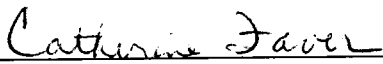
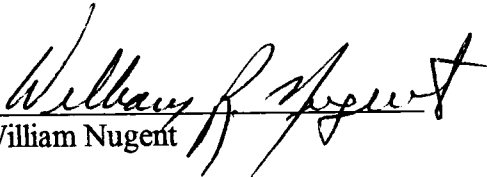


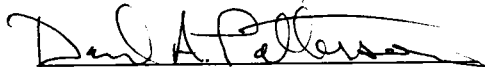
To the Graduate Council:

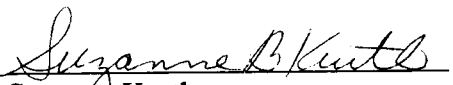
I am submitting herewith a dissertation written by M. Maureen Newton entitled "Rural and Urban Differences in People Living with HIV/AIDS and their Caregivers: Social Support, Types of Need, and Caregiver Burden." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Social Work.


Catherine Faver, Major Professor

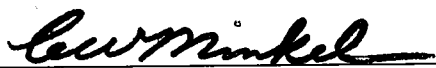
We have read this dissertation
and recommend its acceptance:


William Nugent


David Patterson


Suzanne Kurth

Accepted for the Council:


Associate Vice Chancellor and
Dean of The Graduate School

Rural and Urban Differences in People Living with HIV/AIDS and their Caregivers:
Social Support, Types of Need, and Caregiver Burden

A Dissertation
Presented for the
Doctor of Philosophy
The University of Tennessee, Knoxville

M. Maureen Newton
December 1998

© Copyright by Mary Maureen Newton, 1998

All rights reserved

DEDICATION

This work is dedicated to several important people in my life. First of all, my parents, Kenneth and Mary Newton. They have provided unending support, encouragement, and faith throughout my life. They are the foundation of my support system and words cannot express their importance in my life. This work is also dedicated to my sisters and brothers: Michele, Patricia, Kevin, Ross, and Rick, and to their spouses and children. The support of my family is greatly appreciated and never underestimated. Thanks Mom and Dad for a big family.

I would also like to dedicate this work to all who are affected by HIV/AIDS. I hope this helps us to remain aware that we need each other. Finally, I want to dedicate this work to the memory of those who have been with me along the way and weren't able to make it this far, thank you, thank you.

ACKNOWLEDGEMENTS

First, I owe the utmost thanks and appreciation to Dr. Catherine Faver, my adviser and mentor. Without her support, patience, and endurance I could not have reached this point. She truly is a source of guidance and respect for me.

I also would like to especially acknowledge the members of my committee: Dr. William Nugent, Dr. David Patterson, and Dr. Suzanne Kurth. Thank you for your participation and willingness to share your time and knowledge.

I would like to express my gratitude and appreciation to the College of Social Work at the University of Tennessee. So many people have been supportive and encouraging throughout my education. Kindness and assistance has always come from many sources.

Next, I would like to express my thanks and gratitude to the staff and clients of AIDS Response Knoxville (ARK). Their interest and willingness to participate made this work possible. To the ARK staff, thanks for letting me get in the way. To the ARK clients/study participants and their caregivers, you let me in the door, what a gift!

This academic pursuit has been a long, arduous process and I am grateful for many people who have provided me a boost along the way. I would like to thank my fellow graduate students who started along this path with me, Cinda, Don, and Hussein. They provided the initial support and perseverance to keep me going.

I have also been fortunate in my friendships. Tina M. and Beth F. have offered tremendous support and assistance toward helping me to finish this work. Their willingness to fill in where needed provided me with a sense of comfort and the belief that I would finish.

There have been many others whom are not listed and I am truly appreciative of their pep talks, faith, humor, and especially their presence. Thank you for your commitment.

Finally, the encouragement, support, and patience of Brett L. and Becky J., especially the past two years, provided me additional strength to cross the finish line.

ABSTRACT

This study examines: (1) rural versus urban differences in social support and types of need for people living with HIV/AIDS (PLAs) and (2) rural versus urban differences in social support and burden for caregivers of PLAs. Structured interviews were conducted with a sample of 83 PLAs and 25 caregivers.

Two instruments were used to measure social support: The Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1988) and the Network Orientation Scale (NOS) (Vaux et al., 1986). The Caregiver Burden Interview (CBI) (Zarit, 1990) was used to measure caregiver burden. A needs assessment was constructed to examine PLA types of need.

Multiple regression and *t* tests were used to test hypotheses concerning rural and urban differences in social support and caregiver burden. Rural and urban differences in PLA types of need were explored by examining percentage distributions.

Rural versus urban residence was not significantly related to social support for PLAs. However, PLAs who have a caregiver were significantly more likely to have higher levels of social support than PLAs who do not have a caregiver and PLAs who are gay or bisexual were more likely to have higher levels of social support than PLAs who are heterosexual.

The results of the needs assessment indicate that rural PLAs had a greater proportion of unmet need than urban PLAs. Moreover, almost one-fourth of PLA needs were unmet.

On the NOS measure of social support caregivers in urban areas had significantly lower levels of social support than caregivers in rural areas. In addition, urban caregivers had significantly higher levels of burden than rural caregivers.

Study findings indicate the need to acknowledge the increasing occurrence of HIV/AIDS in other populations and to adjust programs and services accordingly. Currently the Family and Medical Leave Act of 1993 applies only to persons who are legally married to the person who is ill or who are biological family members. Social work and other health and human service professionals need to be aware of the psychosocial characteristics of PLAs, especially regarding the support network, caregiver status, sexual orientation, and mode of HIV/AIDS infection.

TABLE OF CONTENTS

CHAPTER	PAGE
1. INTRODUCTION	1
Purpose of the Study	6
Conceptual Framework	6
Summary	9
2. LITERATURE REVIEW	11
Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome	12
HIV/AIDS-Related Stigma	15
Social Support	18
Caregiver Burden	29
Types of Need and Service Utilization	38
Rural and Urban Residence	48
Statement of the Research Problem	55
3. METHODOLOGY	56
Research Design	56
Sampling and Data Collection Procedures	56
Obtaining the Sample	56
Data Collection	60
PLA Group	60
Caregiver Group	62
Variables and Measures	62
Social Support	63
Caregiver Burden	65
Types of Need	66
Demographics	67
Procedures for Protection of Human Subjects	68
Potential Risks and Safeguards for Confidentiality	68
Procedures for Minimizing Risk	70
Procedures for Obtaining Consent	71
Potential Benefits	71
Limitations	72
Data Analysis	73
PLA Social Support	73
PLA Types of Need	74
Caregiver Social Support and Caregiver Burden	75

