

Treatment and Care Issues Specific to Adolescents Living with HIV: A Supplemental Review

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1. Introduction

With the advent of highly active antiretroviral therapy (ART) and other advancements in human immunodeficiency virus (HIV) care, HIV has been reclassified from an acute, fatal disease to a chronic medical condition (Das, Mukherjee, Lodha, & Vatsa, 2010; Garvie, Lawford, Banet, & West, 2009; Hazra, Sibery, & Mofenson, 2007). For children who are born with HIV, ART has resulted in decreased mortality and morbidity, meaning that children experience a less symptomatic disease course and many of those born with HIV live well into adulthood (Butler et al., 2009; Das et al., 2010; Eley & Nuttall, 2007; Fair, Sullivan, & Gatto, 2010; Marhefka et al., 2008; Mellins et al., 2002; Wiener, Riekert, Ryder, & Wood, 2004). As a result, research has shifted from focusing solely on prolonging survival to considerations of quality of life, sustained overall health, and clinical monitoring of health markers (Garvie et al., 2009). In addition, research is beginning to focus on issues specific to adolescents living with HIV who were born with the virus (perinatally acquired HIV [PaHIV], also known as mother-to-child transmission). Adolescents living with PaHIV face the usual challenges of adolescence while also dealing with their HIV disease (Hazra et al., 2010).

Adolescence is generally thought of as a time of behavioural experimentation and risk-taking, where youth work to assert their increasing independence (Battles & Weiner, 2002; Bush, 2002). As part of this strive for independence, adolescents often face decisions about romantic relationships, sexual activity, and substance use. These decisions are made more difficult for adolescents living with HIV who must also consider issues of disclosure, HIV transmission, adverse reactions to ART, adherence to treatment, and HIV-related stigma (Battles & Wiener, 2002; Bush, 2002; Eley & Nuttall, 2007; Henry-Reid, Wiener, & Garcia, 2009; Koenig, Nesheim, & Abramowitz, 2011; Vijayan et al., 2009). In order to provide appropriate care, treatment, and support for adolescents living with PaHIV, it is important for health and allied healthcare providers to understand these issues (Fair et al., 2010; Koenig et al., 2011).

1.1 Current Literature Review

The current literature review provides supplemental information to a previously completed literature review by the Saskatchewan Prevention Institute titled “Pediatric Care and Support for Children Living with HIV in Saskatchewan.” The previously completed review provides information about common issues facing children aged 6 to 18 years living with HIV that health and allied health professionals should be aware of (e.g., medical conditions, impacts on cognitive and psychological functioning, social determinants of health, adherence, disclosure), along with information about general care and support for children living with HIV. Although there are many similarities between younger children and adolescents in terms of HIV care and treatment, issues such as adherence, disclosure, sexual health, and transition to adult care take on heightened importance for adolescents (Ferrand et al., 2010; Thorne et al., 2002).

Therefore, the current review focuses specifically on these issues as they impact adolescents living with PaHIV (i.e., those between the ages of 13 and 18 years of age).¹

2. Adherence to Treatment

Adherence to ART is associated with dramatic reductions in mortality and morbidity and improved clinical outcomes in adolescent patients (Letourneau et al., 2012; Williams et al., 2006).

Unfortunately, adherence usually worsens in adolescence, adding to the complexity of treating this population (Foster & Fidler, 2011; Mellins et al., 2011; Tassiopoulos et al., 2012; World Health Organization [WHO], 2010). In fact, adherence is often cited as one of the largest barriers to effective care in adolescent patients (Dowshen & D'Angelo, 2011; Vijayan et al., 2009). Wiener et al. (2004) cite studies of adolescent adherence with rates ranging from 28.9% to 61%. Even minimal non-adherence to ART can result in an increased viral load, reduced treatment efficacy, increased risk of contracting opportunistic infections, increased chances of developing resistance to ART, and limited future treatment options (Wiener et al., 2004; Williams et al., 2006). Therefore, it is important that healthcare providers are aware of barriers to adherence faced by adolescents with PaHIV.

