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# Assessment of Support Service Needs of Primary Caregivers of HIV and AIDS Infected Children: A Review of Literature and Suggestions for Practice

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Wright State University  
Boonshoft School of Medicine  
Master of Public Health

**Assessment of support service needs of  
primary caregivers of HIV and AIDS  
infected children:**

A Review of Literature and Suggestions for Practice

Barry Chukwugekwu Eneh

September 30, 2010

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## **Dedication**

To the unsung heroes  
in the fight against HIV/AIDS;  
children, adolescents, their families  
and those who love and care for them.

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ABC

## **Abstract**

Summary: With the advent of highly active antiretroviral treatment, routine screening and treatment options for pregnant women for perinatally acquired HIV and AIDS, infection is on dramatic decline in the U.S. In spite of the declines and the medical advances, primary and informal caregivers of infected children continue to face innumerable challenges with regard to the availability, access and utilization of non-medical supportive service care needs. HIV/AIDS continues to create unique challenges for infected children and the non-infected family caregivers at multiple levels; impacting their relationships, resources and resilience.

Objective: This literature review identifies and assesses the unique and critical support services (non-medical, ancillary and instrumental) needs of informal primary caregivers of HIV-positive children who live within home-based and non-institutionalized settings. The absence of these services may adversely affect caregiver's quality of life, care competency and care-role satisfaction.

Methods: The review began with an extensive search of electronic databases from peer-reviewed journal articles and unpublished best practices from AIDS service organizations and health practitioners. In addition, this review closely examined a caregiver support service initiative namely, the Family AIDS Clinic and Education Services program (FACES) program at Nationwide Children's Hospital, Columbus, Ohio.

Findings: AIDS wreaks devastating medical and psycho-social havoc on children and their families. Unlike cancer or any other chronic disease, the symptomatic child may be the first indicator to the family and the physician that HIV is present in the family. In spite of the cost-saving result of home-based care for HIV-positive children, many caregivers continue to wrestle with remarkable personal burdens, including a sparse social support service system.

Conclusions: Meeting the needs that primary caregivers face will require that health policy makers, administrators, program developers and direct care service providers continue to seek out better ways to understand the real needs of primary caregivers and, to actively involve the caregivers in the development of creative and innovative strategies for providing the much-needed supportive social service care resources.

## **Introduction**

### **Statement of the Problem**

Even though the precise number of HIV-infected children in care is still unknown (Strug & Burr, 2003), according to the Centers for Disease Control and Prevention (CDC) approximately 9,300 American children under 13 years have been reported to be living with HIV (the virus that causes the Acquired Immunodeficiency Syndrome - AIDS) in the United States since the beginning of the epidemic (The Body, 2004).

In the United States, an estimated 120,000 children have at least one infected parent and, 28% of persons with AIDS have children younger than 18 years. The vast majority of HIV-infected children had acquired the virus from their mothers (mother-to-child transmission) or some member of their family.

According to the Centers for Disease Control and Prevention, since the mid-1990s, there has been rapid decline in the number of perinatally acquired AIDS and HIV infection. In part, this is as a result of routine HIV screening, better treatment options for pregnant women, the availability of improved healthcare delivery infrastructure, major investment in clinical research and, the availability of effective medical treatments to prevent mother-to-child transmission of HIV (CDC, 2010; CDC, 2009; May & Egger, 2007; Levi, 2000).

With the advent of highly active antiretroviral treatment, HIV disease is now considered a chronic illness. This is reflected in the decreasing morbidity and mortality among the pediatric population and, the maturation of children living with HIV infection into adolescence (Wiener, Vasquez, & Battles, 2001).



## **Overview of Care-giving for Children with HIV/AIDS**

In spite of the dramatic declines in pediatric HIV incidence and death rates, caregivers of HIV-infected children and adolescents continue to face innumerable challenges with regard to the availability, access and utilization of non-medical supportive social service care needs. To this day, HIV/AIDS in the family presents unique challenges for the infected children as well as the non-infected family members of HIV-infected children (Fair, Spencer, & Wiener, 1995). Evidently, HIV has profound personal and deeply social impact not only on the children it affects, but also on their entire family. Typically, children and adolescents who are dependent on their parents face greater menace because of HIV/AIDS (Schuster et al., 2000).

Most HIV-infected children and their families are inundated with countless pre-existing social problems. For instance; many of these children and their families are more likely to live in inner cities- where poverty, illicit drug use, poor housing, and limited access to and, the use of medical treatment and essential social services may add to the challenges of living with HIV (Bonuck, 1993). Furthermore, some children are at greater risk for HIV/AIDS because of the compromised social-economic status of their parents and family members.

In this literature review, a caregiver is defined as someone who takes key responsibility for a HIV-infected child and, makes most decisions about the child's care, wellbeing and daily activities. When the caregiver is the sole decision maker, he or she is also called the 'primary caregiver'. And when he or she shares this responsibility with someone else, he or she is a 'secondary caregiver' (Strug & Burr, 2003). Primary caregivers who are family members are referred to as familial or informal caregivers. Therefore, the general focus of this review is the primary caregivers of HIV-infected children and adolescents.

Most primary caregivers are biological parents, adoptive or foster parents, grandparents or siblings, nonparent relatives and other informal caregivers (Child Welfare League of America, 1994; Office of the Inspector General, 1997). Generally, it is challenging caring for any sick child, yet, it is particularly demanding caring for a human immunodeficiency virus infected child (Hansell et al., 1998). Pediatric AIDS is both stressful and frightful for the child as well as its caregiver. And as Turner and Cantania (1994) reported, care-giving in the case of HIV disease is exceptionally challenging - mostly because considerable demands are placed on caregivers of HIV-infected children.

Caregivers represent an important network of persons that struggle to meet the daily needs of HIV-infected individuals (Theis et al., 1997). Caregivers are responsible for enabling HIV-infected infants, children and adolescents live and thrive in home-based rather than in institutionalized communities of care. Generally, a caregiver may be formal or informal, paid or unpaid and, may offer their care service directly or indirectly to HIV-infected children. At other times, they simply coordinate paid professional care on behalf of an HIV-infected child.

Caregivers coordinate the threefold relationship between the patient care-recipient, the formal or professional caregivers and the informal primary caregiver. They may assist with some or all of the following activities: housekeeping, personal hygiene, meal preparation, medical care, transportation, financial and legal assistance, spiritual and emotional support (Raveis & Siegel, 1990). Hence, it is deplorable that the vast progress made in the treatment and care for HIV infected persons has not resulted in diminished burden for primary caregivers of HIV and AIDS infected children in the United States.

In fact, until recently, most research concerned with AIDS epidemic focused on persons who are themselves infected with HIV/AIDS. Even then, no other disease evokes such a

devastating social impact or threatens the family unit as HIV/AIDS does. The disease's sphere of influence on families is far-reaching, manifold and deeply felt, particularly, by primary caregivers. Hence, caregivers have been characterized as AIDS' 'Unseen Victims' or 'hidden patients' of the epidemic (Joslin & Harrison, 1998; Lesar, Gerber, & Semmel, 1996; Bonuck, 1993; Schuster et al., 2000).

AIDS in the family devastates the family at least on three fronts: It undercuts family relationships, resources and resilience. As for the primary caregivers who bear the greater burden of HIV/AIDS both physically, emotionally, psychologically, economically, culturally and socially (Knodel & VanLandingham, 2000), HIV has profound impact on them, too. As a result, increased attention must be directed at tackling AIDS impact on primary caregivers.