4. PERSONS LIVING WITH HIV/AIDS RESULTS	77
PLA Sample Characteristics	77
Social Support for Persons Living with HIV/AIDS in Rural versus Urban Areas	96
Tests for the Assumption of Normality	96
Predictor Variables	100
Tests of the Hypothesis on Social Support for PLAs	103
Multiple Regression Results on the MSPSS Measure of Social Support for PLAs	103
Multiple Regression Results on the NOS Measure of Social Support for PLAs	106
PLA Types of Need	108
Summary	113
5. CAREGIVER RESULTS	117
Caregiver Sample Characteristics	117
Social Support and Burden for Caregivers in Rural versus Urban Areas	127
Social Support	128
Tests of the Hypothesis on Social Support for Caregivers	131
Independent-Samples T Test for the MSPSS Measure of Social Support for Caregivers	131
Independent-Samples T Test for the NOS Measure of Social Support for Caregivers	132
Caregiver Burden	132
Test of the Hypothesis on Burden for Caregivers	135
Independent Samples T Test for the CBI Measure of Burden for Caregivers	135
Summary	135
6. DISCUSSION OF FINDINGS	137
Summary of Study Findings	137
Discussion of PLA Findings	139
Social Support for PLAs	139
PLA Types of Need	143
Discussion of Caregiver Findings	146
Social Support for Caregivers	146
Caregiver Burden	147
Study Limitations	148
Implications for Research	153
Implications for Policy	155
Implications for Practice	157
Conclusion	159
REFERENCES	162

APPENDICES

174

VITA

212

LIST OF TABLES

TABLE	PAGE
1. Demographic Description of PLAs	78
2. Relationship Characteristics of PLAs	79
3. Socioeconomic Description of PLAs	80
4. Disease and Health Status Information of PLAs	82
5. Household Composition of PLAs	85
6. Residential Information for PLA Study Sample	86
7. Caregiver Information for PLA Study Sample	88
8. Total PLA Support Received From Caregivers (n = 43) by PLA Rural and Urban Residence	89
9. PLA Living Proximity by Rural and Urban Residence	91
10. PLA Report of Social Interaction by Rural and Urban Residence	93
11. PLA Report of Social Interaction with Caregivers (n = 43) by Rural and Urban Residence	95
12. Proportion of PLA Sample Per Predictor Variable and Dummy Coding	101
13. PLA Means, Standard Deviations, and Ranges of Scores for Multidimensional Scale of Perceived Social Support and Network Orientation Scale by Rural versus Urban Area	102
14. Correlation Matrix of Predictor and Criterion Variables	104
15. Multiple Regression of MSPSS	105
16. Multiple Regression of NOS	107
17. PLA Types of Need Reported by Rural and Urban Residence Percentage Distribution of Need and Met Need	109

18. PLA Met and Unmet Need by Living Situation (n = 83)	111
19. PLA Met and Unmet Need by Monthly Income (n = 83)	111
20. PLA Met and Unmet Need by Stage of Illness (n = 83)	111
21. PLAs (n = 83) with Unmet Need by Rural and Urban Residence	112
22. Total Met and Unmet Needs for PLAs by Rural and Urban Residence	113
23. PLAs (n = 83) with Unmet Need by Rural and Urban Residence including PLAs Somewhat or Very Dissatisfied with Met Needs	114
24. Total Met and Unmet Needs for PLAs by Rural and Urban Residence including PLAs Somewhat or Very Dissatisfied with Met Needs	114
25. Demographic Description of Caregiver Study Sample	118
26. Socioeconomic Description of Caregiver Study Sample	119
27. Number of Days Per Week Caring for PLA	122
28. Length of Time as a Caregiver	122
29. Household Composition of Caregiver Study Sample	123
30. Caregiver Report of Support Provided to PLAs by Rural and Urban Residence	124
31. Caregiver Report of Social Interaction by Rural and Urban Residence	125
32. Caregiver Report of Feeling in the Past Month by Rural and Urban Residence	128
33. Caregiver Means, Standard Deviations, and Ranges of Scores for Multidimensional Scale of Perceived Social Support and Network Orientation Scale by Rural versus Urban Area	130
34. Caregiver Means, Standard Deviations, and Ranges of Scores for the Caregiver Burden Interview by Rural versus Urban Area	134

LIST OF FIGURES

FIGURE	PAGE
1. Geographic Location of Study Participants: Rural and Urban Areas	57
2. Location of AIDS Service Organization for Study Region (AIDS Response Knoxville)	58
3. Frequency Distribution of Unstandardized Residuals for the MSPSS	97
4. Frequency Distribution of Unstandardized Residuals for the NOS	97
5. Normal Probability Plot of MSPSS Measure of Social Support	98
6. Normal Probability Plot of NOS Measure of Social Support	98
7. Residual Prediction Error Plot of MSPSS Measure of Social Support	99
8. Residual Prediction Error Plot of NOS Measure of Social Support	99
9. Frequency Distribution of MSPSS Measure of Social Support for Caregivers	129
10. Frequency Distribution of NOS Measure of Social Support for Caregivers	129
11. Frequency Distribution of CBI Measure of Burden for Caregivers	133

CHAPTER 1

INTRODUCTION

Persons living with HIV/AIDS (PLAs) and their caregivers have an increased need for emotional and physical support due to the impact of the disease on their lives (Koski, 1998). The human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) cause multifaceted and deleterious physical, psychological, and social consequences to persons infected and their support system. HIV infection leads to AIDS, a disease that attacks the human body's immune system. Decreased functioning results thus providing opportunities for an assault of debilitating and frequently life-threatening infections that pose no threat to most healthy people.

By the end of 1997, almost 400,000 persons in the United States had died from HIV/AIDS (Centers for Disease Control and Prevention [CDC], 1997). AIDS is now the second leading cause of death in the United States among persons aged 25 to 44 and the eighth leading cause of death among all persons (CDC, 1997). Continuing advances in medical research have led to increased longevity due to improved treatment regimens. Despite medical advances in the treatment of HIV-infected persons, HIV/AIDS remains a communicable disease that can only be treated, not cured, and is considered a terminal condition. The course of illness is frequently unpredictable. Persons infected with HIV/AIDS may have years of asymptomatic living followed by progressive physical decline or periods of acute illness which may be interspersed with periods of relatively good health.

The unpredictable and frequently lengthy period of illness and resulting physical, psychological, and social devastation of HIV/AIDS culminates in the need for services and support to enhance the ability to cope and the quality of life for PLAs and their caregivers. Formal and informal sources of care and support become overtaxed as a result of this extended burden and the personal trauma of HIV/AIDS. As the number of people infected with HIV/AIDS continues to increase, additional communities will be affected.