Similar to adherence in younger children, adherence in adolescents is influenced by the medications prescribed, patient and family factors, and the characteristics of the healthcare provider (Wiener et al., 2004). Factors that are associated more specifically with adherence in adolescents include depression, substance use, lack of wider disclosure of HIV status, peer relationships, and disorganized social environments (Dowshen & D'Angelo, 2011; Fair et al., 2012; Henry-Reid et al., 2009; MacDonell et al., 2011; Wiener et al., 2004; Williams et al., 2006). Other challenges to adherence during adolescence include the desire for independence, desire to fit in with peers, and the focus on the present rather than future consequences (Koenig et al., 2011). Adolescents may feel that the immediate discomfort or inconvenience of their treatment regimen is too great, particularly if they are feeling healthy (Bush, 2002; MacDonnell et al., 2011; Vijayan et al., 2009). Therefore, they may not feel motivated to make treatment adherence a priority (MacDonell et al., 2011; Merzel, VanDevanter, & Irvine, 2008), particularly at a time in life where they do not want to be different from their peers (Panel on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2011; Rydstrom et al., 2012).

In addition to these factors, adolescents are often encouraged to assume increased responsibility for remembering and taking their medications as they age (Koenig et al., 2011; Steele, Nelson, & Cole, 2007; Williams et al., 2006). Parental illness may also lead to adolescents taking over their own medication related tasks, sometimes before they are ready to do so (Williams et al., 2006). In order to effectively take on this responsibility, adolescents require appropriate information and support (Thorne et al., 2002). Unfortunately, factors known to facilitate adherence (e.g., consistency of daily

¹ Please refer to the previously completed literature review for more in-depth information about medical treatment (ART efficacy, drug resistance, side effects); treatment adherence; physical, cognitive, and psychological effects of HIV; the impact of stigma on treatment and care; disclosure of HIV status; nutrition; and school issues.

routines, and regular use of organizational tools and reminder devices) are not typical of many adolescents' daily lives (Koenig et al., 2011). Hammami et al. (2004) state that many adolescents experience a difficult transition when they become responsible for their own ART. These adolescents need to learn to organize their day around their medications, and may often forget to take them. It is important that adolescents do not take over medication responsibilities before they are ready, but it is also important that they are provided with these skills so that they are able to successfully transition to adult care when the time comes (Koenig et al., 2011).

2.1 Adherence and Mental Health Issues

Accurate diagnosis and treatment of mental health problems has been identified as an important step in improving treatment adherence in adolescents with PaHIV (Mellins et al., 2009; Williams et al., 2006). This is due to the fact that higher than expected rates of mental health problems have been found in PaHIV compared to their uninfected peers (Dowshen & D'Angelo, 2011; Fair et al., 2012; Mellins et al., 2009). These higher rates are likely due to a number of factors including: in utero exposure to maternal HIV and ART, potential maternal substance use exposure, lifelong exposure to their own HIV and ART, and environmental factors, such as poverty (Fair et al., 2012; Fielden et al., 2006; Vijayan et al., 2009). Depression, anxiety disorders, behavioural disorders, and suicide ideation have all been identified as potential mental health concerns faced by adolescents with PaHIV (Battles & Weiner, 2002; Dowshen & D'Angelo, 2011; Fielden et al., 2006; Mellins et al., 2009).

These types of mental health issues and disorders have been shown to negatively impact adherence to ART. Mellins et al. (2012) state that mental health issues can make it difficult for adolescents to evaluate the consequences of nonadherence and to feel motivated to take their medications. The good news is that many adolescents with PaHIV are engaged in comprehensive HIV care programs, which may result in better identification and treatment of mental health problems (Mellins et al., 2012). Effective treatment of mental health problems has been shown to improve adherence levels (Davies, Bachanas, & McDaniel, 2002). In the case of psychotropic drug use for the treatment of adolescents, it is important for healthcare providers to think about the effect of an increased pill burden on adherence and about the potential for drug-drug interactions between psychotropic medications and ART (Mellins et al., 2009).

2.2 Recommendations for Improving Adherence during Adolescence

In order to accurately assess adherence, it is important that healthcare providers ask about adherence at every medical appointment. Any reports of nonadherence should be used as a stepping stone to address barriers and as an opportunity to introduce new problem solving skills (Wiener et al., 2004). Researchers have found that adolescents can be empowered in their healthcare when they are given the opportunity to make choices about their treatment (Koenig et al., 2011; Merzel et al., 2008; Pontali, 2005). For example, adolescents can be given a say in how their medications are administered, when they are taken, and whether they should be changed based on the side effects experienced. According to Pontali (2005), adolescents' ART

regimens should balance the goal of prescribing maximally potent ART with a realistic assessment of the potential for adherence.