Notwithstanding their invaluable service for HIV-positive children, many caregivers are largely invisible to the health care system; some are isolated, powerless, impoverished, unsupported, unappreciated and persistently trapped in a myriad of unmet supportive service needs that could easily minimize the extraordinary burden of care placed on them day after day (Katz et al., 2000).

### **Purpose of Research**

There are three aspects of care-giving in the HIV and AIDS domain, namely: clinical (medical), psychological (emotional) and social support (case management, instrumental or functional) services. And the focus of this literature review is essentially the social support service needs of informal care-givers charged with the continuity of care for HIV infected children within a home-based setting.

The review discusses the unique and critical support service needs of informal primary caregivers for HIV-positive children in the United States. This review aimed at identifying and assessing caregiver needs in relation to the availability, accessibility and utilization of vital

support service needs. Additionally, the review tried to illustrate the health benefits of support services in relation to health outcome improvement, improved caregiver competency, personal satisfaction and the quality of life for pediatric-AIDS caregivers.

This review will benefit health policy makers and administrators, HIV/AIDS program developers and direct care service providers; helping them understand the need to provide the much-needed supportive care resources for infected children and their caregivers in America (Strug & Burr, 2003).

### **Methods**

Research on any aspect of caregivers of minor children with HIV/AIDS is still very limited (Rose & Clark-Alexander, 1998). As a result, the author conducted an extensive search of electronic databases such as: Google Scholar, ERIC, AIDSLINE, PubMed and Medscape. Furthermore, peer-reviewed journal articles published between January 1985 and April 2010 in the following journals were critically reviewed: Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology, American Journal of Pediatric AIDS, American Journal of Public Health, Journal of the Association of Nurses in AIDS Care, Journal of Community Health, Journal of Health and Quality of Life Outcomes, Quality of Life Research, Journal of Social Aspects of HIV/AIDS, Journal of Health and Social Work, Journal of Social Work in Healthcare, Journal of Child Welfare, Journal of Pediatric Psychology and the American Journal of Community Psychology. Lastly, evidence from non-scientific and un-published sources such as best care practices was also utilized.

Literature search was comprehensive and conducted in 3 stages. First, the keywords “children” and “pediatric HIV/AIDS were searched.” Secondly, a separate search for all articles that mentioned “primary caregivers” and “social support service” and “caregiver needs” was

conducted. Thirdly, articles that mentioned ‘caregivers’ social support service needs” and “HIV/AIDS” and “children” were cross-referenced. Finally, citations were narrowed to studies conducted in the United States. This approach was intended to help us understand why; in the face of unparalleled breakthroughs in medical treatment and the on-going care for HIV-positive children there is still more grounds to cover, before we can begin to adequately address the social support needs of informal caregivers who provide care within the home-based environment.

The search across databases yielded a total of 56 articles. The data available from these resources have been used to assess the support service needs of primary caregivers of HIV and AIDS infected children and adolescents in the United States. As is evident in this review, relatively few studies had focused exclusively on the non-medical or ancillary service needs of family members who provide primary care for children and adolescents living with HIV and AIDS.

However, evidence from these sources show that strong social support system for caregivers of HIV-positive children has the capacity to mitigate caregiver stress and health risk factors and, to enhance their coping skills, even when the availability of such services may not always guarantee positive health outcomes for the care-recipient.

The Family AIDS Clinic and Educational Services (FACES) program at Nationwide Children’s Hospital Columbus, Ohio is a premier child and family HIV and AIDS service care program in Central Ohio. Its leadership in this effort makes it a valuable organization to assess in this literature review.

## **Family AIDS Clinic and Educational Services (FACES) Program:**

### Program Background

The HIV Program at Nationwide Children's Hospital Columbus, Ohio is called the *FACES*- Family AIDS Clinic and Educational Services. It was the first family-centered HIV program to be located within a children's hospital in the United States (<http://www.nationwidechildrens.org/family-aids-clinic>). The program was created in 1985 to address the health needs of HIV-infected infants, children and adolescents; assisting them with coping with the devastating effects of HIV/AIDS. It quickly became apparent that HIV-infected children and infected parents stand to benefit if available resources could be offered as a one-stop-shop; essentially a family-centered, multidisciplinary and a comprehensive service approach to care ([www.alumni.nd.edu](http://www.alumni.nd.edu)).

The goal of its comprehensive HIV program was to ensure that children and their families received full support services that would enable them to maintain their dignity and independence within the comfort of their home. The program provides a multidisciplinary care to children, adolescents, women and families infected and affected with HIV/AIDS and, helps families plan and coordinate home-based care services for their HIV-positive child.

The program multidisciplinary care team consists of professionals and associates:

- Physician - Director
- Program Manager- a Certified Social Case Worker
- Infectious diseases specialist
- Pharmacist
- Nurse Practitioner
- Certified Public Health Nurses
- Nutritionist/Dietician
- Administrative Staff
- Secretary

FACES program model integrates services such as HIV treatment, clinical research, HIV education and social supportive services. The program was designed to keep families intact while assisting them in coping with the devastating effects of HIV/AIDS. Built on the idea of a one-stop family-centered and community-based care clinic, the program caters to the medical and core support services needs of HIV-infected children and their families. FACES program has been largely successful with its clinical interventional services. And to this day, it is the only federally funded family-care model available through the Ryan White Care Act- Title IV program in the State of Ohio (<http://www.nationwidechildrens.org/family-aids-clinic>).

Under the Ryan White Care Act -Titles 111 and IV, FACES program is able to offer early child health care intervention, primary care, and the prevention of mother-to-child transmission of HIV/AIDS, health education, voluntary testing, free counseling and treatment for maternal and pediatric HIV/AIDS (The Henry J. Kaiser Family Foundation, 2008; <http://www.nationwidechildrens.org/family-aids-clinic>). The program services also include medical care for HIV-infected children and their parents, prevention services, prenatal counseling of HIV-infected pregnant women to prevent mother-to-child transmission of HIV, psychosocial services for affected families, homecare and hospice care for infected children, transportation, case management, improved access to clinical trials and HIV education outreach to the community

Existing Support Social Services to caregivers of children and adolescents:

**Medical and Clinical Treatment Services**

Medical Care for HIV-infected children and their families- free doctor's visits, checkup, sick care, inpatient/outpatient ER and surgery.

- Access to quality primary care and interventional health support.
- Access to clinical trials and medical equipment supplies.

- Pharmacy - prescription drug and medication vouchers.
- HIV testing and counseling.
- Training on care-giving to mitigate negative stereotypes, nursing care and wound management, drug administration and community health outreach.
- Basic Support - emergency food supply, clothing, transportation to and fro medical appointments
- HIV disease education - drug therapy, adherence strategies, prevention education, disease symptoms management and HIV education outreach
- Legal service and child health advocacy - linking caregivers to professional services, health insurance information, referral and information regarding available resources
- Child care assistance and recreational therapy
- Financial Assistance - income supplementation through the Ryan White Financial Assistance program.
- Women services - prenatal counseling and prevention of perinatal transmission.

