can increase treatment adherence and ultimately improve health. In addition, these children and adolescents may not have to hide medications or delay doses. Negative outcomes include isolation, stigmatization, discrimination, and exposure to other negative attitudes toward HIV that can have effects such as decreased medication adherence and psychosocial complications. (Vreeman et al., 2010) Due to these unfavorable outcomes, HIV infected youth may be less likely to disclose their status to friends due to how high peer approval is placed (Lam, Naar-King, & Wright, 2007).

Disclosure and health.

Disclosing an HIV status can result in delayed disease progression due to increased awareness, participation, and monitoring in the child or adolescent's treatment. These health benefits usually occur once the threat of stigma is lifted since individuals feel that they are able to freely discuss their diagnosis with friends and family, and do not have to hide their medications or other treatments. In a study done in Romania, a country where HIV affects more children than adults, children who disclosed their status to friends during a one-year course had larger CD4+ increases than those who did not. This suggests that once the threat of stigma is lifted, the children feel free to discuss their HIV diagnosis with friends, which may result in health benefits. (Ferris et al., 2007). In addition, children and adolescents undergo serious psychosocial distress due to their age since they are

experiencing a critical stage in development. This biological, cognitive, and social development of these young individuals pose an abundance of physical and psychosocial barriers to managing their chronic illness, including the disclosure process and the attached stigma. (Lam, Naar-King, & Wright, 2007)

Healthcare Implications

Healthcare providers must be aware of the negative implications of the disease in order to understand how certain health and psychosocial behaviors affect the HIV positive individual. Negative experiences (ie. stigma) of the patient can influence aspects of quality of life such as poor treatment adherence and risky behaviors that affect HIV care and transmission. Contributing factors to this include the fact that HIV related stigma early in the AIDS epidemic is seen as a key factor in the spread of HIV, causes social isolation and poor care of self, decreased medication adherence, and so forth. (Nyblade, 2006) Being more knowledgeable about the psychosocial characteristics of the disease and the subsequent consequences on the individual's health behaviors can help healthcare providers give more effective treatment that can address and overcome such factors. This can result in increased treatment adherence, improved psychosocial status, and decreased HIV transmission. (Whetten, Reif, Whetten, & Murphy-McMillan, 2008) In addition, it is important for healthcare providers to avoid using stigma themselves, since caregivers that do so are more likely to have a more accurate understanding or insight into the care and support needs of children and adolescents with HIV (Ferris et al., 2007).

Role of nurses.

Due to the fact that several implications of HIV, such as disclosure of status and stigma, can have psychosocial effects on a child or adolescent with HIV, nursing assessments are imperative. This complete assessment includes a health history, biographical data, reasons for seeking care, present health or illness, past medical and surgical histories, family history and implications on the client, social history and daily activities, review of systems, and so forth. The assessment allows more comprehensive health care planning for the patient since it not only focuses on the physical manifestations of HIV, but also the psychological, emotional, and social ones. (Shaw & Mahoney, 2003)

The role of the nurse is multifaceted since he or she acts as an educator, direct care provider, cause manager, and advocate. Common psychosocial con-

cerns related to HIV nursing care include disclosing the diagnosis to the child, as well as stressors like HIV associated stigma. An important nursing consideration is that these children may have had delayed diagnosis and treatment, which therefore can result in deficits in motor skills, communication (such as expressive language), and behavioral functioning. (Hockenberry & Wilson, 2010)

Analysis of the Literature

Although stigma is frequently correlated with HIV positive individuals that acquired the disease through risky sexual and drug behavior, it still has several negative consequences on children and adolescents who obtain HIV perinatally. Due to their young ages and delicate stages of development, the diagnosis of HIV and the negatively worldwide view of the disease greatly compound the already established demands and expectations of society that these individuals experience. Even though acquiring was out of their control and not their fault, the three types of stigma are still felt. The young person may still blame his or himself, believe HIV was given to them as a punishment for something, question their identity, future, and purpose, as well as other effects experienced by those who received HIV through behaviors. Due to this, one cannot assume that the patient will understand that they did not cause the disease, and appropriate support interventions need to be put into place. Disclosing the HIV status to a child or adolescent is very important for treatment adherence and understanding why they are receiving the treatment, however it is important to understand the psychosocial consequences of this and how it affects behavior.

Recommendations

In order to give more effective prevention of stigma associated with HIV, as well as better care to those who experience it, longitudinal research is needed. This type of research could be used to support results regarding short term effects from cross sectional studies, and develop results for long term effects. Due to the fact that HIV is a fairly new epidemic, research has been mainly focused on adults since that has always been the biggest population with HIV. However, now that the number of children and adolescents being infected is increasing, more research should be obtained to understand the implications of the disease with these types of patients. Potential outcomes of this research include more adequate measures of stigma that reflect the complexity of the elements of

stigma, as well as determining the causality of the relationships of disclosure, stigma, and HIV youth that have been identified in cross sectional research. This would result in a better understanding of the relationship between stigma and the patient's risk behaviors that follow, and also to discover the extent of unmet needs at the individual and policy level interventions. More interventions are needed to reduce stigma as their primary goal or main element in other efforts, so it is important to find out how to confront and eradicate stigma by other means other than HIV education to the community.

Conclusion

Since HIV has several physical, emotional, psychological, and social effects on a person, understanding its implication on vulnerable populations such as children and adolescents is essential. This population is rapidly increasing across the world, and these individuals are the future of the disease and therefore require the same attention and treatment, if not more, as their adult counterparts. As the disease develops and begins to affect more populations, it is becoming apparent where there are gaps in research, as well as how much more time and funding will be needed for these answers.

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