In order to achieve and maintain adherence during adolescence, Gerson et al. (2001) suggest that clinical interventions are needed. Recommended interventions include tailoring the treatment regimen for each patient, providing intensive education and specific counselling, using medication adherence prompting tools like alarms and pill boxes, and ensuring adherence support (Gerson, 2001; Panel on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2011; Pontali, 2005). MacDonell et al. (2011) suggest that interventions to improve adherence should also consider the adolescents' perspectives of ART, particularly the benefits of taking medications and expectations of side effects. Healthcare providers can attempt to increase adherence by highlighting the benefits of the medications and showing the health improvements that are occurring due to medication adherence (i.e., an increase in CD4+ cell counts and a reduction in viral load counts). This information should be shared at each visit, along with a continued examination of other potential strategies to maintain and/or improve adherence (AIDS Info, 2011).

Adolescents can be helped to gain insight into situations that may tempt them to miss their medications in order to help them deal effectively with these situations when they arise (MacDonell et al., 2011). It is also important for healthcare providers to identify those adolescents who have assumed responsibility for their medication taking, along with the factors associated with them taking on such responsibility (Williams et al., 2006). This knowledge can then be used to target interventions for improving adherence levels for each adolescent. As previously discussed, it is also important for healthcare providers to identify and treat adolescents who may be experiencing mental health issues. Antipsychotic medications may help to improve adherence for some adolescents (Williams et al., 2006).

3. HIV Status Disclosure

By the time they reach adolescence, the vast majority of those living with PaHIV know their HIV status (Fernet et al., 2007; Marhefka et al., 2011; Mellins et al., 2002). Such knowledge is vital by this stage for a number of reasons. First, disclosure allows for more involvement by adolescents in their medical care. This can help to prepare them for their eventual transition to adult care (Gerson et al., 2001; Hogwood, Campbell, & Butler, 2012). Second, disclosure can provide adolescents with increased access to resources and support programs. Finally, as adolescents become more independent, sexually active, and more likely to be involved in high risk behaviours, it is important that they have appropriate knowledge and understanding of their disease (Gerson et al., 2011; Hogwood et al., 2012). Such knowledge is necessary in order to prevent the transmission of HIV, re-infection

with another strain of HIV, or infection with other sexually transmitted infections (STIs) (Koenig et al., 2011).²

Once they learn about their HIV status, young people living with HIV face difficult decisions about whether or not to disclose to friends, sexual partners, and other significant people in their lives (Di Risio et al., 2011; Fielden, Chapman, & Cadell, 2011). Decisions about when, how, with whom, and what to disclose are difficult, particularly when adolescents often fear that such disclosure could compromise their relationships with their peers (Fernet et al., 2007; Henry-Reid et al., 2009; Tassiopoulos et al., 2012). Adolescents living with PaHIV also have to contend with familial concerns about confidentiality and discrimination, where disclosure of their own HIV status may result in disclosure of their mother's HIV status as well (Mialky et al., 2001). When adolescents are asked to keep their HIV status a secret in order to protect their mothers, it can have a detrimental effect on their psychological well-being (Mellins et al., 2002; Sherman et al., 2000). Adolescents often associate difficulties with disclosure to fears of stigma, discrimination, and rejection (Di Risio et al., 2011; Fielden et al., 2006; Henry-Reid et al., 2009; Mellins et al., 2002; Rydstrom et al., 2012; Tassiopoulos et al., 2012; Wiener, Battles, & Wood, 2007). Nondisclosure can also result in negative outcomes. For example, nondisclosure can make it harder for adolescents to explain school absences, medications, physical changes, and for many, parental illness and/or death (Hogwood et al., 2012). It is for these reasons that adolescents often see disclosure as desirable but extremely difficult (Hogwood et al., 2012).

Research has shown that adolescents who disclose their HIV status to others tend to experience better psychosocial outcomes, greater likelihood of disclosing to sexual partners, more confidence with peers, and greater resources and support from family and friends than those who do not disclose (Henry-Reid et al., 2009). That being said, many adolescents remain fearful about losing control of this personal information about their HIV status after disclosure to others (Hogwood et al., 2012). Adolescents who disclose their status then need to rely on others to maintain their secrecy. Hogwood et al. (2012) state that disclosure is likely to be part of a much longer process of establishing relationships and testing out other people's reactions. This can be particularly difficult in adolescence, when peer relationships are made and change regularly.

