HIV disclosure to children: a review of the literature

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According to the American Academy of Pediatrics (AAP) many children with perinatally acquired human immunodeficiency virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) are surviving to middle childhood and adolescence (AAP, 1999). AAP also states that half of all new infections in the United States occur in young people between the ages of thirteen and twenty-four (AAP, 2001). The life span of children with HIV and AIDS is increasing. As a result of increased lifespan, the issue of disclosure has become a clinical issue for healthcare providers and families. Disclosure of HIV to children is defined as the process of telling the child their diagnosis. Many families have reason to be reluctant to disclose a HIV diagnosis to a child for reasons such as protection from discrimination, mental health of the child, and parental guilt.

Although sharing difficult news with children may be complicated, disclosure is an important responsibility of healthcare providers as advocates for children and their families. Research is necessary on the issue of disclosure so that healthcare providers will have knowledge on the topic to help educate families during this time. Studies on the impact of HIV/AIDS disclosure to children are very limited. Due to the limitation of research on this topic, a variety of healthcare databases was used to exhaust all literature relevant to HIV and disclosure.

Theoretical Nursing Framework

The nursing framework used for this literature review is Roy’s Adaptation Model (Roy, 1984). Sister Calista Roy developed the nursing theoretical framework called the Roy Adaptation Model (RAM). In RAM there are two metaparadigm concepts relevant to the topic of HIV disclosure to children. The two concepts are person and environment. In this model, the person or recipient of nursing care is called the “adaptive system.” Each adaptive system is in constant
contact with internal and external environments, and the person’s goal is to maintain integrity within environment.

RAM (Roy, 1984) defines three types of stimuli in the environment. Stimuli are part of the input for the adaptation process. The first type of stimuli is called focal stimuli. Focal stimuli are the internal or external stimuli that are the most immediate challenge. Contextual stimuli are the contributing factors that strengthen the focal stimuli. Lastly, residual stimuli are any other stimuli that can affect the focal stimuli but are unknown or unclear. These three types of stimuli act together and influence the person’s adaptation level.

The adaptation level is determined by the person’s coping mechanisms. The RAM (Roy, 1984) categorizes coping mechanisms into either the regulator or cognator mechanism. The regulator mechanism consists of neural, chemical, and endocrine processes, while the cognator mechanism is a cognitive-emotion process that includes learning, memory, and judgment. These coping mechanisms lead to output, that are categorized as either adaptive or ineffective responses. Adaptive responses will promote integrity of the person. Ineffective responses neither promote nor contribute to the goal of adaptation. Output from the regulator and cognator mechanisms becomes feedback for the person.

In a theory driven literature review, the child would be considered an adaptive system. The child is in an environment that has focal, contextual, and residual stimuli. In this review the focal stimuli for the child is the disclosure of HIV status to the child. The contextual stimuli are the other factors in the environment for the child that can affect the disclosure. For example, these could include social acceptance or peers, developmental level of the child, family and support system, socioeconomic status, and willingness for treatment adherence. The residual stimuli are reserved for factors that affect the focal stimuli that are unknown or unclear to us.

Utilizing the input, the child will use coping mechanisms to attempt to achieve adaptation to the new environment. The regulator coping mechanism is the actual physical child, including their neural, chemical and endocrine functions. The cognator mechanism includes the emotional
and cognitive functions including developmental level. Together, these two coping mechanisms will determine the adaptive response.

Review of the Literature

This literature review includes articles associated directly with HIV disclosure and communication to children, disclosure effect on treatment adherence, public disclosure and the stigma, living with HIV, disclosure of other chronic illnesses, and disclosure of maternal HIV diagnosis to their children. Articles on all these topics were included to fully understand the process of disclosure related to the development of children.

HIV Disclosure and the Communication to Children

Research literature

The objective of the study done by Lester et al. (2002) was to assess parental decision making about illness disclosure to HIV infected children. Decision making factors for disclosure and reported outcomes of disclosure are described in the article. Methods included a qualitative analysis of fifty-six children with HIV based on parent interviews, child cognitive testing, clinical assessments, and medical records. Parents completed the Moos Family Relationship Index on family communication patterns, and all children completed cognitive testing using Weschler Intelligence Scales. Also, children who knew their diagnosis were interviewed. The results of the analysis of parental interviews was that the most common age (59%) of the initial disclosure to children was between the ages of six and ten, while only thirty-six percent of initial disclosures were to children less than six years of age. The reason frequently identified by parents to disclose between the ages of six and ten was that the children had their own illness-related questions by this age that precipitated the HIV disclosure. This article also referenced the strong encouragement of the American Academy of Pediatrics to disclose diagnosis of HIV to school aged children (AAP, 1999). According to the results of parental interviews, disclosure after the age of ten occurred at the strong encouragement of the medical professionals and healthcare
providers. One reason of concern and push for disclosure for the healthcare professionals was potential for risk behaviors of the pubescent child.

