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Pediatric Care and Support for Children Living with HIV in Saskatchewan

Prepared for the Saskatchewan Prevention Institute

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Executive Summary

The current review, conducted by the Saskatchewan Prevention Institute, aimed to summarise the issues and challenges commonly faced by children living with HIV in Saskatchewan, along with their care and support needs. Antiretroviral therapy (ART) and other advancements in care have resulted in HIV being reclassified from a fatal disease to a chronic medical condition. While children living with HIV currently face a less symptomatic disease course, they continue to face numerous challenges that can impact their overall health and quality of life. These challenges include those directly related to HIV and its treatment, and those associated with the social conditions often experienced by those living with HIV. For children to receive appropriate treatment and care, it is important for health and allied healthcare professionals to understand the unique needs of these children.

Although there is not a lot of available research on the impact of HIV infection on children's developing immune systems, it is known that children living with HIV are more prone to certain kinds of illnesses, infections, and cancers. Although ART reduces the risk of many of these illnesses and infections, some remain frequent (e.g., bacterial pneumonia). In addition to the direct damage HIV has on the immune system, pediatric HIV infection can damage several organ systems simultaneously, including the renal, cardiac, and central nervous systems. Likely related to this damage, research has shown that HIV can affect children cognitively, developmentally, emotionally, psychologically, and educationally. Children with greater degrees of HIV-related immune deficiency have been shown to have more severe deficits than those without HIV. Therefore, in order to enhance well being and quality of life for children with HIV infection, attention needs to be given to monitoring all aspects of development (physical, cognitive, behavioural, social, and emotional).

The medical treatment of pediatric HIV can also be challenging for children and their families. Challenges related to the medical treatment of pediatric HIV infection include: maintaining adherence to life-long therapy; selecting successive ART regimens considering the limited availability of pediatric formulations and the lack of safety data for children; overcoming extensive drug resistance in multi-drug-experienced children; and managing the side effects of treatment. Side effects can range from nausea, diarrhea, and headaches to memory loss, abnormal fat redistribution, cardiac, and/or renal problems. Children may be particularly vulnerable to side effects of ART as their bodies are still developing, and they are likely to be exposed to ART for long periods of time.

Adherence to ART is another complex area of pediatric HIV care. The effectiveness of ART is dependent on adherence; poor adherence can lead to virologic failure and the development of drug resistance. Adherence is a complex health behaviour that is influenced by the medication prescribed, patient and family factors, and the characteristics of the healthcare provider(s) and healthcare system. Barriers to treatment adherence can arise in association with any of these factors (e.g., medication taste and side effects, age of the patient, familial resources, and accessibility of treatment). Other factors that impact adherence include poverty, parental HIV disease, unstable housing, stigmatization, and limited social

support. Once potential barriers to adherence have been identified, supports can be put in place to improve adherence levels.

As demonstrated by the list of potential barriers to treatment adherence, factors other than the direct effects of HIV can greatly impact the health and quality of life of children living with HIV. Unfortunately, children living with HIV often face problems related to the social determinants of health, including poverty, poor nutrition, social instability, a high incidence of familial substance use, deaths of family members, and issues related to stigma and discrimination. Each of these factors can play a confounding role in pediatric treatment outcomes, either by mitigating or increasing the adverse impacts of HIV. Therefore, one of the challenges of understanding HIV in children is determining which of the biological, psychological, neuropsychiatric, and social factors is most relevant at any given moment.

Finally, other relevant issues for pediatric HIV include: disclosure of the child's HIV status to the child and to others, available support for the child and his/her family, nutritional considerations, and daycare/ school issues. As HIV has become a chronic disease, disclosure has become one of the most important aspects of raising a child living with HIV. Disclosure is seen as more difficult than in other chronic childhood diseases for a number of reasons: infectious disease transmissibility, the potential for stigma and isolation from peers, vertical transmission with potential maternal guilt, and more than one family member living with the virus. Disclosure is particularly difficult for biological parents who may be the source of the child's infection as it may heighten feelings of guilt. Although there is no single, easy guide to deciding when and to whom HIV infection should be disclosed, disclosure is a vital part of comprehensive care for children living with HIV. Research suggests that disclosure should be viewed as an ongoing, dynamic process. As such, disclosure should involve multiple conversations that are tied to the child's cognitive development, clinical status, and social circumstances and should facilitate a gradual deepening of understanding of the impact of HIV infection.

Current research suggests that appropriate treatment of pediatric HIV and associated issues requires a multidisciplinary team approach that includes physicians, nurses, nutritionists, pharmacists, dentists, psychologists, social workers, child life specialists, and outreach workers. It is important for these health and allied health care professionals to understand the unique needs of children living with HIV. These needs can only be fully met if responsibility is shared amongst a multidisciplinary team, where pediatric HIV specialists provide HIV therapy and care of opportunistic infections, and other physicians and allied health care professionals provide primary care and supportive services. Research also suggests that an ideal treatment model for children living with HIV would be the integration of medical, psychosocial, and social services by both primary clinicians and community-based outreach staff. While all healthcare professionals cannot and should not be expected to be knowledgeable about every aspect of care and treatment for pediatric HIV, their assistance can greatly improve the care received by children living with HIV.

*For more detailed information, including references, please refer to the main body of the report.