3.1 Disclosure to Sexual Partners

Perhaps unsurprisingly, adolescents with PaHIV are often particularly fearful about disclosing their status to potential sexual partners (Di Risio et al., 2011; Fernet et al., 2007; Fielden et al., 2006; Marhefka et al., 2011). Specifically, these adolescents often fear negative reactions, loss of relationships, and rejection at a time when peer approval and acceptance is so important. These fears may explain why many sexually active adolescents with HIV choose not to disclose their status to sexual partners (Fair et al., 2012; Vijayan et al., 2009; Weiner & Battles, 2006).

² Unfortunately, 18% of Tassiopoulou et al.'s (2012) 337 participants with PaHIV did not know their HIV status when they had their first sexual experience. These adolescents were lacking information vital to their ability to make safer decisions about sex, highlighting the importance of HIV disclosure to children prior to their initiation of sexual activity.

This nondisclosure persists despite the fact that adolescents are generally clear about their responsibility to protect their partners from infection (Fernet et al., 2007) and despite their knowledge of the potential for legal penalties (Rydstrom et al., 2012).³

On the other hand, some adolescents with PaHIV view disclosure as an important precursor to sexual activity (Marhefka et al., 2011). Of these adolescents, many express difficulty communicating the seriousness of HIV to their partners, while not making their partners so anxious that they end the relationship (Greenhalgh et al., 2012). Adolescents in favour of disclosing to their sexual partners often believe that disclosure will lead to more acceptance of condom use (Greenhalgh et al., 2012; Marhefka et al., 2011). Those who did not disclose their status found other reasons for insisting on condom use (e.g., avoidance of pregnancy). Fernet et al. (2007) state that the adolescents in their study were focused on “reducing the risk of transmission without the possible risks of disclosure” (p. 106). These findings highlight the importance of adolescent-specific tools for facilitating a safe and responsible sexual life (Di Risio et al., 2011; Rydstrom et al., 2012). Adolescents need to be provided with accurate information about HIV transmission and other STIs, the importance of consistent condom use, their legal responsibilities, and how to communicate these facts to potential sexual partners.

4. Sexual and Reproductive Health

With the success of ART, more adolescents with PaHIV are becoming sexually active and making decisions about their reproductive health (Fair et al., 2012). All adolescents face decisions about engaging in different sexual behaviours, safer sex practices, and the risk of STIs. These decisions are undoubtedly more complicated for adolescents living with PaHIV, as they have to consider issues of HIV transmission and status disclosure (Fielden et al., 2006; Steele et al., 2007; Tassiopoulos et al., 2012). According to Marhefka et al. (2011), adolescents with PaHIV are challenged with balancing sexual exploration against protecting others from HIV infection.

Despite these challenges, many researchers have found that the sexual behaviour of adolescents with PaHIV is not very different from their uninfected peers (Brogly et al., 2007; Fair et al., 2012; Landolt, Lakhonphon, & Ananworanich, 2011). According to Landolt et al. (2011), adolescents with PaHIV are “young and inexperienced but curious, and sometimes under the influence of substances” (p. 1). Koenig et al. (2011) report that anywhere from one-quarter to one-third of adolescents with PaHIV are sexually experienced, while 42% of the adolescents with PaHIV examined by Tassiopoulos et al. (2012) reported sexual intercourse. These authors, as well as Cruz et al. (2010) and Elkington et al. (2009), suggest that these rates are similar to those found for uninfected adolescents. Age at first

³ In October of 2012, the Supreme Court of Canada clarified their stance on HIV status disclosure to sexual partners (CBC News, 2012). When the “realistic possibility of transmission of HIV is negated,” those living with HIV are not legally obligated to disclose their status to sexual partners. According to the Supreme Court, this realistic possibility is negated only if the person has a low viral load and a condom is used during sexual intercourse. If both of these conditions are not met, that person is legally responsible for disclosing their status to their sexual partners.

intercourse among adolescents with PaHIV has been reported to be between 13 and 15 years of age (Koenig et al., 2011; Tassiopoulos et al., 2012).