In a descriptive, qualitative study by Nehring, Lashley, and Malm (2000) the mothers’ view of HIV infected children was studied (N=20). The purpose was to identify to whom biological and foster mothers disclose the diagnosis of HIV infection, to discuss their reason for choosing certain persons to share their disclosure with, and to describe the recipients’ reactions. The qualitative approach to the study was a naturalistic inquiry using interviews of mothers, biological or foster, caring for one or more children with HIV infection. Three themes arose from analysis of data. These themes included disclosing for personal support, determining who should know, and telling children their diagnosis. For the purpose of this literature review, the section on telling children and the implications for practice were reviewed. Overall, the study’s authors concluded that disclosure must be age appropriate. Similar to the article by Gerson et al, (2001), the authors encouraged disclosure of HIV status to children of school age. They also noted that by adolescence it was necessary for the child to know their diagnosis. This article suggested that pre-school aged children have their illness discussed with them, but the actual HIV diagnosis did not have to be made known. It specified that HIV disclosure did not happen for these caregivers until the child was age six or older. These authors did agree with the previous article discussed, stating that the disclosure process is a long-term process that could take place over time and that children need to be able to ask questions. Nehring et al. also identified that the support of an interdisciplinary team should be available for psychological support. This study stated a limitation that it was difficult to determine the effect of age given the small sample size. This limitation implies that though the authors determined school age was an appropriate age for disclosure of HIV status, the sample was small and it was difficult to determine if these findings are generalizable for all children.

DeMatteo et al. (2002) explored the family disclosure experience from both the child and adult perspective. A multi-site longitudinal study was used incorporating qualitative and
quantitative methods to provide an opportunity for fifty-four children and fifty-one adults from forty-four families to share the experiences (N=44). Methods for this study included interviews of children who had been told either their own diagnosis or another family member’s diagnosis of HIV and family interviews with mother and child together. The major theme that emerged from this study was trust between parent and child as being the primary determinant of disclosure. The study took place over fourteen years, as the study also viewed disclosure as an ongoing process and not as a single event, as was discussed in the previous two articles. This study differed from prior articles as disclosure occurred across all age groups, from toddlers to young adults. The authors found that more girls than boys were told prior to age eleven and the majority of disclosures occurred between ages eight and thirteen. The median and mean age identified was age ten. A significant finding in the article was that despite the wide-range of ages of disclosure, eighty-six percent of the parents felt that they had disclosed at the right age. Although this article found disclosure across age groups, it was found was that for the child to really understand the meaning of HIV the child needed to be age eleven or older.

Thorne, Newell, and Peckham (1998) surveyed one hundred and eighty-two caregivers of HIV infected children in seven European countries to gain knowledge on disclosure and planning for the future. Questionnaires and surveys were used. Survey results found that age was the most common determinant associated with disclosure. Disclosure of the HIV diagnosis was most likely dependent on the child’s cognitive development.

Common themes in the studies reviewed included that the disclosure process is lengthy process and that the child needs to be around school age in order to understand their diagnosis of HIV. The authors also agreed that age is the most important factor in disclosure. Research by Waugh (2003) revealed that delay of disclosure was most likely due to fear of the child exposing the family to potential discrimination and stigma. Waugh’s study examined the concerns of parents about disclosure of HIV to a school-aged child. Twenty to thirty minute interviews were conducted with parents at clinic visits with discussions about talking to their children about their
illness (N=15). One universal theme that emerged was parents in the studies all said that they needed to wait to disclose to the child until they felt confident that the child would not indiscriminately tell other people. The average age of disclosure in this study was 10.8 years, and ranged from seven to fourteen years old. The parents also stated they felt they would have to disclose by early teenage years prior to the child becoming sexually active. Waugh’s conclusion stated that families need support through the difficult process of disclosure.

In contrast, one article by Wiener, Battles, and Heilman (2000) was reviewed and focused not only on disclosing an HIV diagnosis to the child, but also public disclosure. Public disclosure in this study was defined as children who had shared their name, photograph, and diagnosis to either television or newspaper media. Data was collected on the experience of public disclosure as well as perceived self-competence. An important aspect of this study was that data was collected on perceived self-competence of these children for four years following disclosure of diagnosis. This study completed by Wiener et al., included children ranging in age from ages eight to eighteen, and who had been diagnosed with HIV for eight or more years (N=105). This cross sectional study used the Self-Perception Profile for Children or Adolescents (SPPC/SPPA) to measure self-concept, and also parent and child interviews. In the conclusion of this study it was stated that findings suggested that children who went public with their disclosure perceived themselves as having lower sense of social, scholastic, physical, and global self-competence than those children who had not disclosed their diagnosis to the media. The only positive outcome described public disclosure through the media with the HIV diagnosis for these children was that many of the children received unsolicited gifts, offers to meet famous entertainers, and trips. The authors concluded that these rewards did not outweigh the negative effect of decreased self-competence.

Clinical literature
In a search of the literature some relevant clinical articles were uncovered that support and reflect on the research articles. These clinical articles also found pertinent information on the topics discussed in this literature review. An article by Gerson et al. (2001) described a stage-wise disclosure process used in a pediatric HIV clinic. The five stages included information gathering and trust building, education, determining when the time was right for disclosure, the actual disclosure event, and monitoring post-disclosure coping and managing disclosure related “bumps in the road”. The authors reported that early stages of the process occurred in small steps for many months and years. The actual event of disclosure was influenced by questions asked by the child, fear that the child would not be compliant with medication, and changes in growth and development such as reaching adolescence. The practice implications identified in conclusion were somewhat vague. The authors implied that sufficient time must be scheduled for disclosure and that the child should feel comfortable asking questions. Although the practice implications might be vague, the step wise process described about how to deal with disclosure could be very useful. According to the authors, no matter what age the child was at the time of disclosure all of the steps were appropriate. Also as the authors stated, the child needs to feel comfortable asking questions about their disclosure and diagnosis.