#### Program Successes

FACES program has continued to employ evidence-base guidelines for the treatment of HIV infection in children and, the prevention of HIV-associated opportunistic infections. FACES extended its services in the fall of 1991 to HIV-infected adult-family members of children seen at the FACES Immune Deficiency Clinic. In addition, the program has created improved access to medical providers for all affected families to social work case managers, dieticians, pharmacists, child-life specialists, art therapists and mental health providers. The program has served over 350 children and families since inception (<http://www.nationwidechildrens.org/family-aids-clinic>). And under Title 111 of the Ryan White Care Act of 1990, families are now able to receive assistance with housing, legal services, and emergency food supplies, clothing and other essentials. In summary, FACES comprehensive care model has proven to be highly successful in markedly improving the health and quality of life for children and families with symptomatic and asymptomatic HIV in Columbus, Ohio.



### Program Gaps, Deficiencies and Unmet Needs

In spite of the success of the program, many service gaps still exist. Given that the ongoing and consistent care for young children is largely provided within the household, by primary and informal caregivers, integrated health services which include: physical, dental, vision and psychosocial treatment continue to be largely inadequate for caregivers (Fonseca et.al., 2006; The Consultative Group in Early Childhood Care and Development, 2006). And granted that care and support are two of the three pillars of universal access and, achieving prevention and treatment, still leaves some services unmet. Besides, many of the caregivers for HIV-positive children still do not receive the attention and funding they actually need (Huairou Commission at the International AIDS Conference, 2010).

Below is a list of unmet needs or service gaps on the FACES program:

#### **Medical and Clinical Treatment Needs**

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- Vision screening and glasses, hearing test and aids and, dental coverage.
- Mental health- substance, drug and alcohol abuse treatment coverage.
- Care-giving training and education to mitigate the negative stereotype of care giving, drug administration training, nursing care and wound management and, training on understanding and navigating the health care system.

#### **Emotional and Psychological Services**

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- Training on strategies for breaking bad news to friends and family members.
- Grief counseling support.

#### **Social Support Services**

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- Basic Support- emergency food supply, housing or home repairs, assistance with household items such as furniture, stoves, refrigerators and beds, clothing, transportation to and fro medical appointments, auto insurance, car repairs and maintenance.
- Parental education on HIV- child development and childrearing training, parenting coaching and mentorship, planning for the future, home health care techniques, resource on patient-parent network and support groups.
- Legal protection and child health advocacy
- Child care assistance- help with household tasks.

- Financial Assistance- child care tax credits, property tax incentives, career development and job readiness training, assistance with finding employment/volunteer opportunities and tuition assistance.
- Respite and hospice care services
- Women services and male caregiver assistance programs

Moreover, it is believed that the addition of the following professional disciplines to the program care-team might raise the strength of available services: For example, Program Coordinator

- Patient Care Coordinator
- Public Health Advisor
- Dentist
- Nurse Case Manager
- Program Psychologist
- Testing and Counseling Staff
- Recreation Therapist
- Clinical Chaplain or Clinical Pastoral Counselor

The addition of the above listed professional expertise might help to bridge the huge social support service gaps that currently exist on the FACES program.

## **Literature Review**

### **Care giving Through the Years- the role of informal caregivers**

Home-based care for children with chronic diseases such as HIV/AIDS is an emerging public health practice involving complex and fluctuating roles. In the past, the overwhelming majority of caregivers were women who were not employed outside the home. Today, women make up half of America's workforce and still, many continue to take on the bulk of care-giving responsibilities within their families- caring simultaneously for their sick children, spouses, parents, friends and themselves (Talley & Crews, 2007).

Typically, female care-givers contend with multiple tasks and responsibilities being that they are (as is often the case) their family's bread-winners and their children's primary

caregivers. And many of these women might actually benefit from interventional support service programs themselves as well as from effective public health services, in order to preserve their own health and that of the HIV-infected child placed under their care. Nevertheless, in the past 25 years, care giving for HIV-infected children has become such an important issue that affects the quality of life for millions of people hence; it demands proper attention from the public health policy makers in the U. S. (Talley & Crews, 2007).

Generally, caregivers perform a variety of roles that help HIV/AIDS patients adhere to treatment regimens, avoid unnecessary hospital admissions, reduce their reliance on formal caregivers, remain at home longer, and maintain high quality of life. O'Neill and McKinney (2003) outlined six major areas of supportive services provided by caregivers to infected children: they provide emotional support role (comforting, empathizing, and providing encouragement to HIV-infected children in their time of difficulty). They may help with daily living activities (feeding, bathing, dressing and toileting). Caregivers may also help with instrumental activities of daily living (house cleaning, running errands and providing transportation to and from hospital consultations). And sometimes they are asked to manage financial and legal services for their patient.

And more often than none, caregivers perform health care advocacy and case management duties, for example linking the care recipient with formal and informal services, and communicating with health professionals on behalf of their patient. More recently, some primary caregivers have also been called upon to manage nursing care for their patients (helping them with dispensing medications and monitoring the use of medication, and sometimes administering injections and inserting catheters) (O'Neill & McKinney, 2003). In summary, it is

the ultimate responsibility of a caregiver to ensure that a child receives all required medical treatment and care services (Scannapieco & Hegar, 2002).

In spite of the fact that informal or familial primary caregivers are increasingly being asked to do more for their patients (including to administer pain medications, manage epidural catheters and home infusions, provide wound care, and to identify and manage symptoms and side effects) some caregivers are thrust into these roles with little or no preparation or training (Glajchen & Fraidin, 2001; O'Neill & McKinney, 2003). Hence, it is worthwhile for policy makers and program managers to understand these challenges so as to better develop and empower one of America's most essential health resources namely, natural, familial or informal caregivers of HIV-infected children and adolescents.

#### **Profile of HIV/AIDS Informal Primary Caregivers**

Presently, there is no accurate data available on the proportion of U.S. adults providing home-based care for children with HIV/AIDS (O'Neill & McKinney, 2003). However, scientific data show that infected children require the care and support of someone close and committed to their welfare; someone willing to help them avoid frequent lengthy hospitalizations and grave dependence on costly healthcare services (Reidy & Taggart, 1991).

Over the years, informal primary caregivers, though lacking in professional training for their care responsibilities continue to fulfill this role (Generations United, 2002). And the dynamics of care-giving often impose on a caregiver an upward, downward or lateral caring role. And because informal and primary caregivers generally donate their time and services freely or partially for pay, in order to maintain HIV-infected children at home, their invaluable services often go unnoticed, unappreciated and largely unsupported. Yet, the cumulative impact of their

dedicated services is frequently a cause for substantial monetary savings for their families and society (Theis et.al., 1997).

And while gender differences may make care-giving more difficult for male caregivers, female and male caregivers share many of the same burdens (Marks, 1992). See below for a comprehensive list of Social support services needs for male and female caregivers:

- Access to full **medical care** such as medications and healthcare related resources and, medication adherence protocols.
- Dental, mental, alcohol, drug and substance abuse treatment.
- Access to **social support services**- including up to date information regarding available social support services in the community, understanding the health care system and networking with professional caregivers.
- Full or partial insurance coverage for themselves and their child.
- Housing referral and placement service.
- Employment training and information, and educational and vocational counseling opportunities.
- Child care assistance, guardianship and assistance with child rearing skills.
- Food, legal, advocacy and transportation assistance.
- Financial assistance such as living expense, income supplementation, money management skills and Ryan White Emergency financial assistance.
- Parental and family services: improved personal relationships, educational assistance with an ill child, family disclosure concerns, community support network, planning for the future and parental involvement in policy and care planning, encouragement and respect for the strengths of each caregiver.
- Access to quality case management services, including information and training for persons caring for children living with HIV, development of a comprehensive and individualized care plan, provision of treatment adherence counseling and preparation for complex HIV/AIDS treatments.
- **Prevention and care education:** learning more about the diagnosis and disease transmission mode, disease progression and management, medical care and drug administration and ways to adjust to the disease progression.
- **Emotional and Psychological Counseling-** coping with the possible loss of a partner, with stress, anger, anxiety, guilt, poverty, depression, burnout, stigma, HIV-related discrimination, anticipatory grief and bereavement support.