Also similar to their uninfected peers, a substantial proportion of adolescents with PaHIV report engaging in unprotected sex. For example, 28.6% of sexually experienced adolescents studied by Koenig et al. (2010) reported engaging in unprotected sex despite knowing their HIV status, while 62% of sexually active adolescents in Tassiopoulos et al.'s (2012) study reported such behaviour. These rates of unprotected sex are important in terms of risk of pregnancy as well as risk of transmission of HIV to sexual partners. As previously discussed, disclosure to sexual partners is not very common, ranging from 20 to 40% (Koenig et al., 2010; Koenig et al., 2011; Tassiopoulos et al., 2012). Because many adolescents have low levels of ART adherence, increasing the likelihood of having detectable HIV viral load levels, adolescents with PaHIV may have an increased likelihood of sexually transmitting HIV to their partners (Mellins et al., 2011).

Although research findings about the sexual risk behaviours of adolescents with PaHIV are scarce, research does suggest that sexual risk behaviours are associated with alcohol and other substance use (Elkington et al., 2009; Koenig et al., 2010; Weiner et al., 2007). Fernet et al. (2011) suggest that condom use may be lower in adolescents who see condoms as a reminder of their HIV status. These authors also suggest that condom use may be lower in adolescents with undetectable viral loads. Reports of unprotected sex also appear to be more common in instances of anal sex than vaginal sex (Tassiopoulos et al., 2012). Perhaps explaining this finding, female adolescents in Marhefka et al.'s (2011) study were aware of the HIV transmission risks of unprotected vaginal sex, but not all were aware of the risks of unprotected anal sex. Therefore, it is important that efforts to reduce secondary transmission of HIV to sexual partners include a focus on substance use, as well as reminders about the importance of condom use for all sexual intercourse (including anal sex) even if they are using other contraceptive methods to prevent pregnancy (Brogly et al., 2007).

4.1 Contraception Options

The high rates of unprotected sexual intercourse found among adolescents with PaHIV demonstrate the importance of effective contraception for preventing unintended pregnancies among adolescents who are not practicing abstinence. According to Landolt et al. (2011), the best way to protect oneself from pregnancy and STIs is to use two methods of contraception (male condoms plus another contraceptive). Unfortunately, there has not been a lot of research examining the potential effects of contraception use on HIV disease progression, HIV infectivity, and ART interactions in adolescents with PaHIV (Coetzer, 2011; Landolt et al., 2011). Recent research in women living with HIV seems to indicate that hormonal contraception in those using ART is not associated with HIV disease progression or increased transmission of HIV to sexual partners (Coetzer, 2011; Landolt et al., 2011; WHO, 2009). As with any medication taken alongside ART, it is important that healthcare providers be aware of the potential for drug-drug interactions as they can reduce the efficacy of the contraceptives (AIDS Info, 2011; Panel on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2011; WHO, 2009).

Although sterilization is an option for preventing pregnancy, it is virtually irreversible and is ethically questionable for adolescents. Landolt et al. (2011) report that there is a high probability of regret following sterilization at such a young age. Another contraceptive option that does not increase pill burden is an intrauterine device (IUD). IUDs are sometimes associated with an increased risk of infection and complications, but it has been concluded that the advantages of using IUDs to prevent pregnancy in adolescents with PaHIV outweigh the theoretical risks (Coetzer, 2011; WHO, 2009). Although spermicides also do not increase pill burden, they are associated with higher rates of genital ulcerations, which increases the risk of HIV transmission to sexual partners. Therefore, spermicides are not recommended for adolescents with PaHIV.

In the end, the best contraceptive method is the one that works for the patient (Landolt et al., 2011). In order to make informed decisions for themselves, adolescents need information about the effectiveness, use, risks and benefits, and side effects of each method (Coetzer, 2011). As previously stated, the most effective currently available option for preventing STIs, unplanned pregnancies, and HIV transmission is the dual method of male condoms and either a hormonal contraceptive or IUD (Coetzer, 2011; Landolt et al., 2011; Panel on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2011; WHO, 2009). Adolescents should also be aware of and have access to options for emergency contraception in situations where no other form of contraception was used, when contraceptive failed, or when sex was non-consensual (Coetzer, 2011).