Geographic and residential mobility of persons living with HIV/AIDS has become an issue of concern. Research has found there is a trend toward PLAs returning to the communities where they were raised to be cared for when their health status declines (AIDS/STD News Report, 1996, p. 11). The residential migration of PLAs affects these communities, resulting in additional demands being placed on the local sources of service and support. These community-based resources are frequently unprepared to meet the demands unique to persons affected by HIV/AIDS.

The stigma attached to HIV/AIDS may result in negative responses from the social network surrounding PLAs and their caregivers. Since the onset of HIV/AIDS in the United States, homosexual men and injecting drug users have composed the category of persons with the highest incidence of AIDS. Nonetheless, the prevalence of HIV/AIDS is increasing in other groups of persons in the United States. For example, "From 1991 to 1996, the estimated proportion of adult U.S. AIDS cases attributed to heterosexual contact each year grew from 8.5 percent to 17.5 percent" (CDC, 1997). As the spread of HIV/AIDS expands in populations previously assumed to be at a lower risk for infection, the stigma associated with the disease also expands to these populations (Wallace, 1991).

Research on caregivers for persons with chronic or life-threatening illness has suggested that caregiving creates stress from the physical and psychosocial burden and anxiety related to the caregiving role. Caregivers for persons living with HIV/AIDS suffer from the pressures specific to HIV/AIDS, including the disease stigma, unpredictability of disease progression, and the fact that the disease is most prevalent among young adults, leading to premature deaths for persons not normally afflicted with serious health problems. These usually long-term care demands may culminate in physical and mental exhaustion and incapacitation of the caregiver, which may result in a loss of support for the PLA. Understanding the effects of HIV/AIDS on caregivers, including caregiver responses to caregiving, will enable the development of resources to address their needs.

Due to the nature of HIV/AIDS and the impact on the physical and emotional health of infected persons, an array of services to address these issues is necessary. Healthcare-related services necessary to the PLA may include medication therapies, nutritional services, hospitalization, home health and hospice care, as well as long-term care services such as nursing home care, assisted living, or residential hospice care. Anticipated social service needs may include mental health counseling, financial assistance, housing assistance, legal services, and substance abuse treatment. The cost of providing these services for persons with HIV/AIDS continues to increase. The lifetime healthcare cost of a person infected with HIV is expected to exceed \$100,000 (Bonuck, 1993).

Understanding the health and social service needs of PLAs is essential to the development of necessary programs and services to serve this population. Identifying PLA needs and determining whether or not they are met leads to questions regarding

accessibility and appropriateness of services as well as PLAs' willingness to use services. Awareness of need for and use of services will allow for the development of policies and implementation of programs and services adequate to address the complex issues surrounding the care of persons living with HIV/AIDS.

Research reinforces the belief that social support and social networks can facilitate help-seeking behavior and influence individual use of formal and informal services. The environment of PLAs and their caregivers may impact the relationship in which social support can be enhanced or nullified. Understanding patterns of social support systems, including service availability, accessibility, and identifying system gaps are necessary for program planning, development, and implementation appropriate to meet the needs of those affected by HIV/AIDS.

Green (1993) has suggested that sources and forms of social support may differ among cultures or social classes and between the sexes. Due to the complexities of social relationships, it is essential to consider various factors that may reinforce the perception and impact of social support, especially in vulnerable populations such as PLAs and their caregivers. In fact, social support has been found to be vital to the fostering of coping mechanisms needed by PLAs to enhance their quality of life (Bechtel and Swartzberg, 1993).

HIV/AIDS research primarily has focused on large metropolitan areas where the greatest incidence of HIV/AIDS in the United States has been found to occur. Still, the percentage of people living with HIV/AIDS continues to increase throughout all communities of the United States. In fact, the AIDS rate in rural areas of the United

States rose 80 percent between 1991 and 1995, compared to increases of 47 percent in metropolitan areas and 64 percent in small metropolitan areas. (American Medical News, 1996). Consequently, the number of persons caught in this personally, physically, and socially threatening epidemic is increasing rapidly in smaller and rural communities.

Stigma and prejudice associated with HIV infection appear to be more prevalent in small towns and rural communities. A lack of tolerance for alternative or "deviant" lifestyles as well as an exaggerated concern for being viewed as having high moral standards is common (Nieto, 1989). Accordingly, these communities may not advocate providing assistance and resources regarding HIV/AIDS due to the tendency to not address judgmental attitudes and the belief that HIV/AIDS is only a problem for urban communities and populations outside the norm. The limited formal resources available in small or rural areas cannot be stretched to accommodate the frequently specific needs of PLAs and their caregivers. In addition, concerns about confidentiality may decrease the PLA's willingness to use local services and support. In 1996, Sowell reported that many PLAs preferred to travel outside their community for services rather than risk disclosure of their HIV status and possible discrimination at home.

Because specific knowledge is lacking regarding PLAs and their caregivers in small and rural communities, current local resources may inadequately address their needs. Research into the experiences of PLAs and their caregivers in rural and urban areas is needed because rural populations have been studied rarely, especially areas traditionally having a lower incidence of HIV/AIDS.

Purpose of the Study

The focus of this study is to examine the experiences of people living with HIV/AIDS and their caregivers living in rural and urban areas. The specific purposes of this study are to: (1) determine the characteristics of PLAs living in rural versus urban areas; (2) determine whether differences exist in social support for PLAs living in rural versus urban areas; (3) determine the types of needs for PLAs living in rural versus urban areas; (4) determine the characteristics of caregivers of PLAs living in rural versus urban areas; (5) determine whether differences exist in social support for caregivers of PLAs living in rural versus urban areas; and to (6) determine whether differences exist in caregiver burden for caregivers of PLAs living in rural versus urban areas.

Conceptual Framework

The ecological systems framework is the comprehensive theoretical perspective used to address the research problem. The ecological systems perspective is well suited to the current research as well as social work practice. Included in the framework of ecological theory is the facilitation of goodness of fit between the environment and individual needs which impacts personal development and the ability to function (Germain and Gitterman, 1996). Goodness of fit relates to the social and psychological fit of individuals in their environments and how problematic situations and events contribute to a lack of fit. The person-in-situation focus emphasizes the importance of the social environment in the promotion of optimal personal functioning. Maximizing personal functioning frequently requires adaptation of the environment to meet the needs of individuals attempting to exist within that environment: " People change their physical and social environments and are

changed by them through processes of continuous reciprocal adaptation" (Germain and Gitterman, 1980, p. 5). Theoretically, adaptation occurs when, for example, needs for physical or environmental support are fulfilled through formal networks such as institutions, public health departments, and community-based human service organizations and/or informal networks such as family, friends, and neighbors. The function of social work can be seen as attempting to combine or integrate the formal with the informal in order to improve adaptedness and functioning between the individual and his or her environment.