In their study Ogu and Wolfe (1994) showed that, because HIV/AIDS infected children have complex care needs, their primary caregivers tend to seek help for their own needs almost

always, late in the process, if at all. Hence, they may need to be duly educated about how to protect themselves and other members of their family against HIV and the lingering impact of caring for a HIV-positive child. Hence, caregivers need help in coping with the stress and scope of care and, with their own life situation (Reidy & Taggart, 1991).

### Men as primary caregivers

Due to the deaths of mothers and the need to provide some kind of parental guardianship, many fathers are likely to assume parental role and, share in the responsibility for the care and well being of one or more infected children (Wiener, Vasquez, & Battles, 2001; Strug & Burr, 2003). In comparison to previous generations, today's fathers have taken on a more visible role in caring for children with chronic illnesses such as HIV/AIDS (Rodriguez, 1996).

Nonetheless, there is relatively little research information regarding the role and, the needs of fathers involved in the care of their children. Fathers have typically been left out of HIV/AIDS research and sadly, of the service care delivery system. Consequently, a father's needs as a parent and primary caregiver have been largely ignored by policy makers and programs managers and, frequently omitted from professional literature (Strug & Burr, 2003). Nevertheless, the role of men in the care of their children is undeniably essential.

Many fathers continue to play a very important role in their children's lives (Fair, Spencer, & Wiener., 1995). And caring for a HIV/AIDS infected child presents numerous unique and complex social issues for a male caregiver; including the need for emotional support to help them better perform their parenting roles (Strug & Burr, 2003).

Research shows that male primary caretakers have huge need for social support services in order to cope with the psychological challenges posed by an absent spouse and a child inflicted with an incurable and stigmatizing disease of HIV. Most of all, it is difficult for some

fathers to juggle the complex demands of work, social life and childrearing. Other care-giving challenges fathers face include dealing with the important medical, psychological and developmental problems attendant to raising an HIV-infected child (Greif, 1998; Anderson., 1998; Strug et.al., 2002).

In addition, male parents may face many barriers trying to access services such as physical health services and mental health treatment, counseling, recreational and other support services for themselves. Similarly, fathers express the need for assistance with parenting lessons, with disciplining their child and with support in their relationship with their significant others; with obtaining medical information and insurance services, disease management, accessing social support services, and disclosing their child's diagnosis to family members while planning for the future (Wiener, Vasquez, & Battles, 2001).

Some male primary caregivers have also been found to be without adequate savings, stable employment, regular income, health insurance coverage, extended family support and, lacking confidence in their parenting skills. Hence, a critical next step for program planners for fathers caring for their HIV-infected children should be to develop models of care that adequately respects the strengths of each male caregiver as well as enables them to access gender-specific support services needed for the exercise of their assigned roles (Strug & Burr, 2003; Wiener, Vasquez, & Battles, 2001).

#### Summary of specific social support service needs of male caregivers

- Physical, emotional, mental, spiritual and financial support.
- Child care and parenting skills training- dealing with the medical, psychological and developmental issues attendant to raising an HIV-infected child, coaching, mentoring and disciplining a child.
- Support with building and maintaining relationships- with their child and a significant other, finding their way in their care-role, with juggling the complex demands of work, childrearing and social life, group network and emotional care.

- Assistance with navigating the health care system, with improving the quality of their care, their access and utilization of available medical and support services.

### Women as primary caregivers

Women have been found to be the most frequent primary caregivers for their families, friends and extended families. The relatives who most frequently provide care for HIV-infected children are maternal grandmothers, aunts and great grandmothers and great aunts (Benedict, Zuravin, & Stallings, 1996; Scannapieco & Hegar, 2002).

Overall, the experience of women caring for children with HIV/AIDS has been well documented in the literature. Women continue to be one of the ranking subgroups to be largely impacted by HIV disease. Many women have also been infected by their male sexual partners who use drugs or indulge in other risky sexual behaviors. Others have had to support their own drug habits through prostitution. In all, many women are faced with socioeconomic stressors that exacerbate the negative consequences of HIV for their physical and mental well-being. Most of these women are poor members of minority groups who have responsibility for dependent children, grandchildren and family members.

In addition, insufficient financial resources frequently compound the multidimensional responsibilities that women feel toward their family, being for the most part, the primary caregiver and provider for their families. Many of these women live in high-crime areas, and can only obtain low-wage jobs with few benefits. Many are uneducated, and rarely have access to a health care facility except for emergency health services (Bunting, Bevier, & Baker, 1999; Wofsy, 1987). Many of the women have needs that are unique to them as women, as primary caregivers and principal bread winners for their families.

According to Hacki, Somlai, Kelly and Kalichman (1997), development of effective support services is particularly challenging with impoverished women, for whom HIV infection



is but one of many life stressors. Most of all, women have generally received more attention for their potential role as *infectors* than for the problems they face as *infectees* and primary caregivers.

For this reason, formal care providers and health care professionals must assist women to identify the issues they confront as caregivers and help them develop programs and services that adequately address the problems associated with their care of HIV-infected children and adolescents in the United States. Take for example, in designing effective support services for female care providers and their families, health care professionals must also endeavor to facilitate interventions to improve the daily lives of this population (Bunting, Bevier, & Baker, 1999). It is critically important to ensure that at least four categories of their core needs are adequately addressed, namely: finances, social support services, education matters and treatment for mental health issues. Other support services specific to this group will be: gynecological services including HIV medication adherence and a comprehensive care and treatment for HIV-positive women.

#### Grandmothers as primary caregivers

Young men and women are dying off from HIV/AIDS leaving their children to the care and upbringing by familial and informal caregivers, especially grandmothers. As Mason and Linsk (2002) rightly observed, HIV/AIDS epidemic is one of the reasons for an increase in grandparents and relatives providing care for HIV-infected children and adolescents (Office of the Inspector General, 1977; Skolnik, 2004).

Having a son or daughter diagnosed with HIV/AIDS comes at a great personal cost especially to grandmothers who feel obligated to step in and care for their grandchildren when they have been diagnosed with HIV/AIDS. The number of grandmothers who are caring for their

grandchildren has increased substantially in the last three decades. In some places, this phenomenon has been referred to as “skipped-generation parenting” or “kinship care” (Joslin & Harrison, 1998).

Given that children with HIV/AIDS are particularly at risk for losing their biological mothers to AIDS due largely to parent’s seropositive status, grandmothers or great-grandmothers easily transition into primary caregivers for HIV-infected children (Caliandro & Hughes, 1998). A case study by Hughes and Caliandro (2000) showed that grandmothers are for the most part, the primary caregivers of children with HIV infection in the U.S.