4.2 Pregnancy

Despite having similar rates of unprotected sex, Foster and Fidler (2011) found that adolescents with PaHIV had lower pregnancy rates than their uninfected peers. Koenig et al. (2011), however, reported that rates of first pregnancies among 15-19 year olds living with PaHIV was comparable to that of the general U.S. population, with 17.2% of those living with PaHIV having a pregnancy within these ages. Again similar to their uninfected peers, the majority of these pregnancies were unplanned. Therefore, it is vitally important that sexual education and reproductive health counselling begin early and address pregnancy planning as well as HIV transmission (Koenig et al., 2011).

It is also important to remember that many adolescent girls with PaHIV may one day choose to have children. Research has shown that up to 65% of these girls intend to have a child one day (Fernet et al. 2007). Therefore, they must be provided with accurate information about becoming pregnant without transmitting HIV to their partners and about reducing the likelihood of transmitting HIV to their babies. For girls who do become pregnant, whether it is planned or not, it is critical that they received information about the importance of adherence and other health behaviours for achieving viral suppression, avoiding caesarean section, and preventing perinatal transmission of HIV (Cruz et al., 2010). Reassuringly, rates of perinatal transmission from adolescents living with PaHIV to their babies have been very low to date (0 to 4%) (Foster & Fidler, 2011).

4.3 Human Papillomavirus (HPV)

In their investigation of pregnancy rates among adolescents with PaHIV, Brogly et al. (2007) found that cervical abnormalities were higher in this population than among those not living with HIV. The authors suggested that the higher rates of cervical abnormalities may be due to the increased susceptibility and persistence of HPV in adolescent girls living with HIV. Although HPV is known to be strongly associated with the development of cervical cancer, most HPV infections in young women leave the body without treatment.

Unfortunately, in adolescent females with HIV, rates of HPV infection are high and are more likely to be persistent (Moscicki, Ellenberg, Farhat, & Xu, 2004). The persistence of HPV is associated with CD4+ cell counts, such that lower CD4+ cell counts are associated with an increased likelihood that the HPV infection will persist. This persistence is strongly associated with the development of invasive cancer. Therefore, Moscicki et al. (2004) suggest that HPV prevention is important for this group of young women. They further suggest that vaccine trials for the prevention of HPV infection should be targeted at adolescents living with HIV. According to the Gardasil Access Program (2013), Gardasil (a vaccine against infections and cancers caused by HPV) has not yet been fully investigated in people living with HIV.

5. Additional Stressors

Along with issues around adherence, disclosure, and sex, adolescents with PaHIV face a number of additional stressors. Experiences of adolescence while living with HIV are often complicated by poverty, violence, racism, unstable families, homelessness, abuse, parental substance use, and parental illness or death (Battles & Wiener, 2002; Fielden et al., 2011; Henry-Reid et al., 2009; Mellins et al., 2009; Vijayan et al., 2009). Loss of loved ones is a common theme for these adolescents, with more than half of Battles and Wiener's (2002) participants stating that they had lost at least one close relative or friend to HIV. Stigma is another recurrent issue faced by people living with HIV (Ayres et al., 2006; Mellins et al., 2011). Experienced and perceived stigma are related to adherence, disclosure, and mental health issues (Swendeman et al., 2006; Vijayan et al., 2009).

These issues can greatly increase the risk of substance use, which can then lead to increased sexual risk behaviours, as discussed above, and decreased adherence to ART (Battles & Weiner, 2002; Henry-Reid et al., 2009; Mellins et al., 2009). These behaviours can be detrimental to the health and well-being of adolescents living with HIV and may place others at risk for secondary HIV transmission (Mellins et al., 2009). Elkington et al. (2009) suggest that adolescents living with PaHIV may engage in substance use as a way to cope with their stresses or as a way to fit in with their peers. All of the factors discussed in this section contribute to the daily stress experienced by adolescents living with PaHIV (Domek, 2009; Foster & Fidler, 2011). It is important that healthcare providers are aware of these stressors and of the possibility of substance use, so that they are able to monitor adolescents and provide appropriate support when needed.