Ecological systems theory offers a broad framework for supporting the practice of professional social work, focusing on the interactions of people within the environment. However, ecological theory is a broad framework that is difficult to simplify as well as to test, yet it provides the groundwork from which to build a more specific approach to studying people affected by HIV/AIDS.

The stress appraisal perspective (Lazarus and Folkman, 1984) and the stress-adaptation framework (Givens, Collins, and Givens, 1988) provide solid conceptual links to the current study. The foundation of the stress appraisal approach is the belief that a person's cognitive appraisal of a situation or event involves the process of categorizing or evaluating in order to attach meaning and significance to the situation. This framework suggests that "the way a person appraises an encounter strongly influences the coping process and how the person reacts emotionally" (Lazarus and Folkman, 1984). Hence, it offers an appropriate conceptual structure for studying persons' reactions to living with HIV/AIDS disease.

The stress-adaptation framework addresses a model of factors influencing the reactions of caregivers to caregiving. This approach focuses specifically on the cognitive appraisals of persons performing the role of a caregiver. This relates to the current study in the examination of caregiver burden and the perception of social support of caregivers for PLAs.

Psychological stress has been reported as an event that is perceived by a person as burdening or exceeding his or her adaptive resources which may possibly endanger his or her well-being (Lazarus and Folkman, 1984). It is proposed in the current study that PLAs and their caregivers will experience situations or events such as stigma, prejudice, fear, and discrimination, which are stressors unique to these populations that have negative repercussions on personal well-being.

Differences in factors affecting social support and caregiver burden have become of increasing interest and importance in the research literature, especially in studies of physical and mental illness. Variability in response to stressors has been found to be related to many factors, including individual, social, and environmental circumstances. Further research on persons affected by HIV/AIDS will benefit from the inclusion of multiple criteria to study the individual outcomes as a result of this disease epidemic.

Social work research into HIV/AIDS populations is imperative in directing us toward the ultimate goal of social work practice, which is to pursue optimal functioning of persons in problematic areas of life (Day, 1989). Social work as a profession is mandated to promote the general welfare of society (National Association of Social Work [NASW] - Code of Ethics). The AIDS epidemic has presented many challenges to fulfill this

mandate. In fact, studies have found that social work professionals are inconsistent in addressing the problems and needs resulting from HIV/AIDS (Peterson, 1991; Ryan, 1991). Regardless, professional social workers must be responsible for engaging in an active role regarding the social impact and response to HIV/AIDS.

Social work practice includes recognizing the complexity of systems that impact the individual without separating the person from the environment. The ecological perspective in combination with stress appraisal and stress adaptation frameworks are well suited to social work practice and research. This focus emphasizes the importance of the social environment in the promotion of optimal personal functioning and the importance of individual reactions in adapting to stressful events, such as the effects of HIV/AIDS.

Summary

Because the incidence of HIV/AIDS is increasing in all communities, it is imperative that all health and human service professionals have a better understanding of the needs and concerns of these PLAs and their caregivers. The community framework for rural areas can be significantly different than for urban areas. It is vital to understand these differences to better meet the needs of PLAs and their caregivers attempting to adapt in these communities.

This study is a cross-sectional survey of a convenience sample of PLAs and their caregivers living in rural and urban areas. The study examines characteristics of PLAs and their caregivers while measuring differences related to rural and urban living conditions. The next chapter reviews the literature on the background and personal impact of HIV/AIDS, HIV/AIDS-related stigma, caregiver burden, PLA types of need and service

utilization, social support, and the social environment of HIV/AIDS, specifically for rural and urban communities.

CHAPTER 2

LITERATURE REVIEW

Due to the recent upsurge in HIV/AIDS disease transmission in the United States, the majority of research in this area has been conducted in the past ten to fifteen years. Initial identification of the incidence of HIV/AIDS in the United States was made in the early 1980s. Because HIV/AIDS is a relatively new phenomenon, very few empirical studies have explored differences in the impact of HIV/AIDS on social support for people infected and social support and burden for caregivers, especially for those living in small or rural areas compared to those living in urban, metropolitan areas. As a result, it is necessary to include a review of the literature regarding persons affected by other life-threatening or chronic illnesses and their caregivers in addition to the existing research on HIV/AIDS.

Much research regarding social support has focused primarily on persons with chronic or life-threatening illnesses and their caregivers. Important discoveries have focused primarily on the elderly, persons with dementia, or persons with chronic developmental disabilities. The following studies examine factors relevant to the current study and how they impact sample populations with AIDS and populations with similar characteristics and needs, such as those suffering from dementia or chronic life-threatening health problems.

Changes occur rapidly in relation to the affects of HIV/AIDS for persons infected and their support system. Ongoing research is necessary to identify problems and needs for those affected by HIV/AIDS in order to develop or maintain appropriate programs,

resources, and interventions to alleviate or reduce the negative consequences associated with HIV/AIDS.

An important gap in research involves the condition of PLAs and caregivers in communities where past transmission rates have been lower and the social views continue to emphasize stigma and prejudice. This study plans to improve upon the existing literature by identifying factors that will describe differences in HIV/AIDS in rural versus urban communities related to social support, caregiver burden, and the types of needs of persons living with HIV/AIDS.

The following review of the literature describes the relationships among variables proposed in the current study. The review contains a brief background concerning HIV/AIDS, an overview of the role of stigma associated with HIV/AIDS, sections on social support, caregiver burden, types of need and unmet need, and research on the effects of living in a rural or urban residence relevant to the current study.

Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV/AIDS)

The human immunodeficiency virus type 1 (HIV-1) is considered to be the etiologic agent that causes AIDS (Casey, 1995). Because HIV-1 is a retrovirus, it has the ability to reverse the usual flow of genetic information. This characteristic in HIV infection results in the attack and destruction of CD4+ T-lymphocyte cells, which have an invaluable purpose in the operation of the human immune system (Casey, 1995).

The CDC classify persons as being infected with HIV or having AIDS. The current surveillance case definition of AIDS as reported by the CDC includes "all HIV-infected

persons who have < 200 CD4+ T-lymphocytes or a CD4+ T-lymphocyte percentage of total lymphocytes of <14. This case definition also incorporates 26 clinical conditions, such as herpes simplex, Kaposi's sarcoma, wasting syndrome, cervical cancer, and recurrent pneumonia" (Morbidity and Mortality Weekly Report [MMWR], 1992, p. 41).