A study of grandparents providing primary care for children affected by HIV/AIDS, Schable and colleagues (1995) found that grandparents and other relatives cared for 20 percent of children living with HIV-infected parents (Schable, et al, 1995).

In their own study, Linsk and Mason (2004) estimated that primary caregivers’ ages ranged between 25 to 77 years, with a mean age of 48.5years. Most caregivers lived on an annual income of less than \$30,000 per year. And they varied in three major ways: in the type of task they performed for the infected child, the amount of time they devoted to caring for their child and their living arrangement.

In the African-American community for instance, the predominant reason why the grandmothers cared for their HIV-infected adult children and parented their grandchildren was the belief that families come first and should stay together at all costs (Minkler, Roe, & Price, 1992).

Historically, African American women have been called upon to provide instrumental and affective support needed to sustain their families (Winston, 2006). This tradition has been richly preserved in both low-income families as well as single-women households (Hughes &

Caliandro, 2000). Overall, the role of an African-American grandmother included that of “kin-keeper” and “guardianship of the generations” (Minkler, Roe & Price, 1992). Even though care-giving is not a role that many grandmothers actively sought, they readily assumed care-giving responsibilities with little regard to its impact on their health; mainly to protect their grandchildren and family. At the same time, some grandmothers take on this responsibility in order to demonstrate their strong commitment to the child and to ensure the child’s optimal welfare (Hughes & Caliandro, 2000).

In a case study of grandmothers who provided primary care for HIV and AIDS infected children, none of the grandmothers admitted feeling any regrets about their decisions to become primary caregivers. Instead, they were willing to learn more about the diagnosis and how to manage the medical care responsibilities (administering medicines and taking the child to clinics for treatment) and, increasingly finding joy in their care of their ‘special grandchildren’ (Hughes & Caliandro, 2000).

Some grandmothers also spoke about teaching their grandchildren to live life and not to dwell on the inevitability of death. And for most of these women, the future meant actively taking care of these children until one of them grew too weak and infirm and, at worse, died. And for most of them, an important source of their strength was their faith and their spirituality. And much like the mothers of HIV-positive children, finance was an important concern for grandmothers. For instance, some grandmothers did not have an automobile, and would depend on other people and largely on public transportation for shopping, hospital visits and church attendance (Hughes & Caliandro, 2000).

As a result, researchers strongly recommend the mobilization of resources needed to provide care for infected children and, the provision of adequate social support programs for

grandparents raising their HIV-positive grandchildren as a way to ensure their physical, mental and emotional health and that of the child under their care (Hughes & Caliandro, 1996; Hughes & Caliandro, 2000; Skolnik, 2004).

In contrast to male caregivers, support services for caregivers in North America, albeit inadequate, have focused on women and their needs. Little is known about the stressors that male caregivers, who are frequently the next line of caregivers, experience when they become primary caregivers (Paton, 1992).

#### Relatives as primary care providers

To this day, family or kinship caregivers, nonparent relatives or formal foster parenting and adoptive care are among the most important resources for the child welfare system in America. Kinship caregivers' have become a major resource for caring for children in our society. And available data show that government funds were easily made available for formal, foster and adoptive care, whereas informal care arrangements (when a relative takes in a child) do not often qualify for similar financial and other forms of assistance (Sherbourne & Stewart, 1991).

However in order to ensure the well being of children in care, public health policy and practice must continue to address the support and interventional needs that kinship caregivers contend with on daily basis (Scannapieco & Hegar, 2002; Linsk and Mason, 2004). The needs of family caregivers may include medical treatment, psychological counseling and up to date information regarding available social support services as well as opportunities to network with other caregivers.

More often than not, their need for social support services is underrated and thus, goes unmet. However, the absence of these vital resources threatens the optimal health outcome for

caregivers and care-recipients alike. Hence it is critically important that healthcare professionals namely; case workers, social workers, child health and welfare workers, behavioral specialists, chaplains, spiritual counselors, policy makers, health administrators and trained care volunteers fully understand the needs and challenges faced by informal primary caregivers who attend to the daily needs of HIV infected children.

Without a doubt, the health care system can be overwhelming at times hence; informal primary caregivers who provide in-home care often act as advocates for the children to get the requisite resources to meet their needs (Scannapieco & Hegar, 2002).

Despite the critical role played by kinship care providers of HIV-infected children, relatively little is known about how this evolving family care dynamic might affect the physical, mental, emotional, economic and social life of these caregivers. Much the same way, little is actually known about how the interplay between the lack of caregiver social support and the oft overwhelming medical, economic, and psychosocial demands placed on family systems by the AIDS epidemic impact the health and well being for caregivers for HIV infected children and adolescents in the U.S. (Lesar, Gerber, & Semmel, 1996).

### **Caregiver Burden- the negative effects of care-giving**

Psychologists use the term “caregiver burden” to describe the physical, mental and emotional problems associated with care giving (Pakenham & Dadds, 1995). The burden of care may include the loss of income due to missed days at work, family frictions, and reduced social contacts, diminished physical and mental energy.

According to O’Neil and McKinney (2003), multiple factors contribute to caregiver burden including the fact that care giving often comes as an unexpected role, requiring a caregiver to restructure their preexisting obligations, career and other plans in order to

accommodate the needs of a sick child (Pearlin, Aneshensel, & LeBlanc, 1997; Brown & Powell-Cope, 1992).

Besides, most caregivers make a commitment to care for the children until they were grown, gone, married or dead. Simply, the duration of care is frequently indeterminable. Most of all, caring for an infected family member invariably takes enormous physical toll on a caregiver's health. And sometimes, caregivers are unable to obtain routine health screenings and, may eventually encounter health problems that could have been averted. They may also become depressed because of the overwhelming demands of their responsibility (Talley & Crews, 2007).

In addition, the progressive enlargement of a caregiver's role over the course of illness may require further adjustments in family, work and social commitments (Raveis & Siegel, 1991) and, adjusting to the disease progression can be especially difficult for younger caregivers who are both inexperienced and scarcely thrilled to give up their career plans in order to take care of HIV-infected child (Turner, Catania, & Gagnon, 1994).

Most caregivers reported that specific financial needs was the most pressing need, followed by housing needs, living expenses and income supplementation, health and medical care costs, bereavement support, transportation costs and access to convenient support services. Most of all, primary caregivers would like to obtain intermittent professional help with raising their child (Mason & Linsk, 2002).

Good enough, since the mid-1990s persons with HIV have been living longer; however, this has increased the length of time and the intensity of caregiver involvement (Theis et.al., 1997; Fleming et.al., 2000). Besides, many families still suffer severe economic hardships when a key wage earner is forced to reduce work hours or leave paid employment entirely in order to care for a sick relative (Armstrong, 2000).

And to this day, the stigma surrounding HIV disease and the community rejection of victims often extends to relatives and friends who provide care; making it difficult for caregivers to benefit from extended family and community support networks. As a result, rather than face stigmatization, caregivers often conceal their care giving role, choosing to withdraw from social relationships and several community activities (Armstrong, 2000; Wilder, 2000).

More than anyone else, HIV-positive parents and informal- primary caregivers face additional challenges that may increase their sense of burden (Bor, 1990). Take for instance, the energies and resources of a family may be quickly drained when the AIDS virus infects a child; and many families are easily overwhelmed or paralyzed by the demands placed on them as a result (Bennett, 1987). Hence, caregivers continue to contend with unmet needs for social and financial assistance.

