



Medical nonadherence in pediatric HIV: Psychosocial risks and intersection with the child protection system for medical neglect

Corry Azzopardi^{a,c,*}, Mark Wade^{a,d}, Robyn Salter^b, Georgina Macdougall^b, Michelle Shouldice^{a,e}, Stanley Read^{b,e}, Ari Bitnun^{b,e}

^a The Hospital for Sick Children, Division of Pediatric Medicine, 555 University Avenue, Toronto, Ontario, Canada M5G 1X8

^b The Hospital for Sick Children, Division of Infectious Diseases, 555 University Avenue, Toronto, Ontario, Canada M5G 1X8

^c University of Toronto, Factor-Inwentash Faculty of Social Work, Toronto, Ontario, Canada

^d University of Toronto, Department of Applied Psychology and Human Development, Toronto, Ontario, Canada

^e University of Toronto, Faculty of Medicine, Toronto, Ontario, Canada

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ABSTRACT

Nonadherence to antiretroviral treatment has serious health implications for HIV-infected children, at times warranting referral to child protective services (CPS). The current study of 134 children with perinatally acquired HIV infection aimed to investigate rates of treatment adherence and CPS involvement, multilevel variables associated with nonadherence, and the manner in which these risks operated together in the prediction of adherence outcomes. Risk factors for nonadherence were grouped on the basis of confirmatory factor models, and factor score regression was carried out to determine which factors were uniquely predictive of adherence. A series of indirect effects models were then tested in order to examine how these factors operated together in the prediction of adherence. Results showed that almost half of the sample demonstrated suboptimal adherence to treatment, and in one-fifth, CPS was involved for medical neglect. Caregiver Health, Caregiver Involvement, Caregiver Acceptance, and Child Adaptation were predictive of nonadherence, and together explained 54% of the variance in treatment adherence. There were significant indirect effects of Caregiver Health on adherence that operated through Caregiver Involvement and Child Adaptation and an indirect effect of Caregiver Involvement on adherence through Child Adaptation. Findings extend current literature that has independently linked various factors predictive of medical adherence in pediatric HIV by showing separate but simultaneous associations with nonadherence and unique pathways to adherence involving multilevel risks. Healthcare and child welfare implications are discussed.

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Introduction

There are more than 3 million children living with human immunodeficiency virus (HIV) globally as a result of inadequate or inaccessible prevention programs (World Health Organization, 2011). With the advent of highly active antiretroviral therapy (HAART), HIV-associated mortality and morbidity have declined dramatically. Among 3,553 HIV-infected children followed in the Pediatric AIDS Clinical Trials Group 219/219C study, the mortality rate declined from 7.2 per 100 person

* Corresponding author.

years in 1994 to 0.5–0.8 per 100 person years between 2000 and 2006, concomitant with increased use of HAART (Brady et al., 2010; Gortmaker et al., 2001). The estimated 6-year survival rates for birth cohorts pre-1985, 1985–1989, 1990–1994, 1995–1999, and 2000–2006 were 81%, 90%, 93%, 97%, and 99%, respectively (Brady et al., 2010). The 10-year survival rates for HAART and non-HAART recipients were 94% and 45%, respectively (Kapogiannis et al., 2011), further demonstrating the remarkable impact of HAART. Moreover, the rate of hospitalization declined from 6.49 to 0.60 per 100 person years between 1994 and 2001 (Viani, Araneta, Deville, & Spector, 2004). Admission rates for acquired immune deficiency syndrome (AIDS)-associated conditions declined from 15.6% in 1994 to 0% in 2001. Similar trends for both mortality and morbidity have been consistently observed in other developed countries (Goetghebuer et al., 2009; Judd et al., 2007).

The potential benefit of HAART is, however, dependent on timely diagnosis of HIV infection and timely initiation of and near full adherence to HAART. Several studies have demonstrated that sustained viral suppression, a robust surrogate measure of treatment effectiveness, requires in excess of 95% adherence with prescribed regimens (Gross et al., 2006; Lima et al., 2008; Paterson et al., 2000). Other studies have shown that better adherence correlates positively with virologic suppression, increased CD4 count, and, in some, reduced mortality (Farley et al., 2008; Gross et al., 2006; Lima et al., 2008; Van Dyke et al., 2002). Virologic rebound with evidence of antiretroviral drug resistance is substantial when adherence drops to moderate levels (70–89%), which is likely a consequence of subtherapeutic serum medication levels (Harrigan et al., 2005; Sethi, Celentano, Gange, Moore, & Gallant, 2003). Estimates of full adherence to HAART by children and adolescents with HIV in high-income countries range from 20 to 100%, with almost half being less than 75% adherent, and thus at risk for compromised health outcomes (Simoni et al., 2007). Despite improvements in medication tolerability and physiological side effects, illness chronicity and demanding treatment courses, combined with multifaceted psychosocial stressors, continue to pose considerable long-term challenges that impede successful clinical management of HIV.