HIV infection and AIDS include a wide spectrum of disease conditions. Acute HIV infection tends to refer to a somewhat asymptomatic stage of infection. At this stage many people do not exhibit or recognize any notable reactions to infection. Depending upon the condition of the individual, years may go by before recognizable symptoms occur. Symptomatic HIV infection develops when persons identify obvious changes in their physical condition, such as weight loss, severe night sweats, and initial problems cancers and opportunistic infections, such as pneumonia. Occurrence of symptoms usually means that CD4+ T-cell counts have fallen to a range of between 200 and 500. CD4+ T-cell counts for healthy persons normally range between 800 and 1200 (American Red Cross, 1997). When a person's CD4+ T-cell count drops below 200, he or she is classified as having AIDS and usually exhibits frequent problems with opportunistic infections. At this point treatment regimens frequently become ineffective, and infections and/or cancers overburden persons with AIDS, usually culminating in death a short time later.

Multiple factors are thought to take part in determining disease progression in persons infected with HIV. Resistance to drug therapy, personal behavior, individual immune status, strength of the infecting virus strain, race, sex, and age are all thought to play a role in disease progression (Casey, 1995). While some persons may continue to remain healthy

and exhibit intact immune responsiveness, overall survival time with HIV infection has specifically been noted up to 15 years, and long-term survivors are described as persons living more than eight years with HIV infection (Phillips, 1994). In addition, psychosocial influences such as loneliness and stress may contribute to active or dormant HIV activity (Phillips, 1994). Hence, persons infected with HIV face a multitude of issues in terms of coping with and treating their infection. New treatment regimens may continue to elevate longevity and improve quality of life, yet it is still thought that all persons infected with HIV will progress to AIDS and eventually death.

While treatment for HIV/AIDS is improving, no vaccine exists to prevent the spread of this disease. It is currently estimated that nearly one million persons in the United States are infected with HIV and that over 600,000 persons have AIDS (CDC, 1997). The CDC suggest that these findings underestimate the impact of HIV infection on mortality in the United States (MMWR, 1995).

Incidence of the HIV virus was initially found to occur primarily in gay men living in large, urban epicenters. Transmission occurred primarily as a result of sexual behavior and the infectious nature of the disease. Since that time, injecting drug use (sharing used needles) has become a significant behavior linked to the transmission of HIV/AIDS in the United States. Through December 1997, 33 percent of AIDS cases were directly or indirectly associated with injecting drug use (CDC, 1997).

As previously illustrated, the CDC have a specific definition of AIDS for case surveillance and for classifying persons as being infected with HIV or as having AIDS. For the purpose of this investigation, the term HIV/AIDS refers to the entire spectrum of

HIV infection and AIDS disease, and PLA will be used to describe individuals with a positive test for HIV infection, at any stage of the illness.

HIV/AIDS-Related Stigma

HIV/AIDS has reached epidemic proportions. It is a social, environmental, emotional, and physical threat to the world. Despite the fact that HIV/AIDS is an infectious disease that is preventable, it is lethal if contracted.

AIDS has also been called an epidemic of stigma (Herek and Capitano, 1994; Herek and Glunt, 1988). The stigma associated with homosexuality and drug use has tainted the perception of persons infected with HIV as well as their caregivers (Crandall, 1991; Beedham and Wilson-Barnett, 1995). In most communities, persons living with HIV/AIDS are viewed with fear and prejudice. The stigma attached to AIDS "has been used to refer to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, as well as the individuals, groups, and communities with which they are associated" (Herek and Capitano, 1997; Herek and Glunt, 1988). One example of stigma impacting a person infected with HIV/AIDS made national news. "Ryan White was a young male hemophiliac diagnosed with AIDS who was expelled from school and whose family had to sue to have him reinstated" (Wicklund and Jackson, 1992, p. 258). A federal HIV/AIDS support program was named after him as a tribute to his struggle and to bring national recognition to a program funded specifically to address the needs and problems of persons living with HIV/AIDS.

HIV/AIDS, referred to as a modern-day plague, has reconstructed our views regarding life, death, and relationships. The existence of distinct modes of transmission for

HIV/AIDS allows infected persons to be classified as worthy or unworthy of our caring, empathy, and respect, based upon the type of behavior or event that led to infection. In general, gay men, intravenous drug users, and prostitutes have been the primary populations categorized as likely to be infected with and affected by the disease. Unlike other plagues noted throughout history as collective scourges or catastrophes, AIDS has been categorized by some as the 'wrath of God' rightly visiting specific subgroups of our society. Consequently, as the spread of AIDS continues, other members of society are at risk of being infected and affected.

Even as the base of the U.S. population infected with HIV/AIDS expands, there remains the tendency to view infected persons as in some way unworthy and not deserving of our empathy, care and respect. This stance is strengthened in the knowledge that HIV infection is preventable and usually occurs as a result of personal choices regarding individual behaviors (Weiner, Perry, and Magnusson, 1988). Societal views about how HIV/AIDS is transmitted influence the issues facing persons affected by HIV/AIDS.

Stigmatization and fear negatively affect many life opportunities for PLAs, such as employment, housing, and access to medical treatment. Even healthcare providers display behaviors that have impeded the treatment of PLAs due to personal beliefs, values, and fears. For example, a 1990 survey of healthcare workers found that "most of their sample believed that they should have the right to refuse to care for patients with HIV/AIDS" (Currey, Johnson, and Ogden, 1996, p. 189). And a survey of 2,004 physicians conducted in 1991 found at least 50 percent of the respondents, if given the choice, would avoid care of persons with HIV/AIDS (Sowell, 1996, p. 111).

HIV/AIDS invokes a variety of feelings and responses from PLAs and caregivers, including stigma, isolation, fear of infection, fear of abandonment, guilt, and psychological and/or physical fatigue (Bonuck, 1993). Close family and friends can help PLAs and caregivers cope with stressful circumstances by buffering the impact of stigma and offering emotional support, physical assistance, and access to HIV/AIDS information and services.

An early phenomenon in the identification and treatment of HIV/AIDS was the response of the gay community. The gay male population responded through commitment and solidarity regarding caring for their own. Over time, however, the role of the family in providing care and support to PLAs has become more evident and necessary. Growing numbers of PLAs returning to places of origin, i.e., family homes, have placed increased pressure on more communities to respond based upon expanding needs. As communities have been made aware of their families' emerging needs, they have been forced to acknowledge their responsibility for providing the places and personnel to meet them.

Many individuals with HIV/AIDS desire or need to return to their family of origin for care, especially at the terminal stage of illness. Geographical distance may be one barrier to PLAs wishing to return home. Lack of finances necessary to move, failing health, or inadequate HIV/AIDS resources in small communities may influence care received by PLAs and support from family members. In other cases, biological families may withdraw from the PLA, therefore warranting a redefinition of the family. Lack of involvement by the family of origin in the care of the PLA results in situations where persons who are not biological family members are undertaking tasks that family members have typically performed (Bonuck, 1993). If friends and acquaintances also withdraw, the PLA must

rely on formal resources for care and support. This leaves the PLA at risk in communities where HIV/AIDS-specific resources are lacking or nonexistent.