And pediatric AIDS, with the likely infection of both mother and child, evinces the loss of autonomy and an increase in financial dependency on the part of caregivers. Hence, most caregivers will continue to take on significant burden and face potentially serious health problems as a result (Talley & Crews, 2007). Take for instance in a situation where the primary wage earner is also the primary caregiver, she or he may eventually face the loss of income for time taken off from work for medical appointment, diagnosis and other care-demands (Reidy & Taggar, 1991). And where caregivers are less able to work, families may be forced further into debt and poverty as they struggle to pay for care-related costs, for funeral expenses, and care of affected children (Skolnik, 2004).

### **Rewards and Benefits of Care-Giving**

Despite the burden brought about by the care for HIV-infected children, grandparents and other informal primary caregivers often report that caring for an HIV-infected child is rewarding.

They express relief and happiness at being able to provide a good home for their grandchildren (Linsk & Mason, 2004). Some families even perceive the sick grandchild as a blessing to the family; haven given them a second chance at child rearing and a renewed sense of purpose in living (Kelley & Damato, 1995).

A study by Arno, Levine, and Memmott (1999), offered important insights on the economic value of informal primary caregivers. They estimated an average of 17.9 hours per week on informal care giving, at a wage rate of \$8.18 per hour, thus bringing the total care worth at \$196 billion, an amount equivalent to 18% of total health care spending in the U.S. At any rate, caregivers maintain that the rewards of care giving for a child by far surpass the burden therein:

- It offers them a strong sense of meaning and identity.
- A greater opportunity for learning more about their child and themselves.
- An opportunity to acquire improved competency in child rearing.
- It offers moments of true intimacy and a privilege to be part of a young life.
- And a greater appreciation for life as a whole.

#### **Gaps and Unmet Caregiver Needs – healthcare and Social Services deficits**

In their research with caregivers for children that are HIV positive or at risk for HIV-positive, Reidy and Taggart (1991) itemized the specific needs of caregivers: First, the need to maintain bodily and physical integrity of the care-recipient and, to possess relevant health information and knowledge relevant to the maintenance of bodily integrity of a caregiver. This includes the need to know the modes of transmission of HIV; how to prevent the spread of infection, and how to protect infected children from other infections and co-morbidities.

There is also the need to obtain honest answers to their numerous questions, to be informed and periodically updated on available AIDS treatment options, the different roles of the health professionals and a network of informal resource persons with whom they come in contact



with, so as to access resource data and learn to deal with associated stress. Thus caregivers need basic knowledge and skills pertinent to the care they provide to their loved ones. They also have the need to discuss the issues and ramifications of the disease for the infected child and to access a network of informal resource persons.

To this end, a multidimensional assessment must be utilized to identify and address an array of support and interventional needs that primary care providers might have (Scannapieco & Hegar, 2002). Furthermore, caregivers have the need to be understood and respected by hospital personnel and professional care providers for doing what they know and believe to be right for the child under their care (Reidy & Taggart, 1991).

Sometimes, families accord the greatest importance to the need to be supported by health care personnel who follow the infected child. Thus they have the need for a continuity of care for their child and to develop relationships with the providers who follow their family (Reidy & Taggart, 1991). They may also need professionals like a psychologist to help them deal with their own feelings, with the fear of the unknown and, to figure out who would look after their child in the event that death should strike (Reidy & Taggart, 1991).

Caregivers often have the need to understand the full extent of the threat posed by HIV/AIDS as well as the full extent of susceptibility of their family to HIV disease. They need to learn the daily precautions necessary to prevent the spread of HIV infection to others in their household or within the child's immediate social environment. Obviously they need to understand the hygienic measures needed to reduce the secondary infections associated with HIV virus (Nelson & Album, 1987).

Thus, it is fair to say that a few gaps still exist between primary caregiver needs and the available social support resources. Take for instance, it would be helpful to link caregivers to

available healthcare services so as to reduce their burden and promote their physical and mental health (Talley & Crews, 2007). Equally important is the assistance of caregivers with household tasks, with transportation for their child when he/she has a hospital appointment, assistance with writing letters and paying bills, and with financial assistance to reduce the chronic penury in which caregivers often live. The failure to meet these basic needs sometimes result in increased anxiety and the inability of a caregiver to address the threats associated with the AIDS virus for themselves and their child.

Most of all, the issues unique to caregivers of HIV-infected individuals such as the stigma of AIDS, fear of contagion, the possibility of multiple losses, and a high degree of uncertainty in terms of the unpredictable trajectory of the disease requires that caregivers maintain an identity outside their caregiver role in order to avert the looming devastation with stress and depression. Besides, most caregivers would like to know their child's medical history, to be assisted with specialized disease care management education, with resolving their housing needs, health insurance coverage, income supplementation, psychological counseling and opportunities to network with providers and other caregivers.

Some caregivers have also entertained the fear of losing the slim support and financial assistance provided by the child welfare system. These caregivers would welcome a renewed assurance that they could have access to vital information and interventional assistance with their child's behavior issues and/or special needs (Mason & Linsk, 2002).

Unfortunately, some of these services are not always available. At other times, the stigma associated with HIV often complicate caregiver access to services (Schuster et al., 2000). In all, the unmet health care and social needs of male caretakers points to their need for counseling in order to increased their access to medical services and to a third party reimbursement plan.

According to Strug and Burr (2003), there are four elements in a service program that have proven to be most effective in caring for caregivers: working with the whole family, active case management, continuous access to providers and, the co-location of clinical and support services. Other key elements that might improve effectiveness are: community outreach initiatives, peer support and education for caregivers, life skills training and advocacy for caregivers.

Data also shows that higher HIV-related specific knowledge, plus improved self-efficacy and counseling are important empowerment tools in meeting the challenging needs of care giving for HIV-infected children. In some instances, the presence of these conditions have been implicated in better clinical outcomes for caregivers and care-recipients alike (Nicholson et al., 2006).

Therefore, support social services are considered important buffer for family caregivers of children living with HIV or dying from AIDS. And without the leverage of a critical support structure, informal caregivers will be less able to manage the burden presented by caring for a sick HIV-infected child in the U.S. (Levine, 1995).

## **Discussion**

As more and more HIV-infected mothers die or become too ill to care for their children, it becomes absolutely necessary to find better ways to support grandmothers, male caregivers and all informal caregivers in parenting for HIV-positive children within home-based care situations. To this end, researchers agree that it is critically important to conduct a thorough needs assessment of the current service delivery system to more fully understand the peculiar experiences of each group of primary, informal and familial care-givers. Such an assessment must identify effective approaches to meeting the gender-specific supportive service needs of caregivers (Draimin et al., 1998).

While much has been written about the support service needs of mothers, grandmothers and female adoptive parents of HIV-infected children, little is known about the specific social support service needs of male caregivers, particularly the barriers they face in trying to access medical, psychological treatment and most importantly, the case management services for themselves and their HIV-infected children. Available literature show that the programs primarily directed at this population of primary caregivers seem to be too few and far between. In fact, most of the educational programs for caregivers of people with HIV/AIDS may have targeted strictly male partners caring for gay men with HIV/AIDS (Theis et al., 1997).