Given the dependence of HIV-infected infants and children on caregivers to ensure compliance with medical care plans, poor adherence meets the threshold for medical neglect in some circumstances due to associated (actual or potential) serious health repercussions, consequently warranting the involvement of child protective services (CPS). The intersection between pediatric HIV and the child welfare system elicits a host of clinical, legal, and ethical dilemmas; the subject, however, has garnered little attention in the literature. Identifying barriers to treatment compliance is an essential first step in designing supportive healthcare and child welfare interventions that optimize adherence, thereby promoting healthy development.

Correlates of Pediatric HAART Adherence

There is a growing body of research investigating a range of child, family, treatment, and environmental variables associated with adherence to HIV therapy in pediatric populations (Haberer & Mellins, 2009; Kahana, Rohan, Allison, Frazier, & Drotar, 2013; Simoni et al., 2007; Steele & Grauer, 2003; Vreeman, Wiehe, Pearce, & Nyandiko, 2008). Perhaps among the most salient factors predictive of decreased HAART adherence are those intrinsic to the relatively fixed medication regimen itself, including complicated formulations, frequency and precision of dosing schedules, poor palatability, adverse effects, dietary constraints, restricted availability, and alterations in regimens as children grow (Pontali, 2005; Reddington et al., 2000; Van Dyke et al., 2002). In addition to the practical burdens of treating perinatally acquired HIV, the prolonged administration of medications serves as a continuous reminder of the potentially fatal disease and can take a serious psychological toll, particularly for infected caregivers.

Another important intersecting set of factors that impact adherence behavior include attributes specific to the infected child, including gender, developmental stage, cognitive status, knowledge of HIV diagnosis, treatment fatigue, physical and mental health, and psychosocial functioning (Haberer & Mellins, 2009). Studies generally show a decline in adherence as children transition into adolescence and assume greater autonomy in medical management (Marhefka et al., 2008; Mellins, Brackis-Cott, Dolezal, & Abrams, 2004; Williams et al., 2006), suggesting that the nature of compliance barriers vary with developmental phase. For instance, medication refusal because of undesirable taste may be more of an impediment for toddlers, whereas for teenagers, problems related to premature assumption of responsibility in the context of developmental delay, substance use, rebellion, apathy, and mental illness assume greater importance. Depression and anxiety, for example, have consistently been shown to be associated with poorer adherence among youth with HIV (Reisner et al., 2009). A finding difficult to discern from the effects of age, Marhefka, Tepper, Brown, and Farley (2006) reported a positive correlation between knowledge of HIV status and nonadherence. Van Dyke et al. (2002) and Williams et al. (2006), however, failed to find a significant relationship between the two.

Especially relevant for HIV-infected infants and young children largely reliant upon their families for care, parental characteristics may also be meaningful predictors of pediatric HAART adherence. Factors that impede a caregiver's capacity to follow through with a program of treatment, such as impaired functioning or inadequate material resources, are very likely to have a negative impact on overall adherence behavior and, by extension, child health outcomes. For example, lower caregiver education (Malee et al., 2009; Williams et al., 2006) and income (Marhefka et al., 2006) have been associated with lower pediatric HAART adherence, although DiMatteo (2004) noted that sociodemographic effects are generally small in magnitude and moderated by sample and regimen variables. More clear is the relationship between caregiver adjustment and pediatric treatment adherence. Mellins et al. (2004) found nonadherence to be strongly associated with high caregiver stress, worse caregiver–child communication, less disclosure to others, and poorer quality of life. Other studies have reported positive correlations between nonadherence and caregiver psychological distress (Marhefka et al., 2006), alcohol use (Jaspan, Mueller, Myer, Bekker, & Orrell, 2011), and forgetfulness (Buchanan et al., 2012; Marhefka et al., 2008). Caregiver knowledge

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