Fear, stigma, contagion, incapacitation, and death all become primary concerns of PLAs and their loved ones. The decision to inform others regarding HIV seropositive (infected) status becomes a grave concern. Fear of others' reactions and guilt over previous high-risk activities impact the disclosure of testing positive for HIV/AIDS. Consequently, social responses to HIV/AIDS provoke difficult and complex questions regarding reactions to this disease. This study will focus on how a stigmatizing condition (HIV/AIDS) leads to differences in social support and types of need for PLAs and social support and burden for caregivers in rural versus urban communities.

Social Support

Previous research has demonstrated the importance of social support in adapting to stressful life events (Cobb, 1976; Cohen, 1988; Cohen and Wills, 1985; Etzion, 1984; Hays, Turner, and Coates, 1992). "Social support can have a direct impact upon psychological symptomatology *and* can mediate the psychological consequences of stressful circumstances" (Thoits, 1985, p. 52).

Social support has been defined and studied in a variety of settings. Cobb (1976) has defined social support as information leading persons to believe they are cared for, loved, esteemed and valued, and belong to a social network of communication and mutual obligation. Specifically, "social support refers to the structure, functioning, or subjective evaluation of interpersonal relationships" (Depner, Wethington, and Dayton 1984, p. 38) (Barrera, Sandler, and Ramsay, 1981; Norbeck, Lindsey, and Carrieri, 1981). Social

support is only support if the individual believes it is available, adequate, and wanted, including beliefs and interactions related to and outcomes of social support (Adelman, 1989; Albrecht and Adelman, 1987; Rook, 1984).

Social support has been used to describe various aspects of social relationships, including "(1) the existence, quantity, and type of interpersonal relationships (network structure or social integration), (2) the functional content of these relationships (emotional, psychological, tangible, or informational support), and (3) the perceived quality or adequacy of this support" (Fiore, Coppel, and Cox, 1986; Green, 1993; Kaplan, 1977). The characteristics of relationships specific to social support include, for example, the number of persons in the support network, residential proximity of persons in the support network, frequency of interaction with these identified persons, and quality/satisfaction of interactions within the existing social network (Berkman, 1984; Shinn, 1984).

In general, social support has been defined as including the perception and/or existence of the following: (1) emotional support, (2) esteem support, (3) instrumental support, (4) informational support, and (5) network support (Fiore, Becker, and Coppel, 1983; House, 1981; Sarason, et al., 1987).

Research describing the impact of social support with regard to HIV/AIDS has been limited, with existing literature tending to reflect the issues surrounding gay or bisexual men in large metropolitan areas (Hart, Fitzpatrick, and McLean, 1990; Namir, Wolcott, Fawzy, and Alumbaugh, 1987). Nonetheless, overall findings regarding social support for PLAs suggest that access to support from various relationships such as parents, friends,

co-workers, and members of the household is essential for the emotional well-being of PLAs (Bechtel and Swartzberg, 1993; Linn, Lewis, Cain, and Kimbrough, 1993; Ostrow, 1989). The quality of these relationships may be of greater importance than the actual number of persons within the social network. Consequently, the belief in the adequacy of supportive relationships is more valuable than the actual conditions of the relationship (Barrera, 1981; Dimatteo and Hays, 1981; Henderson, Byrne, and Duncan-Jones, 1981).

The increasing mobility of families, urbanization, and the loss of community commitment have resulted in PLAs and caregivers searching for additional sources of social support. Replacements are being sought through formal organizations, i.e., AIDS service organizations, public health departments, and informal groups with similar backgrounds or characteristics, such as gay-affiliated support groups, groups for persons with drug addictions, and caregiver support groups.

Social network factors such as amount and type of service availability, personal values and beliefs regarding use of services, and knowledge of available services influence the individual utilization of formal sources of support. Persons providing support and care within the social network of PLAs may affect the PLA's perception, need, and willingness to access formal services (Birkel and Repucci, 1983)

Gaps in knowledge continue to exist regarding social support for PLAs and their caregivers, specifically for those living in rural communities. The literature on social support for other populations is important because of the potential for positive outcomes as a result of enacted support to enhance the quality of life for persons facing the HIV/AIDS epidemic.

Bloom, Fobair, Spiegel, Cox, Varghese, and Hoppe (1991) examined the effect of six measures of social support on the social role functioning and psychological well-being of long-term survivors of Hodgkin's disease. A sample of 403 individuals participated in the study. These individuals were being treated either for early- or advanced-stage cancer. Independent variables in the study included several different measures of social support.

The results of this study supported the authors' belief that social support is multidimensional, i.e., "the type of support provided effects outcomes differentially" (Bloom et al. 1991, p. 112). These findings suggest that a relationship exists between social support and psychological well-being.

A study conducted by Dunkel-Schetter (1984) investigated social support and cancer. The sample for this study included 79 cancer patients (68 were women). The purpose of the study was to examine social networks, perceived support, satisfaction with support, and problems in relationships for the sample population. Qualitative and quantitative methods of data collection were employed in the study.

Findings from the study indicated that medical care providers were meaningful sources of support for persons with cancer. The results suggested that healthcare providers who offered informational and emotional support were seen as helpful and that the patients wanted family and friends for emotional support and not for advice or information (p. 89). That being so, it seems who is providing what kind of support is an essential component in facilitating coping with stress for persons diagnosed with cancer.

The study conducted by Patterson, Shaw, Semple, Cherner, McCutchan, Atkinson, Grant, and Nannis (1996) examined the effects of depressed mood, negative life events,

social support, and coping on the rate of HIV/AIDS disease progression on a group of men from a large urban area, San Diego, CA. Several standardized measures were used in the study: the Hamilton Rating Scale for Depression, the Psychiatric Epidemiology Research Interview, the Social Support Questionnaire, and The Ways of Coping Questionnaire-Revised.

Results of their study on 414 gay and heterosexual men suggest that depressive symptoms and social support were important predictors of both symptom onset and time until death. This study offers preliminary support for the previously mentioned predictors, yet the authors stated other symptoms such as diet, lack of sleep, and behavioral differences may have had a confounding effect on depression in predicting symptom onset and time until death. Nevertheless, the findings do suggest that further study into the impact of these and other psychosocial variables on persons with HIV/AIDS disease is warranted.