6. Transitioning to Adult HIV Care

As adolescents living with PaHIV approach adulthood, the issue of transitioning from pediatric care to adult HIV care arises (Dowshen & Angelo, 2011; Thorne et al., 2002; Vijayan et al., 2009). Making a complete transition to adult care is impossible if disclosure of HIV status has not been made to the adolescent (WHO, 2010). Therefore, it is important that adolescents are informed of their HIV status, and that discussions about the need to transition are started early. Foster and Fidler (2011) define transition as “the planned purposeful process that addresses the medical, psychosocial, and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated health care systems” (p. 12). This definition highlights the fact that transition requires both planning and meeting the needs of individual adolescents as they move through the process. The age at which transition occurs differs among regions, but usually falls between the ages of 17 and 24 years. Fair et al. (2010) state that the readiness of the patient and the patient’s developmental age should determine the appropriate time for transition.

The idea of transitioning to adult care can be overwhelming and anxiety-provoking for adolescents living with PaHIV (Maturo et al., 2009; Thorne et al., 2002; Wiener et al., 2007). One of the difficulties faced during this process includes the increased responsibility for self-care and monitoring that is placed on the young adult (Fair et al., 2010). Up until this point, many adolescents living with PaHIV have been physically, psychologically, and emotionally dependent on their families and healthcare providers (Bush, 2002). Initially, children born with HIV were not expected to live very long and, thus, many were not taught the skills needed to care for themselves independently (Battles & Wiener, 2002; Vijayan et al., 2009). For example, Vijayan et al. (2009) found that regardless of their age, many adolescents were unable to state the medications they were on and how often they were supposed to be taken.

Another difficulty that is often encountered during the transition process is the reluctance to leave the comfort and familiarity of pediatric care (Fair et al., 2010; 2012). Many adolescents living with PaHIV have been seen in the same clinic for their entire lives and often view the pediatric staff as “part of the family” (Dowshen & D’Angelo, 2011). The transition process can then leave adolescents with a feeling of deep loss. This feeling of loss may be worsened by the significant differences that exist between the pediatric and adult HIV clinic models, including the increased number of patients served, increased expectations of patient independence, and the decreased length of appointments (Fair et al., 2010; Vijayan et al., 2009). Other support services are often more fragmented from medical services in the adult care approach, making it more difficult for patients to access all of the care and support they need (Dowshen & D’Angelo, 2011).

A successful transition to the adult medical care model takes time and advance planning (Hazra et al., 2010). Planned transition programs have been shown to improve clinic attendance, disease control, and self-management, while direct transfer to adult services has been associated with

poorer attendance and adherence, resulting in increased disease-related mortality and morbidity (Foster & Fidler, 2011). Preparatory approaches that are flexible and gradual, in which communication is started early, are deemed to be the most effective way to handle transition to adult care (Bush, 2002; Dowshen & D'Angelo, 2011; Panel on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2011; Thorne et al., 2002). Other important steps include encouraging the development of life skills in adolescents living with PaHIV (appointment management, symptom recognition, medication management), close communication between pediatric and adult care providers throughout the process, inviting adult providers into the pediatric setting, and tailoring the approach of adult care providers for newly transitioned adolescents (Dowshen & D'Angelo, 2011; Miles, Edwards, & Clapson, 2004; Vijayan et al., 2009). Adult care providers need to keep in mind the lack of autonomy many adolescents experience in pediatric clinics, meaning that adult providers may have to work with these patients to help them take control of their healthcare (Vijayan et al., 2009). Many adolescents appreciate this aspect of the transition process, stating that they enjoy their new sense of independence and being treated as an adult (Fair et al., 2010).

Effective health care transition is an important component of ensuring healthy futures for adolescents with PaHIV (Dowshen & D'Angelo, 2011). Therefore, it is important that pediatric care providers have a formal plan for transitioning adolescents to adult HIV care (Bush, 2002). Some of the healthcare providers interviewed in Fair et al.'s (2010) study recommended utilizing tools, such as checklists and patient workbooks, to aid in the transition process. The National Resource Center of the AIDS Education and Training Centers has developed adolescent transition tools and workbooks designed to help healthcare providers to better prepare their patients for transition to adult care (see <http://www.aids-ed.org/aidsetc?page=home-search&post=1&SearchEntry=adolescent+transition>). These materials address topics such as knowledge of health condition, health literacy, medication management, sexual health and family planning, personal social supports and community resources, education and career goals, and legal rights. The Hospital for Sick Kids in Toronto, Ontario also provides information and tools for transitioning adolescents to adult care (see <http://www.sickkids.ca/Go-Positive/Graduating-from-SickKids/index.html>).