The American Academy of Pediatrics (AAP) issued a policy statement in January of 2001 on the disclosure of illness status to children and adolescents with HIV infection. The policy statement included recommendations that reinforced most of the previous research findings. The Academy’s recommendations include the need for professional health care counsel in the disclosure process, and that disclosure should be individualized according to child’s developmental stage, cognitive ability, clinical status, and social circumstances. These recommendations also included discussing illness without actually using the term HIV until the child is school-aged when disclosure was strongly encouraged. Another recommendation echoed by research was that adolescents should be informed of diagnosis prior to becoming sexually active. A difference in these recommendations not noted in the previous literature was that the
American Academy of Pediatrics addressed the belief that adolescents are capable of making decisions about their treatment and participation in clinical trials, with encouragement of adolescents to include their parents in their care.

Another American Academy of Pediatrics policy statement (1999) had recommendations that disclosure should be leveled at a child’s level of cognitive development and psychosocial maturity. The AAP stated that the exact diagnosis and prognosis of the disease is less important in discussions with young children, but as they matured they should be fully informed of the nature and consequences of their illness and encouraged to actively participate in their medical care. The Academy supported this statement by referencing children with other chronic illnesses, such as cancer, who exhibited better coping skills and fewer psychosocial problems when appropriately informed about the nature and consequences of their illness. The AAP stated that it is the primary care provider’s responsibility to make an independent assessment of a child’s readiness for disclosure.

In summary, this section revealed that age and developmental level play an important role in the decision to disclose the diagnosis of HIV to a child. All articles agreed that disclosure is a long process that is completed over time. Also, most focused on the cognitive level of the child to determine the most appropriate age to disclose with most frequently focused on school aged children as they are able to ask appropriate questions. The most common range of ages when children were told their HIV status was between the ages of six and fourteen with the median age around ten. All articles recommended disclosure by adolescence since the teens need to know their status due to increase risk, including sexual activity.

**Disclosure Effect on Treatment Adherence**

**Research literature**

A qualitative study by Hammami et al. (2004) examined factors that influenced treatment adherence to highly active antiretroviral therapy (HAART) in a pediatric population. Eleven
primary caregivers were interviewed to assess their child’s treatment adherence and factors that influenced adherence. The data suggested that coping with HIV and the process of good adherence may be interrelated. A part of coping with HIV has to do with knowledge of the diagnosis. In some cases in this study, disclosure of the HIV status was necessary to overcome child’s resistance and maintain treatment adherence. Most caregivers in this study revealed that they gradually explained to their children that they had to take medications because they would become ill without them, but preferred not to mention HIV until the child could understand the meaning. Caregivers did say that children became more cooperative after disclosure. The authors concluded that improving knowledge in the children, motivating them to participate in treatment, and improving their skills to cope with the disease helped with treatment adherence. This finding supported the idea that children would maintain improved treatment if they knew of their HIV status.

Giacomet et al. (2003) investigated rates and determinants of adherence to antiretroviral therapy in Italian children infected with HIV (N=129). The study was an observational, cross-sectional study. Data was gathered through a structured interview with the caregivers of the children. Out of one hundred and twenty-nine children, ninety-four were on HAART regimens. No significant difference was found between age and the stage of HIV infection, but unlike any other article in this review the authors found that children who were aware of their HIV status were less adherent to their antiretroviral medications. These authors found that psychological issues were much more determinant of adherence rather than clinical or sociodemographic features. The authors suggested that due to psychological factors impacting adherence, disclosure was recommended starting as early as eight or nine years of age in combination with support to increase adherence in children with HIV.

Wiener, Rickert, Ryder, and Woods (2004) studied thirty-five adolescents between the ages of eleven and twenty-one years of age who were being treated for HIV. The instruments used for this study were the Clinical Nurse Ratings (CNR), Retrospective Self-Report Interview
of Medication Use, daily phone diaries, demographic questionnaires, and laboratory reports of viral loads. The authors maintained that many factors affected the long-term HIV medication adherence, including disclosure. An example presented was that as a child entered adolescence, developmental issues increased which effected adherence. In particular, one conclusion applied to the issue of disclosure and adherence. This conclusion revealed that the ability to get an accurate sense of medication adherence from the child or adolescent was possible when combined with honesty, respect, and other aspects of open communication. It was unclear if this article included disclosure as part of the honesty and open communication aspect of this statement.

Steele et al. (2001) completed a study that examined caregivers of thirty HIV infected children on active HAART in order to assess methods of adherence and educational efforts when compared to perceived vulnerability. Three questionnaires were given to forty-nine caregivers. The authors also assessed adherence by pill counts and caregiver interviews. Results reported indicated that caregivers perceived their children as vulnerable. Numbers of medications and measures of adherence were associated with this perception of vulnerability. According to the authors, CD4 and viral loads were also significantly related to perceived vulnerability. Results showed that caregivers of children on treatment for HIV infection perceived that their child was at moderate risk of negative outcomes (e.g. infection, death), and that caregivers perceived few barriers to adherence.