Persson, Hanson, Moestrup, and Ostergren (1994) conducted a study in Sweden to determine whether relationships exist between social networks, social support and the CD4+ count in HIV positive gay and bisexual men. Persons diagnosed with AIDS were not included in the study. Data were collected using a structured questionnaire from 47 participants at one point in time. In this study, the individual's social network referred to his or her social ties. Social support referred to the individual's interaction within his or her social network.

The most significant finding from the study was in reference to social participation. Low social participation and low satisfaction/adequacy of social participation scores were

found to be associated with a low CD4+ count. Results of the study reinforce findings from previous research suggesting that social support affects physical well-being, especially in persons with serious or chronic illnesses. The study also reinforces the idea that quality and quantity of support within the network may be significant factors in determining the positive or negative impact of the social network.

Hays, Turner, and Coates (1992) studied social support, health status, and depression in persons living with HIV/AIDS. The study emphasized the affect of social support and HIV-related conditions for a sample of gay men.

In this work, data were collected from 508 single, gay men aged 25-54, then collected again one year later. The study was conducted as a part of the San Francisco Men's Health Study. Multistage probability sampling was used in census tracts in San Francisco identified with the highest incidences of AIDS in 1984 (Hays et al., 1992). Individuals included in the sample were interviewed face-to-face and given a physical examination with follow-up exams at six-month intervals, as well as a self-administered questionnaire.

The critical finding regarding social support was that "greater satisfaction with social support received was associated with less current depression and less increase in depression one year later" (Hays et al., 1992, p. 467). Each type of support accounted for a significant percentage of variance in depression.

The persons sampled in this study may be unlike other AIDS-affected populations. This sample was composed of primarily white, middle-class, college-educated, gay-identified men in San Francisco. The impact of social support in this population may not

be applicable to other populations affected by AIDS, such as women, injecting drug users, other socioeconomic groups, and persons residing in smaller or rural communities.

The levels of knowledge regarding HIV/AIDS and related resources and support should be higher for persons living in or near San Francisco due to early incidence of the disease in this metropolitan area. In addition, there has been a commitment by persons within the San Francisco area to address the needs of those infected. It is not certain what significance HIV/AIDS information and availability of AIDS-specific resources and services have on caring for persons living with AIDS and their caregivers.

Linn, Lewis, Cain, and Kimbrough (1993) examined how social support and perceived coherence affected the psychosocial well-being among persons with HIV illness in a study of 132 HIV-infected adults. The researchers asserted that self-esteem and anxiety in persons with HIV will impact their "level of perceived coherence, i.e., the extent to which individuals derive meaning and purpose in their lives." (Linn et al., 1993, p. 255).

Linn and colleagues enrolled study participants from the following HIV care and referral centers: Nashville Cares in Nashville, TN, the Louisville Health Trust in Louisville, KY, and AID to End AIDS in Memphis, TN. This study used a non-random convenience sample thought to be representative of the predominantly white, well-educated, HIV-infected gay male population in the cities included in the study. As a result of this sampling technique, persons less seriously ill were underrepresented due to their ability to seek help outside their home, hospital, etc. Respondents were categorized as being HIV positive, having AIDS-related complex (ARC), or having full-blown AIDS.

Three instruments were used for data collection in the study; each were Likert type scales measuring self-esteem, anxiety, and coherence. Results of the study reinforced the researchers' expectation that higher levels of social support may result in improved psychosocial adjustment of adults to HIV illness and that higher levels of coherence may result in higher levels of self-esteem and lower levels of anxiety. As has been found through other investigations, the stage of HIV illness was not a predictor of psychosocial well-being among the sample surveyed. Causal attributions are not applicable in this study, and the sampling technique and the cross-sectional design limit the expansion of cause and effect.

Zich and Temoshok were pioneer investigators in the study of social support and HIV illness. Beginning in 1984, they conducted their study early in the disease epidemic. The researchers examined social support in terms of emotionally sustaining and problem-solving types of help. They hypothesized that "social support would be positively associated with measures of hardiness and negatively related to self-report measures of physical and psychological distress" (Zich and Temoshok, 1987, p. 195). The measure of hardiness in this study represented a "measure of psychological strength, coping resources, and adaptive capacities" (Zich and Temoshok, 1987, p. 198).

Consumers of healthcare services from two medical clinics comprised the sequential sample for the study. The measures employed to collect data in this study were implemented within two to eight weeks after a report of an HIV positive diagnosis. A structured interview was used to collect information regarding physical symptoms, and a self-report questionnaire packet included measures of social support, mood states,

hardiness, anxiety, and hopelessness. A total of 103 persons agreed to participate in the investigation, 50 diagnosed with full-blown AIDS and 53 diagnosed with AIDS-related complex.

A significant demographic difference between the AIDS and ARC groups was found in employment status. Only 25 percent of participants with ARC responded as being unemployed, while 67 percent of the AIDS sample reported being unemployed. The authors postulated this was due to the more serious physical symptoms that usually plague persons with AIDS compared to those with ARC. Yet no significant difference in income level existed between the two groups.

Through correlation analysis it was found that "for both persons with AIDS and with ARC, the more available social support was perceived to be, the less hopelessness and depression were reported" (Zich and Temoshok, 1987, p. 206). Unfortunately, correlational analyses do not allow for the prediction of causality. Sample selection strategies and the use of cross-sectional design measures are also study limitations that prohibit the determination of causality. Additional limitations of the study include the period of time of the data collection and the limitation of the sample to the city of San Francisco.

Because this study was conducted in an earlier period of the HIV/AIDS epidemic, it does not address the breadth of treatment innovation, information, resources, services, and support that have exploded since this earlier period. Nor does the study address issues of HIV-infected populations outside the gay community and the increasing stigma associated

with HIV/AIDS. These findings do illustrate that perceived social support is significantly related to distress levels in persons with AIDS and ARC (Zich and Temoshok, 1987).

Baker and Seager (1991) directed an investigation comparing the psychosocial needs of hospice patients with AIDS to those with other diagnoses. They also assessed the amount of social support each group received from family members, church congregation members, and neighbors (Baker and Seager, 1991). An additional aspect of the study included a survey of hospice staff members and differences between working with AIDS and non-AIDS patients. Data were collected from patient charts for individuals who had died between 1985 and 1990. The sample consisted of 11 persons whose death was related to AIDS and 36 persons whose death was non-AIDS related.

An important finding of the study refers to the number of contacts between the hospice psychosocial staff and patients with AIDS. "AIDS patients required contact over two and one half times as often by telephone and over twice as often in person as other hospice patients" (Baker and Seager, 1991, p. 64). Significant differences also existed in the amount of community support received. AIDS patients apparently lacked neighbor support, leaving them with significantly less social support than hospice patients with other diagnoses, possibly explaining the significant increase in hospice staff contacts required by the AIDS patients.

