

CAREGIVERS OF CHILDREN INFECTED AND/OR AFFECTED BY
HIV/AIDS

by

SCOTT DOUGLAS RYAN

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Thesis Adviser: Dr. Victor K. Groza

Mandel School of Applied Social Sciences
CASE WESTERN RESERVE UNIVERSITY

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This dissertation is dedicated to my sister, Pamela Marie Ryan (1960-1984), and
our parents, who understand what it is to care for and lose a child from
HIV/AIDS.

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Caregivers of Children Infected and/or Affected by HIV/AIDS

Abstract

by

SCOTT DOUGLAS RYAN

This study examines the experiences of individuals caring for children who have been infected and/or affected by HIV/AIDS. This experience may include stressors that interrupt and transform the entire family's life. These stressors include juggling the HIV positive child's medical appointments and hospitalizations, as well as the emotional impact of the birth mother's own illness. Unfortunately, many of these families are faced with difficult or unsupportive social networks, as many HIV positive caregivers may have alienated previous relationships. This study builds upon the previous research through the utilization of a clear theoretical frame, the Stress-Coping model, that provides specific factors whose relationships can be measured and explored. As such, this research attempts to examine the differences between birth mothers and other caregivers on key demographic, stressor and social support variables. In addition, this study, utilizing a multiplicative interaction regression model, explores the buffering effect of specific sources of social support upon the caregiver.

A sample consisting of 212 caregivers was obtained. Many caregivers are in poor health, with some also caring for additional sick children. However, birth mothers have more health difficulties that place limits on their activities in the home, lower formal education, less support from their family, friends, and church/spirituality than their

counterparts. Birth mothers also reported more perceived stress and less arousal than did other caregivers. Yet, it was also found that other caregivers provide care for significantly more HIV positive children, as well as more other ill children. There were no differences between birth mothers and other caregivers on illness management, support from the index child, connections with the community, and formal service support. However, the most consistently significant variable in the regression equations was caregiver health limits, with two social support variables also showing significance. Support from friends has a main effect, and child support's interaction with illness management had a significant impact. Thus, it may be that some sources of social support exert a buffering effect while others demonstrate a main effect, depending upon the specific crisis at hand. This possibility demands further examination, and could greatly influence future practice and policy development.