Consequently, there is the lack of detailed information about informal primary male caregiver needs for physical, emotional, mental, spiritual, and financial needs to ensure consistency of care for their children and, optimal health and wellness for themselves.

Furthermore, evidence from best practices suggest that smaller percentage of men versus women continue to utilize medical care, social services, mental health and counseling services, substance abuse treatment and emotional support, housing, transportation, financial assistance, parenting skills training and child care services (Strug & Burr, 2003). Therefore, program services targeting under-served male caregivers of HIV-infected children must include policy and practices that will address these lapses and, provide prevention education, specialty medical care, male-specific support services, psychological services, logistical support and community outreaches that would guarantee a continuum of care for all primary caregivers.

Furthermore, it is critically important to prioritize the allocation of limited resources to improve the quality of their care. In an era of grave limited resources, it is believed that an effective needs assessment should provide credible information that might enable healthcare professionals, policy makers and case managers to focus scarce social support service

improvement programs on the development and maintenance of efficacious support services for all pediatric HIV-caregivers in the U.S. (Wen & Gustafson, 2004).

Unlike any other chronic disease, HIV could easily devastate an entire family. Take for instance, in the case of childhood cancer, when a child is afflicted with cancer its parents may or may not have any traits of the disease. In most cases, parents are still able to care for their sick child without the fear of becoming infected and, eventually separated from their child because of their own medical condition. With HIV, the symptomatic child is often the first indicator to the family and their physician that HIV was present in the family. More often, caregivers for HIV-positive children are afraid of contagion and also burdened with anticipatory grief for the death of their child and perhaps, another member of their family.

Most of all, HIV places a huge financial burden on the family. Undoubtedly, the unpredictable course of the illness is equally frightening. And besides, the stigma associated with the epidemic of HIV often compels caregivers not to disclose to friends and family the extent of their suffering, for fear of discrimination and ridicule. Implicitly, this lack of social support compounds the situation for infected and affected families, forcing many caregivers into utter helplessness.

### **Limitations and Implications of Evidence**

Obviously, there are several limitations of this literature review. First, there is limited research on this topic, plus the fact that much of the available research information is obsolete. Nonetheless, this review was intended to provide answers to key questions such as: who is providing care for HIV-infected children within home based settings? What is the range of support services available to informal primary caregivers? What support service needs are still unmet among this population? And how might healthcare professionals and formal care

providers improve access, utilization and quality of support services available to informal and primary caregivers of HIV infected children in the U.S.?

An attempt at these questions have revealed that caregivers, especially male primary caretakers have specific support service needs that are either not being fully met by existing programs or are simply limited in their scope and availability; take for instance the issue of networking, child care and parenting skills training (Strug & Burr, 2003). Caring for HIV-Infected children with limited emotional support and, inadequate social support services is naturally a major challenge for both male and female caregivers; whether they have shared or primary care taking responsibilities for an infected child. And for male caregivers; no matter how intact and put-together a male primary caregiver might look on the surface, countless male caregivers experience stress, anxiety, grief and depression whether they live alone or have shared responsibility for one or more infected and affected children (Pivnick & Vargas, 2000; Wiener et al., 2001). Therefore, establishing innovative and non-threatening approaches to reach particularly, male caregivers will enable them to fully take charge of their own health and their care-giving responsibilities to their children. And by all accounts, improving the life and health of informal primary caregivers (male and female) is a worthwhile public health investment for the U.S. health system.

### **Ideas for Future Research**

It is important for clinicians and field experts to understand the factors that might serve as barriers to parenting success and caregiver confidence (Nicholson et al., 2006). Therefore, future research should focus on the gender-specific support service needs of male and female caregivers within home-based settings, and the culture-fitted needs of all primary caregivers.

Furthermore, a longitudinal research with male caregivers is necessary to learn more about their perception of support service needs and the barriers they actually face in trying to access social support services. It is believed that there might be substantial difference between what providers perceive to be the service needs of male caregivers and the actual challenges caregivers experience in their caring role.

Further research should also clarify the impact of the various challenges and burdens placed specifically on pediatric primary and informal HIV care-givers (male and female), particularly when they are familial caregivers. In summary, it will be useful knowledge to ascertain the impact-differential of pediatric HIV on the quality of life for primary caregivers, especially when they are family members (Lesar, Gerber, & Semmel, 1996).

### **Recommendations**

Reliance on informal caregivers without considering the caregivers' ability to provide care can create a stressful and potentially unsafe environment for the caregiver and the care-recipient (Navaie-Waliser et al., 2002). In the HIV/AIDS context, the burden of care is exacerbated by the continuously growing scarcity of both medical and a whole range of social supportive services.

Findings from this literature review suggest three most important needs for significant caregiver health and wellness improvement and program transformation. They are social support, psychological and medical services:

#### **Social Support Services**

In addition to their roles as hands-on care providers and care managers, family-caregivers also are trusted companions, surrogate decision makers, and patient's advocates (Navaie-Waliser et al., 2002). And many caregivers meet the demands of caring for their child in the midst of their own at-risk or deteriorating health and wellbeing.

It is highly recommended that any meaningful support service improvement must involve caregivers in the design and implementation of effective health and social protection systems to alleviate their burdens. In addition, a comprehensive HIV care response must offer all caregivers unlimited and on-going access to support service information, an assurance of food and nutrition security, of full or partial financial compensation, respite care and capacity building opportunities, periodic recognition for their work, respect and supervisory support for their care-responsibilities for America's children.

Caregivers and children dealing with HIV/AIDS need healthcare professionals who will collaborate with them in solving their life's most challenging problems, not health experts who would adjudicate their fierce battle with the AIDS disease. Fair enough, HIV patients, caregivers and professionals bring different kinds of expertise, perspective and experience to the situation. It is worthwhile for professionals to treat a caregiver as a "colleague in caring". Such a collegial relationship in the care for HIV-infected children has the potential to offer both formal and informal caregivers new and better perspectives in their caring endeavors. Therefore, both must be valued and appreciated for what they offer to HIV+ children.

Finally, in order to reduce the burden of care and household poverty, program managers and policy makers must also develop livelihood initiatives for caregivers. They should build the capacity of community-based organizations to get involved in the provision of core HIV support services.

### **Medical and Physical Treatment**

Furthermore, HIV treatment must guarantee that all caregivers have access to free or subsidized physical, dental, vision, mental, drug and substance abuse treatment and, to vital medical information, latest research developments in HIV treatment and medications, advances



on ways to live better and happier with HIV and, to medical and financial preparations for patients and their families. Health professionals must endeavor to provide on-going training, technical support on the use of home-care equipment, adherence to complex medication formulae, relaxation techniques and how to care for themselves as caregivers.

Clinical and support services for people affected by the HIV epidemic must be radically family focused (Schuster et al., 2000). Hence, the challenge for health researchers and practitioners is to better assist infected children and their families in identifying and accessing services that can prevent and remediate stresses from HIV. In this regard, strategies that help families adjust and adapt to the many psychosocial problems associated with the HIV infection is a great complement to all preceding advances in the prevention, care and medical treatment for HIV (Lesar, Gerber, & Semmel, 1996).