7. Beneficial Support for Adolescents

Although adolescents with PaHIV face a number of challenges, they can successfully overcome these challenges when they are provided with appropriate treatment, education, and support. The research on sexual and reproductive issues highlights the need for individualized sexual and reproductive health education for adolescents with PaHIV (Fernet et al., 2007; Fielden et al., 2006). Adolescents living with PaHIV are experimenting with sex, and many are engaging in behaviours that can result in unplanned pregnancies and can place their partners at risk for HIV infection (Tassiopoulos et al., 2012). Therefore, the importance of comprehensive reproductive health and HIV transmission prevention for these adolescents cannot be overstated (Brogly et al., 2007). Researchers suggest that interventions should include addressing internal barriers to safer sex, negotiating relationships, disclosure and potential criminalization of transmission, routes and risk

factors for HIV transmission, and condom and other contraceptive use (Brown et al., 2000; Foster & Fidler, 2011).

Foster and Fidler (2011) suggest that this education should occur prior to the onset of sexual activity, and should be presented as simple repeated messages appropriate to the developmental stage of the adolescent. It is also important for healthcare providers to work with adolescents' existing motivations. For example, female adolescents have been found to be motivated to use condoms in order to prevent pregnancy, prevent infection with STIs, and by a sense of responsibility toward their partners (Fernet et al., 2007; Marhefka et al., 2011). Interventions focused on safer sex should attempt to build on these motivations, while also enhancing the behavioural skills necessary for negotiating safer sex (Landolt et al., 2011).

In terms of disclosure to peers and sexual partners, health and allied healthcare providers can help adolescents decide when and how to disclose their HIV status to others (Henry-Reid et al., 2009). Role playing and peer support have been identified as helpful methods for sharing ideas about how to broach disclosure with other people (Hogwood et al., 2012). Peer support groups also give adolescents the opportunity to be open about their HIV status, meet other adolescents living with HIV, and discuss issues related to HIV in a supportive environment (Di Risio et al., 2011; Thorne et al., 2002). With today's technology, adolescents can get support from their peers through online chat rooms, texting, and instant messaging. Such approaches may be particularly helpful for youth who do not yet wish to openly disclose their status to others (Fielden et al., 2011; Rydstrom et al., 2012).

The research summarized in the current review provides evidence that medical care alone is not sufficient for adolescents living with PaHIV. Instead, adolescents with PaHIV require coordinated multidisciplinary support services in order to fully benefit from their medical treatment. These multidisciplinary teams should include adherence support, reproductive health counselling, mental health counselling, and educational/vocational planning (Bush, 2002; Domek, 2009; Koenig et al., 2011). Johnson et al. (2003) state that successful treatment is facilitated when linkages between healthcare and support services are seamless, preferably occurring in the same location.

Treatment of adolescents with PaHIV involves those with extensive ART experience and potentially limited treatment options (Foster & Fidler, 2011; Panel on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2011). Therefore, it is important that ART treatment regimens are individually tailored to the adolescent. The goal of many adolescents living with PaHIV is to live as normal a life as possible, even while living with HIV (Di Risio et al., 2011; Hogwood et al., 2012). Health and allied healthcare professionals should work together to help adolescents achieve this goal.

8. Conclusions

The challenges faced by adolescents living with PaHIV can put these adolescents at risk for poor health and quality of life outcomes (Mellins et al., 2011). These factors also increase the possibility of onward transmission of HIV to sexual partners (Ayres et al., 2006). Therefore, it is vital that adolescents with PaHIV receive appropriate treatment, care, and support from a multidisciplinary team. According to Davies et al. (2002), appropriate treatment for adolescents with PaHIV must include emotional support for coping with HIV, interventions to improve treatment adherence and decrease the occurrence of high risk behaviours, mental health services, and preparation for transitioning to adult care. Careful follow-up of these adolescents is needed to further understand the long-term impacts of HIV itself and prolonged exposure to ART (Foster & Fidler, 2011).

Although not the focus of the current review, research shows that adolescents who are perinatally exposed to HIV, but not infected, often face many of the same issues as their infected peers. For example, Mellins et al. (2011) found that perinatally exposed adolescents have similar rates of behavioural health risks and mental health problems as those who were infected with HIV. Findings such as these suggest that all children born to women living with HIV should be monitored and should have access to a range of psychosocial services.

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