Lyon et al. (2003), described the development of a program which combined family group and peer approaches to increased adherence to antiretroviral therapy in HIV positive youths. The twenty-three children studied were between the ages of fifteen and twenty-two, and the study included twenty-three family members as “treatment buddies.” This study revealed that there was an increase in baseline knowledge of HIV among HIV-positive youths from 1998 and 2000 as measured by a ten item questionnaire and focus groups. The article concluded that involving family members in a supportive environment, as well as peers, may be one technique to improve adherence to complicated HAART medication regimens. They also concluded that beliefs in
efficacy of HAART therapy and general knowledge of HIV increased over time due to the increase in public knowledge and publicity of treatment of HIV from 1998 to 2000.

The American Academy of Pediatrics policy statement in November of 2004, based on a report titled, *Integrating adherence to highly active antiretroviral therapy into children’s daily lives: A qualitative study*, concluded that coping with HIV and the process of establishing adherence are interrelated. Eleven primary caregivers of HIV infected children were interviewed to assess child adherence and influencing factors. This article revealed that in many cases, disclosure was a necessary step to overcome the child’s opposition to antiretroviral medication adherence. This policy noted that when children do not feel sick, they do not understand why they have to take the medication. Therefore, caregivers often decided to gradually explain to children that if they did not take the pills they would become sick. Many parents felt that the child was too young to understand what HIV meant until school-aged. Overall the article noted that the majority of adherent caregivers felt child adherence to medication regimens was much more cooperative following disclosure.

*Clinical literature*

Chesney (2003) completed a review of HAART adherence. The review focused on current understanding of adherence reporting, improvement of adherence, and the improvement in outcomes of HIV and AIDS related to adherence. A portion of this review that applied to disclosure of HIV status to children revealed that children maintained better adherence when caregivers believed in the treatment and when the child was involved in the decision-making. Also, using treatment buddies or enlisting family members and significant other were helpful strategies in increasing adherence.

The common finding applicable to disclosure from the articles reviewed on the topic of treatment adherence in children on antiretroviral medications was that, in order to improve adherence, a need for social support existed and that the child needed to be an active partner in
care. Involvement of family members and peers lead to increased adherence. Other common findings included tailoring the medication regimen to the patient’s lifestyle, openly discussing side effects, and provision of positive feedback to the child. Provision of social support and allowing the child to be an active partner in care, could suggest that the children may need to know their diagnosis. The American Academy of Pediatrics policy (2004) stated that disclosure is a necessary step to overcome opposition to medication adherence as children were more cooperative after disclosure. Only one study (Giacomet et al., 2003) found that children were not more cooperative with HAART after disclosure, and also recommended that psychological support was needed as an adjunct to disclosure.

Public Disclosure and Stigma

Research literature

Sherman, Bonanno, Wiener, and Battles (2000) examined the physiological and psychological consequences of children’s self-disclosure of their HIV/AIDS status to their friends. Data was collected twice, at one year intervals, from sixty-four children, between the ages of eight and eighteen, and also from their caregivers. Methodology included interviews of the children, CD4 counts, the Social Support Scale for Children (SSSC) and the Self Perception Profile for Children or Adolescents (SSPC/SSPA), and completion of Child Behavior Checklist (CBCL) by caregivers. Results included that children who had disclosed their HIV positive diagnosis to their friends during the one year period had a significantly greater increase in CD4 counts than children who had not told their friends. These findings are consistent with adult studies that demonstrate displayed positive health outcomes with self-disclosure. This study also examined behavioral changes and self-concept issues with the children who disclosed their diagnosis to friends. Although these findings were not significant, the authors concluded that any positive psychological benefit generated from self-disclosure was nullified by the negative social stigma. This study did demonstrate that self-disclosure to friends improved CD4 percent of the
child with HIV, but this did not change the impact of the negative social stigma. In other words, there were only physiological benefits and no psychological benefits that occurred with disclosure to friends.

*The paradox of public HIV disclosure*, (Paxton 2002), involved interviews with seventy-five HIV-positive adult speakers from countries in Africa and Asia-Pacific on the impact of public disclosure. The people interviewed revealed that disclosure did lead to discrimination because of the stigma of HIV, but speaking out was extremely rewarding to the affected person. Public disclosure led to a less stressful, more productive life and overall sense of well-being. A limitation to this study was that it again focused on adults and not children, but stigma is an important aspect to research with children, as well as adults, when looking at disclosure of HIV status and may have similar ramifications.

*Clinical literature*

Due to the stigma associated with HIV/AIDS it is important to examine coping with stigma. Joachim and Acorn (2000) explored the theoretical difference between visible and invisible chronic conditions. The article presented a beginning framework that described the relationship between the elements of stigma and the decision to disclose or hide a chronic illness based on the visibility or invisibility. These authors identified that there are risks with hiding or disclosing a condition, including being rejected or stigmatized and having difficulty dealing with the responses of others. People with a visible illness have less of a choice in disclosure than those with invisible illnesses. Since HIV is “invisible,” this framework may help nurses to understand the vulnerability in disclosing and help children decide when to disclose to others.

