

Pediatric adherence: Perspectives of mothers of children with HIV

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Abstract

This study approached pediatric adherence practices from the perspective of mothers of children with HIV in the USA. The study aimed to articulate what is involved in the daily life experience of giving or supervising a child's HIV medication (i.e., adherence practices) in order to clarify, in more dynamic terms than is often found in adherence research, what promotes or impedes adherence. A team-based qualitative analytic approach was used to analyze the narrative responses of 71 maternal caregivers of children with HIV to interview questions regarding the activities and stresses of caring for a child with HIV. Four themes of dealing with medication on a daily basis that impacted mothers' adherence practices emerged from the analysis: (1) Mothers' attitudes and feelings related to adherence practices. (2) The impact of the medications on adherence practices. (3) Interactions of mothers and children related to adherence practices. (4) Developmental issues and responsibility for medication adherence. These themes, taken together, demonstrate the contextual and longitudinal factors that impact adherence and illustrate the complexity of influences on adherence practices. We found that adherence practices were impacted in a positive way by mothers' commitment to adherence, and in a negative way by feelings of stigma and guilt, by the effects of bereavement on children and by children adopting their mothers' attitudes about medications. The interactive process of giving medication was shaped by children's behavior, mothers' developmental expectations for children, and, for mothers with HIV, their adherence for themselves. We found that pediatric adherence often came at a cost to the caregiving mother's well-being.

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Introduction

Research has shown that nonadherence to prescribed regimens is common, whether the disease is acute or chronic, or whether the patient population is adult or pediatric (DiMatteo, Giordani, Lepper, & Croghan, 2002). Adherence to HIV medications follows the same pattern (Albano, Spagnuolo, Berni Canani, & Guarino,

1999; Eldred, Wu, Chaisson, & Moore, 1998). Non-adherence in HIV is particularly problematic given recent studies that indicate that taking antiretrovirals at subtherapeutic levels can lead to the development of symptomatic HIV disease and/or create drug resistance to some or even all of the currently available HIV medications (Gavin & Yogev, 2002; Sethi, Celentano, Gange, Moore, & Gallant, 2003).

Finding the key distinctions between adherent and nonadherent patients in order to design interventions has proven difficult. Studies of HIV drug therapy in

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adults have found that demographics are not effective predictors of adherence (Chesney, 2000; Lerner, Gulick, & Dubler, 1998; Tsasis, 2001). In children with HIV, the search for predictors of adherence is complicated by the lack of consistent methods of assessing adherence across studies (see Steele & Grauer, 2003 for review).

Some researchers have proposed an alternative approach—that of studying adherence from the patients' perspective (Hill, Kendall, & Fernandez, 2003; Laws, Wilson, Bowser, & Kerr, 2000; Remien et al., 2003; Vermeire, Hearnshaw, Van Royen, & Denekens, 2001; Wu, 2000). Research with a focus on the patients' experience has shown that medication adherence is a dynamic phenomenon that is shaped in part by the patients' personal and cultural attitudes, beliefs, feelings about medication, and experiences in taking medication. For example, Conrad (1985), in a study of 80 people with epilepsy, found that the stigma often associated with epilepsy affected how some people felt about their medications: "For some it is as if the medication itself represents the stigma of epilepsy" (p. 35).

Adam, Maticka-Tynedale, and Cohen's (2003) study of 35 men and women taking highly active antiretroviral therapy found that participants' personal definitions of adherence guided their medication practices. For example, patients, following their own definition of adherence, adjusted their doses and reworked their food rules. Remien et al.'s (2003) study of 110 men and women with HIV found a spectrum of factors affected medication practices. These factors included medication beliefs, trust in care providers, side effects, toxicity concerns, regimen demands, competing concerns, mood states, substance abuse, social support and ambivalence.

Research that approaches adherence from the perspective of the patient could also be useful for addressing the complex issues that are particular to pediatric adherence. Adherence in children with HIV is complicated by the fact that adherence involves an interaction between parent and child (Steele & Grauer, 2003). A number of pediatric adherence researchers have proposed ways of addressing this dynamic aspect of pediatric adherence. For example, the focus of research could shift from measuring static variables to examining family interactions (Glasgow & Anderson, 1995; Steele & Grauer, 2003), or to taking into account family context and life demands (La Greca & Bearman, 2001). It has also been proposed that pediatric adherence should not be viewed as an either-or variable (Fielding & Duff, 1999; Lerner et al., 1998) but rather as a continuous process (Lemanek, Kamps, & Chung, 2001). Research that framed the problem in this way could seek to identify different patterns of adherence practices (Adam et al., 2003; Hill et al., 2003).

A dynamic analytic approach that undertakes to understand the person's perspective on medication and adherence affords researchers and care providers a wider

understanding of adherence, including the ways that people with HIV are successfully adherent (Malcolm, Ng, Rosen, & Stone, 2003). For pediatric adherence, viewing adherence from the perspective of the parent could illuminate these dynamic and interactive processes and their impact on adherence practices.

This study approaches pediatric adherence practices from the perspective of mothers of children with HIV. Our goal is to articulate what is involved in the daily life experience of giving or supervising a child's HIV medication (i.e., adherence practices) in order to clarify what promotes or impedes adherence in more dynamic terms than is often found in adherence research. The data come from open-ended interview questions regarding the activities and stresses of caring for a child with HIV. The data do not come from explicit answers to questions about the frequency of adherence. The study examines two areas that impacted adherence practices—the mothers' perspective on the medications, and the interaction between mother and child around medications.

Method

Sample and procedures

The data for the present analysis are drawn from the Maternal Caregivers Study, a multisite study of a convenience sample of 300 maternal caregivers of children with HIV, of children with chronic illnesses, and of healthy children, who were interviewed between June 1999 and June 2002. Potential participants were recruited and screened by general pediatric and specialty clinics in San Francisco and Oakland, California, and in the New York City area. The clinics referred qualified potential participants to the study interviewers. To be included in the study, participants had to be biological, foster, or adoptive mothers or other female relatives who were the co-residing primary caregiver of a child for at least 6 months and be either English- or Spanish-speaking. The clinics' recruiters excluded potential participants with evident psychoses or severe cognitive impairment. Interviewers obtained informed consent at the time of the first interview. The Institutional Review Boards at all three recruitment sites approved the study's consent procedures.

Of the 97 maternal caregivers of children with HIV who were recruited into the study, 71 provided one or more accounts of administering or supervising their children's medications in response to open-ended interview questions concerning caregiving activities. That such a large number of participants responded with narratives about giving medication indicated that this caregiving activity was an important and recurring daily life event faced by these mothers. This finding prompted

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