### **Emotional and Psychological**

Thirdly, the provision of psychosocial and emotional support must include free training for caregivers on how to manage a whole range of human emotions including anger, guilt, grief, stress, depression and burnout and, knowing when to ask for help. Caregivers must also receive reasonable preparation and counseling on the potential dangers to anticipate in care-giving and how to handle these changes in the physical and emotional state of their child. Caregivers will also benefit from training on how to start or where to find a net work of support groups of caregivers for improved access to standard HIV information, home-care resources and, relief/outlet for their own emotions.

Ultimately, caregivers will benefit from assistance with developing their other interests and relationships besides their care-role and, with handling end of life issues or planning for hospice or respite care for an infected child.

## **Conclusion**

Fixing the current lapses in the HIV/AIDS home-based care system will require targeted ongoing outreach and the motivation of trained health professionals to offer a continuum of care that is sensitive, gender-specific, timely, innovative and cost-effective. Mounting empirical evidence suggest that HIV-infected children continue to live with their caregivers under conditions that are non-conducive for optimal health outcome for the caregiver and care-recipient. It is believed that a closer attention to the support social service needs of primary caregivers would mark another turning point in the fight against HIV/AIDS. This is not only a moral imperative; it is also a cost-effective public health approach to solving the existing inadequacies within the system.

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## Appendices

### Appendix A

## Essential Public Health Competencies and Core Skills

Specific competencies and skills achieved during completion of this research project.

#### 1) Analytic and Assessment Skills

- Problem definition and skills in literature review, data analysis, and evaluation of public health program operations.
- Formulation of research question, objectives, data sources, methodology, outline, abstract, references, literature review and interpretation of all relevant data.
- Identification of relevant and current data information sources and application of data collection processes, information technology applications and computer systems retrieval and storage strategies.
- Recognition of how data illuminates scientific, economic, medical, ethical, political and overall public health issues.
- Identification of the limitations of research and scientific evidence and the importance of observations and interrelationships of data.

#### 2) Policy Development and Program Planning Skills

- Collection, summarization and interpretation of information relevant to the research topic.
- Provision of guidance and direction on critical and complex program issues and the development of policy implementation plans: including goals, outcome, process objectives, implementation steps and mechanisms to monitor and evaluate program outcomes for effectiveness and quality.

#### 3) Communication Skills

- Skills in developing comprehensive materials designed to communicate effectively (in written and oral forms) to health professionals/researchers.
- Continuous correspondence and interaction with the Research Guidance Committee – my Chair and Reader.
- Advocacy for public health programs and resource support for target population.
- Effective presentation of accurate demographic, statistical, programmatic, and scientific information for professional and lay audiences.
- Solicited input from individuals and organizations in unbiased manner, respecting their points of views and promoting the expression of diverse opinions and perspectives.

#### 4) Basic Public Health Sciences Skills

- Knowledge of the theories, concepts, principles, practices, methods, and techniques of administering public health program and development of project objectives, milestones and timeline.
- Definition, assessment and understanding of the health status of primary caregivers; including the determinants of health and illness, factors contributing to health promotion, disease prevention and factors influencing their use of health services.
- Application of the basic public health sciences including behavioral and social sciences, biostatistics, epidemiology, environmental public health, and prevention of chronic and infectious diseases and injuries.

#### 5) Community Dimensions of Public Health Practice Skills

- Collaboration with community agencies to promote the health of the population, identification of community assets and available resources and clear description of the role of government in the delivery of health services to the study population.

#### 6) Financial Planning and Management Skills

- Knowledge of budgeting methods and funding requirements to manage, oversee and monitor program performance and funding.
- Development of strategies for monitoring program performance and determining budget priorities.

#### 7) Leadership and Systems Thinking Skills

- Identification of internal and external issues that may impact delivery of essential public health services (strategic planning) and development, implementation and monitoring of organizational performance standards.
- Creation of values and shared vision and the use of leadership principles to guide health related actions.

## Appendix B

### Project Timeline - Culminating Experience Project

<b>May</b>	<b>June</b>	<b>July</b>	<b>August</b>	<b>Sept.</b>
Research Proposal	Continue Data Collection	Submit First Draft	Write Literature Review	Submit Manuscript
Approval of CE Proposal	Submit Draft	Review Manuscript	Write Discussion	Write Abstract
Data Collection	Review Manuscript			Acknowledgements
Literature Review				Apply for Defense
				Prepare for Defense
				Publish Research
			Graduation	

Data Collection

Submit Research Proposal

Literature Review

Continue Data Collection

Submit the First Draft of Manuscript

Review of Manuscript

Write Final Draft

Write the Research Abstract

Write Acknowledgements

Complete Final Manuscript

Submit Manuscript and Apply for Defense

Publish Research Project

Apply for Graduation

Write Text of Oral Presentation

Prepare for Oral Presentation

Oral Presentation

Graduation

THE WHITE HOUSE  
Office of the Press Secretary

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For Immediate Release

October 29, 2010

**Presidential Proclamation- National Family Caregivers Month**

**BY THE PRESIDENT OF THE UNITED STATES OF AMERICA  
A PROCLAMATION**

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Every day, family members, friends, neighbors, and concerned individuals across America provide essential attention and assistance to their loved ones. Many individuals in need of care -- including children, elders, and [persons with disabilities](#) -- would have difficulty remaining safely in their homes and community without the support of their relatives and caregivers.

Caregivers often look after multiple generations of family members. Their efforts are vital to the quality of life of countless American seniors, bringing comfort and friendship to these treasured citizens. However, this labor of love can result in physical, psychological, and [financial hardship](#) for caregivers, and research suggests they often put their own health and well-being at risk while assisting loved ones. Through the National Family Caregiver Support Program, individuals can help their loved ones remain comfortably in the home and receive assistance with their care giving responsibilities. This program provides information, assistance, counseling, training, support groups, and [respite care](#) for caregivers across our country.

My Administration's [Middle Class Task Force](#), led by [Vice President Joe Biden](#), has made supporting family caregivers a priority, and we are working to assist caregivers as they juggle work, filial, and financial responsibilities. We made important progress with this year's Affordable Care Act, and because of this landmark legislation, Americans will be able to take advantage of the Community Living Assistance Services and Supports (CLASS) Program. This voluntary insurance program will help individuals with long-term care needs to maintain

independent living, as well as compensate family caregivers for their devoted work.

Our businesses and companies can also contribute to families' ability to care for their loved ones in need. By offering flexible work arrangements and paid leave when care giving duties require employees to miss work, employers can enable workers with caregiver responsibilities to balance work and family obligations more easily. Such efforts impact countless lives across our Nation, easing concerns and contributing to the well-being of individuals and families as they go about their daily lives.

During National Family Caregivers Month, we honor the millions of Americans who give endlessly of themselves to provide for the health and well-being of a beloved family member. Through their countless hours of service to their families and communities, they are a shining example of our Nation's great capacity to care for each other.

NOW, THEREFORE, I, BARACK OBAMA, [President of the United States of America](#), by virtue of the authority vested in me by the [Constitution](#) and the laws of the United States do hereby proclaim November 2010 as National Family Caregivers Month. I encourage all Americans to pay tribute to those who provide care for their family members, friends, and neighbors in need.

IN WITNESS WHEREOF, I have hereunto set my hand this twenty-ninth day of October, in the year of our Lord two thousand ten, and of the Independence of the United States of America the two hundred and thirty-fifth.

**BARACK OBAMA**

<http://www.whitehouse.gov/the-press-office/2010/10/29/presidential-proclamation-national-family-caregivers-month>