Literature reviewed on public disclosure and stigma revealed that stigma is one of the leading reasons as to why parents choose not to disclose an HIV diagnosis to their children. The articles reviewed indicate that there are risks with public disclosure due to the stigma related to the disease. The article by Sherman et al. (2000) stated that children disclosing their HIV status
to their friends experienced the psychological benefits and had an increase in their overall CD4 counts. On the other hand, most other articles reviewed concluded that stigma of HIV is still present in society. Public disclosure can lead to discrimination due to the stigma of this disease, and positive psychological benefits from disclosing to friends were sometimes nullified or outweighed by the social stigma. Research indicated that parents may be correct in being cautious about disclosing due to stigma, however public education on HIV will hopefully continue to decrease the degree of stigma present with HIV.

**Living with HIV: Psychosocial and Developmental Outcomes**

*Research literature*

A study done by Mellins et al. (2002) examined patterns of HIV disclosure to seventy-seven perinatally HIV infected ethnic minority children, three to thirteen years of age. The authors also explored the association between knowledge of HIV status and emotional and behavioral outcomes. The majority of children in the study did not know their HIV status, and the ones who did tended to be older and had lower CD4 counts. To assess disclosure, semi-structured interviews of the children, medical records of the children, and mental health behaviors as reported by caregivers were used. Results found that HIV status disclosure did not result in increased mental health problems. A trend was found that children who knew their diagnosis tended to be less depressed than those who did not.

Another study exploring psychosocial issues in perinatally HIV infected children was completed by Mialky, Vagnoni, and Rutstein (2001). This study was designed to explore some of the medical, educational, and psychosocial aspects of school-aged and adolescent children. A chart review of eighty-five HIV infected children was conducted to obtain data. Forty-three percent of the children had been told their HIV diagnosis, with the average age of disclosure at nine years of age, and all children knew their diagnosis by age twelve. More than half of the children in the study had suffered severe medical or physical symptoms from HIV, however their
immune systems were intact at the time of the study with positive CD4 counts. An increased need for special education services in school was found in this sample. A limitation to this study was that there was no control group of uninfected children with which to compare school performance and attendance or development issues. As a result it was not possible to determine whether these results were attributed to the HIV infection, drug therapy, or other environmental factors. The authors suggested future studies address psychosocial needs as these children continue to reach adolescence and adulthood.

In a study (N=80), Battles and Wiener (2002) examined the psychosocial factors associated with the long-term survival rate of pediatric HIV. The study used the Social Support Scale for Children (SSSC) and the Self Perception Profile for Children or Adolescents (SSPC/SSPA), along with parent questionnaires. The study found that disclosure was positively correlated to social support, self-competence, and decreased problem behavior. The authors concluded that social support and open communication about the diagnosis were essential, particularly at an age which decisions about relationships, sexual activity, drug use, and plans for the future were occurring. A limitation of this article was that children were eligible to be part of the study only if they had been diagnosed at least eight years prior to the study and knew their diagnosis.

Blanchette, Smith, King, Fernandes-Penney, and Read (2002) compared fourteen children with HIV to eleven control children who were siblings, to look at neuropsychological functioning in school-aged children. The children with HIV ranged in age from six to fourteen years of age, as were the siblings in the control group. Participants were administered an extensive number of tests including Weschler Intelligence Scale for Children-Revised (WISC-III), Wide Range Achievement Test-Revised (WRAT III), Visual-Motor Integration (VMI), and all had brain computerized tomography scans (CT). All of these tests were part of a comprehensive assessment of the child’s development. The results indicated that school-age children with HIV infection generally do well academically with respect to their
neuropsychological development. There were no significant differences between school-aged children with HIV and the sibling control group on measures of academic achievement. Despite the finding that cognitive development was normal, subtle motor impairments were documented in children with HIV infection. The children with HIV had lower performance on measures of fine motor skill and motor strength. The authors suggested that further research is needed to address whether fine motor skills could provide a behavioral marker for immune system compromise in HIV children.

Wolters, Brouwers, Civitello, and Moss (1997) found that expressive language was significantly more impaired than receptive language of children infected with HIV (N=29). This longitudinal study was focused on assessing receptive and expressive language functioning of children with HIV disease. Children with HIV were administered an age appropriate standardized language test and general cognition measure prior to starting antiretroviral medications and these same tests were administration again at six and twenty-four months after start of medication. The tests used were the Reynell Developmental Language Scales, Clinical Evaluation of Language and Fundamentals Revised (CELF-R), and also the authors used CD4 counts and CT scans of the brain. No significant difference was found between baseline and six months results, but there was a language score decline noted at six and twenty-four months from baseline. Cognitive function remained stable. The conclusion was drawn that, expressive language was more impaired than receptive language in children with HIV despite treatment.

Clinical literature

Ledlie (2001) published a commentary on how increased longevity of children with HIV has given new meaning to challenges such as treatment regimens, medication adherence, and disclosure of diagnosis. There are also new challenges for adolescents with HIV including relationships, intimacy, college, and careers. Ledlie offered her perspective as a Pediatric Nurse
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Practitioner on these challenges. Ledlie described a multidisciplinary, family-centered support group for adolescents. The importance of family-centered support was encouraged in the article. Although the articles on this topic did not focus on disclosure specifically, they provide information on how HIV as an illness affects children in their lives. These articles indicated that there are sometimes special educational services needed in the school setting, but none of these studies conclusively demonstrated that these special needs were actually due to the HIV. When exploring language, expressive language was more affected than receptive language, cognitive development was normal, but fine motor and motor strength could be affected.

Disclosure of Other Chronic Illnesses

Due to the limited amount of nursing research done on disclosure of HIV to children, it is important for nursing and other health disciplines to look at disclosure of other chronic illnesses to children. Exploring disclosure issues of other chronic illnesses can potentially apply to disclosure of HIV to children. Also, looking at literature on other chronic illnesses may help to give knowledge on areas that are needed for future research on disclosure of HIV diagnosis to children.

Research literature

Williams and Healy (2001) completed a study of disclosure of minor mental health problems in order to explore people’s experiences, concerns, and beliefs about disclosure. This was a qualitative study in which theoretical sampling and in depth interviews were done with forty-seven users and non-users of mental health services. Even though this study was focused on mental health issues such as depression, the authors concluded that there was the potential for stigma with mental health issues and the decision for disclosure in caregivers was a complex process.
Hospice nursing has also researched the issue of disclosure. Lorensen, Davis, Konishi, and Bunch (2003) explored ethical issues that nurses have reported in the disclosure of a terminal diagnosis. Although with the use of antiretroviral therapy HIV is not necessarily a terminal diagnosis, ethical issues are a major part of disclosure. One hundred and six hospice nurses in Denmark and Norway completed questionnaires. All respondents supported the ethics of disclosure to terminally ill patients. They believed truth telling related to the diagnosis was a patient’s right. For hospice, continuity of disclosure addresses how much information, under what circumstances, and when to provide it is the central issue. Perhaps these are similar when disclosing HIV status to a child.

Kreicbergs, Valdimarsdottir, Onelov, Henter, and Steineck (2004) had four hundred and forty nine parents of children who had died of cancer between 1992 and 1997 complete questionnaires. The results indicated that none of the parents who had talked about death with their child had regrets, but twenty-seven percent of parents who did not talk about death to their dying child did regret not doing so. The most common factor in deciding to talk about death was the child’s age. Although this article involved disclosing and talking about death it may be important to consider these findings when considering talking about and disclosing HIV status to children.

Similar to discussing death, Farrell, Ryan, and Langrick (2001) examined breaking “bad news” to a child. These authors evaluated a workshop to prepare health professionals for breaking “bad news” in a pediatric setting. Nurses and physicians attended workshops and then completed questionnaires following the workshops (N=45). The workshop was a one day, multi-professional, training workshop. Results of the questionnaires revealed that clarity of the message being disclosed is a vital component of any disclosure of “bad news”.

A review of research by Farrell (2001) revealed that a caring and sensitive attitude displayed by the health professionals is also important. This research did however mention that although the *British Medical Journal* indicated that medical expertise compensates for any
perceived lack of sensitivity (e.g., that if a patient had to choose between a competent versus a sensitive doctor), the patient would choose the competent practitioner (Farrell, pg 774). This article indicated that it is important for healthcare professionals to not only have knowledge in the healthcare field but to also be educated on breaking bad news and disclosing.

Clinical literature

Joachim and Acorn’s (2000) work was much more specifically applicable to the topic of disclosure of HIV. As reviewed previously, these authors began to present a framework for describing the relationship between the elements of stigma and the decision to disclose or hide a chronic condition based on its visibility or invisibility. Compelling in this work was the hypothesis that a person with a chronic visible condition has less of a choice about disclosure than those with an invisible illness. For example, a child with cerebral palsy cannot hide their diagnosis as a child with HIV might. The framework described that there are risks to both disclosing and not disclosing. There is a risk of stigma and if the disclosure is not supported, there may be stress. A conclusion from the article is that nurses need knowledge of possible outcomes of disclosure or not disclosing in order to assist individuals in making informed decisions.

Kunin (1997) examined the questions of patient autonomy and of parental responsibility and prerogative in the context of pediatric oncology. Kunin discussed that there are many ethical implications when treating a life-threatening illness in children. The central issue of the article was to involve the child with communication of information about the child’s illness and treatments, as well as the child’s participation in the decision making process. In the discussion of autonomy with children, Kunin noted it is not always necessary to treat the child as autonomous, rational decision makers in order to treat them with respect; it is instead more important to use developmentally appropriate language and give choices to the child concerning their treatment. The author stated that in several studies of open communication with pediatric
cancer patients about the nature of their illness and treatments, open communication was found to enhance coping skills and decrease overall stress and anxiety related to treatments and procedures. The article reviewed also gives reason to believe that informing pediatric cancer patients early in their diagnosis as opposed to delayed disclosure, or nondisclosure, could enhance long term emotional and social adjustment. In conclusion Kunin pointed out that a multidimensional approach to ethical dilemmas is necessary.

An article that explored the information needs of young children and adolescents with cystic fibrosis by Hinton, Watson, Chesson, Mathers and Sandra (2002) noted that there is an increasing need to involve patients in healthcare decisions. Good, quality patient information can make people feel better by knowing that their problems are real and recognized, and therefore be better able to cope with their problems. The need for children with cystic fibrosis to follow daily medication regimens is similar to the daily antiretroviral medications that HIV infected children must follow. This review looked at children reviewing information materials on cystic fibrosis, including talking with a nurse specialist, internet, and booklets. The article also recognized that many children with cystic fibrosis who are required to follow daily treatment regimens also have significant problems with adherence.

Wolfe (2004) reviewed the topic of discussing terminal diagnosis with a child from his personal medical experience as well as from reviewing other literature on the topic. Wolfe concluded that there is evidence that young children have an understanding that death exists and that the time to talk to a child frequently arrived when the child knew that something was very wrong.

Examining issues involving disclosure of other chronic illness in children can help healthcare providers to compare those issues to disclosing a diagnosis of HIV to children. Mental health issues in children bear commentary with HIV due to the negative social stigma involved. Williams and Healy (2001) noted that there is always a risk with disclosing illness associated with stigma; it is important for healthcare professionals to be guided and educated in the
disclosure process to best help patients and their families. Mental health problems are “invisible” and often stigmatized illnesses, as is HIV in most cases. Cancer or even cystic fibrosis may be more “visible” to the public, but there is much less stigma involved with these illnesses. Kunin (1997) noted that in disclosing to children, use of developmentally appropriate language needs to occur in order to assist them to be involved in their care and be able to make choices. Research revealed early disclosure in children with cancer increased emotional and social adjustment (Kunin). This increase in emotional and social adjustment may be altered in a child with HIV due to the stigma. A common theme in the literature reviewed on cystic fibrosis and cancer disclosure and sharing information may apply to HIV children. This theme was that with more information about their illness, the children were better able to cope and displayed less stress and anxiety with treatments.

Disclosure of Maternal HIV Diagnosis to Children

Research literature

Kirshenbaum and Nevid (2002) completed a study of fifty-eight HIV positive women with children concerning the information that the women choose to share or not share with their children about their own HIV status. The study involved the women completing two research questionnaires and an interview. Children in the study learned about their mothers’ diagnosis at an average age of seven years, and had been aware of the diagnosis for a mean of three years. Disclosure of HIV specific information increased with the child’s age. Significantly, children who were instructed to keep the diagnosis a secret tended to display more behavior problems than those not asked to keep it a secret. The study did conclude that literature supports telling over not telling and supports open communication of illness to children in a manner appropriate to the child’s cognitive level. A limitation of this study was the small sample size and reliance of mothers as informants on their child’s adjustment.
In contrast, a study by Nostlinger et al. (2004) concluded that the healthier the parents were as a result of antiretroviral therapy, the greater their decision to not disclose, because of fear of discrimination. Quantitative data was collected in a sample of African caregivers through structured interviews (N=628). The disclosure rate to children who were aware of parental HIV status was ten percent. The study also concluded that discrimination was a major obstacle, but that the silence or keeping the diagnosis a secret longer could extend the stigma due to fewer people educated about HIV.

Although the article by Mellins et al. (2002) was conducted on HIV mothers rather than children, it is valuable to this review. This study examined the association between mental health, substance abuse, and treatment adherence in minority mothers with HIV. A disclosure questionnaire was developed to assess one hundred and twenty-eight mothers concerning their communication to their children about their HIV status. The results were remarkable, revealing that only nine percent of the mothers had told all of their children about the HIV status. The article did not go into more detail about how this affected families and children, but did discuss the need for integrated care of mental health, substance abuse, and medical treatment of HIV.

Wiener, Battles, and Heilman (1998), utilized data from the larger study, described previously, on parental decision to disclose or not disclose the child’s HIV diagnosis to the child, and examined data that explored the factors associated with parents’ decisions to disclose or not disclose their own HIV status to their children. Seventeen families in which both child and parent were HIV infected were interviewed. Children were between the ages of five and eighteen. All of these caregivers were the child’s biological parent. Non-disclosing caregivers were more depressed than parents who disclosed their diagnosis to their children. Mothers feared rejection from the child due to guilt of their personal behaviors or choices that resulted in infection. The average age of the child at disclosure of their parent’s HIV status was nine years. Seven of the ten parents who had not disclosed their diagnosis to their child said that they would disclose when their children were old enough to understand the diagnosis. Parents who hesitated to disclose the
HIV diagnosis expressed their belief that their child was too young to understand the implications. While parents who had disclosed their HIV status did not indicate an overwhelming feeling of positive change since disclosure, none said that their relationship with their children had worsened. Overall, the parents who shared their diagnosis were unanimous in their belief that it was the right decision. A guide was provided to help families through the disclosure process. The guide stated that pre-school children cannot differentiate among differences in diseases, and that the school-age the child is able to ask more questions. Again, the concept of disclosure process over time was emphasized.

Lee and Rotherman-Borus (2002) examined parental disclosure of HIV status to their children exploring three topics, including trends in disclosure, factors associated with parental disclosure, and the impact of disclosure on adolescent children. Data were obtained using parental interviews of one hundred and fifty four parents. Results indicated the parents were more likely to disclose to older children, with mothers disclosing more often than fathers. Disclosure was more common among parents who were in poor health. The key result of this study was that most disclosure processes to children were done over time, similar to the findings in the articles on disclosure of children’s HIV status. More problem behaviors and negative family life events among the adolescent children in the study were noted.

Pilowsky, Sohler, and Susser (1999) studied twenty-nine women between the age’s of twenty-four and forty-seven years of age using a Parent Disclosure Interview (PDI). The women were interviewed twice. The study concluded that this PDI instrument was reliable to elicit information regarding disclosure of HIV status to family members, including adults and children. Although this article did not reveal as much information on the effect of parental disclosure on children, it did demonstrate that there is a reliable instrument for assessing parental disclosure. Possibly this instrument can lead to a new instrument or survey used for disclosure of HIV status to children.
Vallerand, Hough, Pittliglio, and Marvicsim (2005) completed a study on the process of disclosing HIV serostatus between HIV positive mothers and their HIV negative children. The study included thirty-five women and nineteen children between the ages of ten and eighteen who were aware of their mother’s HIV status. Mothers were interviewed about their experience and about disclosure of diagnosis to children. Children were also interviewed about having a mother who was HIV positive and about disclosure issues. The study found that the child’s developmental level was a major factor in the mothers’ decision to disclose. The biggest reason cited for not disclosing was the mothers felt need to protect the child. For children, the event of disclosure generated shock and fear. While about half of mothers described disclosure as positive most children perceived it as negative, primarily due to fear. The authors concluded that it is important to evaluate how a child perceives and feels about disclosure. The limitation to this study is that these children were HIV negative.

In general literature revealed it is important to examine issues surrounding maternal disclosure of HIV as it can be relevant to disclosure of positive HIV status to children. These studies revealed that disclosure of maternal HIV can affect children in different ways and it is important to assess how the child is coping. Kirshenbaum and Nevid (2002) reported that children who had to keep the HIV status a secret had more behavior problems, while Wiener et al (1998) found that non-disclosing parents were more depressed than those parents who disclosed their HIV status to their children. Some parents felt that their children were too young to know their HIV status. Lee and Rotherman-Borus (2002) found that parents were more likely to disclose to adolescents or older children. It was also found that maternal disclosure to children was generally completed over time. Vallerand et al (2005) found that while some children perceived disclosure as a negative, the importance of assessing how a child feels and adapts to disclosure is crucial.

Discussion
The literature reviewed deals with the disclosure process of a disease diagnosis. Topics in the research included disclosure and communication to children, disclosure effect on treatment adherence, public disclosure and stigma, disclosure of other chronic illnesses, and maternal disclosure of HIV status to their children. The research supports that disclosure should be completed over a long period of time to promote best adaptation of the child to the diagnosis of HIV.

The articles reviewed revealed that age and developmental level play an important role in the decision to disclose HIV diagnosis to a child. Most articles focused on cognitive level of the child in order to determine the most appropriate age to disclose, with school aged children most frequently identified as an appropriate age. Most articles suggested that by adolescence, the child should know their status due to increase risk behaviors, including sexual activity.

Literature suggested the need for family and peer support for the child during the disclosure process and to help with medication adherence and treatment after disclosure. Authors recommended that the child be an active participant in the care and treatment plan. All but one article reviewed on the topic of treatment adherence found that children were more cooperative after disclosure of their HIV status; conversely some authors found that stigma with the potential discrimination was one of the leading reasons that parents choose not to disclose HIV to a child.

Disclosure of HIV status to a child can affect the child’s life in more ways than discrimination. In the articles reviewed, it was evident that many times there were needs for special education services in the school setting, although none of the articles indicated that these special needs were actually due to the HIV disease process or to the disclosure of diagnosis.

Reviewing the research concerning disclosure of other chronic illnesses in children provided insight on disclosure of HIV to children. Any illness that is associated with stigma, or any “visible” illness can lead to risk for discrimination. Research on other chronic illnesses in children such as cancer, cystic fibrosis, or mental health illnesses indicated that when disclosing to children, no matter what the illness is, developmental level was most commonly used to
determine the appropriate time to disclose. Some literature suggested that early disclosure can lead to increased emotional and social adjustment, but regardless of age, developmentally appropriate language should be used. Research on other illnesses revealed that with other chronic illnesses the more information the child knew, the less anxiety the child had with treatment.

In the articles researching maternal disclosure of HIV status to their children, findings revealed that it was important to frequently assess how a child was coping, and that maternal disclosure was often completed over time. These two points can also apply to disclosure of a child’s own HIV status. The articles on maternal disclosure also suggested disclosure occurring over time with assessment of how a child is feeling about their diagnosis.

It was apparent in most of the articles concluded that to disclose HIV to a child, the child should be school-aged in order to have the cognitive and developmental level necessary to understand their diagnosis. Prior to school age it was recommended that illness be discussed with the child, but the term HIV would not have to be used due to the child’s incomplete understanding of the term HIV. Another conclusion echoed in the literature was that it is necessary for adolescents to know their diagnosis, especially before the possibility of sexual activity.

Although research has begun to address disclosure of HIV to a child, much more detailed research is needed to include more about ethics, stigma, adherence, and social acceptance. Articles from many healthcare disciplines were used to exhaust the topic of HIV disclosure to children; a lack in nursing research on this topic was found. Although there is a lack of nursing research on disclosure of HIV status to children, the suggestions in this literature review are still relevant to assist nurses with the disclosure process, and to guide families through the disclosure process. The literature review can also assist in nursing education on HIV disclosure to children and to stimulate nursing research on the topic.
References