Perhaps the finding of this investigation most significant to the current study is the observation that 73 percent of the AIDS patients "had returned to the community expressly to be with family in the last months of their lives" (Baker and Seager, 1991, p. 68). This point strengthens the perception that some families are willing and able to care

for their loved one with AIDS. It does not propose an explanation for how this decision impacts the PLA or caregiver emotionally, socially, or physically. Nor does this factor describe the environmental or community issues that arise when PLAs return to small communities unprepared and unwilling to accept them. As a result, returning home to be with family may increase social isolation since a significant geographical distance may exist between PLAs, friends, and/or partners.

These studies illustrate the significance of studying the impact of social support for persons living with AIDS and their caregivers. Social support may lessen problems with anxiety, depression, coping, and relationships. On the other hand, the lengthy, chronic, and debilitating disease trajectory resulting from HIV infection may exhaust support resources over time. The complex issues of stigma and prejudice regarding HIV/AIDS also may result in negative consequences involving support resources. The positive or negative effects of social support may depend upon the environment, as well as the person(s) providing the support (formal or informal resources), quantity, quality, structure, and availability of support.

Studies of social support have increased over the past 20 years, especially in relation to illness and aging. Studies of social support for PLAs has generally been limited to populations in large metropolitan areas with greater prevalence and incidence for HIV and AIDS. Consequently, limited research exists describing social support in small and rural communities and/or areas with lower rates for HIV/AIDS. The continued growth of HIV/AIDS validates the need for additional studies in populations that were previously

thought to be less affected by this epidemic and were consequently not targeted in previous research.

Caregiver Burden

Caregiver burden has been characterized by the multiple chronic and often severe stressors associated with caregiving. Caregiver burden has been defined as the physical, psychological or emotional, social, and financial problems that can be experienced by persons caring for someone who is physically or mentally impaired (George and Gwyther, 1986; Pratt, Schmell, Wright, and Cleland, 1985; Zarit, 1990). Caregiver burden has also been linked with the objective and subjective experiences of caregiving for the caregiver. Thompson and Doll (1982) proposed that “objective burden reflects disruptions in finances, role, family life, supervision, and neighbor relations, whereas subjective burden refers to feeling embarrassed overloaded, trapped, resentful, and excluded” (p. 380).

Research findings suggest that caregivers experience chronic and severe stressors associated with the caregiving role. These stressors may involve physical demands of providing care, such as bathing and lifting the care recipient; financial demands, including medical care and respite care costs; as well as emotional strain resulting from observing the physical and cognitive decline, and frequently the eventual death of a loved one.

Family caregivers have sometimes been referred to as the “hidden victims” of caregiving—those who suffer by being caregivers (Fengler, and Goodrich, 1979; Takigiku, Brubaker, and Hennon, 1993). Caregivers of PLAs have a lengthy involvement with a loved one whose heightened social and physical support needs may continue for many years, resulting in the increasing and extended need for relief and support. Persons

significant in the lives of PLAs have been described as “hidden grievers” due to the anticipatory feelings of loved ones toward the impending death of persons diagnosed with HIV/AIDS and the associated fear and stigma surrounding this disease (Murphy and Perry, 1988).

There has been a growing interest in the effects of HIV/AIDS on families, caregivers, partners, and others significant to persons living with AIDS. Limited research exists to clarify whether there are specific problems, issues, needs, or concerns of such persons affected by HIV/AIDS. It is speculated that HIV/AIDS has deleterious effects on those persons with significant relationships to PLAs. Past research from other populations with chronic and terminal diseases has demonstrated that caregiving can be generally viewed, at the least, as a stressful task. In fact, Cantor (1983) found in her groundbreaking research that emotional strain was the most significant problem affecting caregivers and that the closer the bond between patient and caregiver, the more stressful the caregiving role (p. 603). More recent research supports the previous finding and suggests there is “variability in how successfully individuals accommodate and adjust to caregiving responsibilities” (Braithwaite, 1996, p. 139).

Variability in response to caregiving has been found to be related to many factors, including individual, social, and environmental circumstances. The fact that HIV affects social networks beyond the ‘nuclear family’ (traditionally, two parents and children living in the same household) has meant researchers have had to re-examine definitions of families (Bor, Miller, and Goldman, 1993).

Further research on caregivers will benefit from the inclusion of multiple factors for studying the outcomes of the caregiving role in HIV/AIDS-affected populations. Ongoing research has resulted in contradictory findings regarding patient-caregiver bond and stress, burden, and coping. Therefore, it remains vital to engage in research investigating factors significant to the relationships of informal caregivers to persons who are ill.

Liebermann and Fisher (1995) investigated the impact of dementia on the physical and mental health of all family members caring for an ill parent or spouse. The study sample included spouses, adult children, and spouses of adult children. A total of 97 patients and spouses, 186 adult children, and 97 spouses of adult children participated in the study.

These researchers contended that the severity of the dementia will have a negative effect on family members' health and well-being. Data collection efforts included the use of measures to identify severity of illness, gender, caregiving hours, services, and health and well-being. Measurement instruments included questionnaires, checklists, rating scales, mental status exams, etc. Results of the study indicated that the severity of the patients' illness was associated with measures of physical health in the families of persons who suffer from chronic, dementia-type illness. The findings suggest that chronic, debilitating illnesses may have negative health consequences for caregivers, which may include more than just the primary caregiver (Lieberman and Fisher, 1995, p. 102).

A study by Clair, Fitzpatrick, and La Gory (1995) examined primary caregivers of elderly persons to assess the role of social support and psychological resources in reducing the negative impact that life stressors have on caregiver burden and depressive symptomatology.

These investigators used a psychosocial resources approach to understanding stress in caregivers. They proposed that acute stressors in the lives of caregivers may be significantly related to caregiver depression in response to the psychosocial resources available to cope with the acute event.

A sample of 110 caregivers were chosen to participate from a group of caregivers identified through two VA Medical Center geriatric primary care clinics. Significant findings support the premise that caregiver burden is a result of chronic stressors and that caregiver depression appears to be a result of acute stressors (p. 208). Understanding the impact of chronic and acute stressors for caregivers is necessary for planning programs and services appropriate for intervention and support of caregiver needs.

Gilbar (1994) produced a study comparing the perceptions of elderly cancer patients and their spouses regarding the burden of caregiving. The study was conducted in Israel with a small sample size of 32 patients and spouses. In this study caregivers reported more burden than was reported by the patients and patients identified their needs and problems as less burdensome to the caregivers than the caregivers themselves reported. While sample size and other limitations prevent generalizing results to other populations, it is important to note the potential for conflicting perceptions between samples of caregivers and patients regarding needs, problems, stress, and support.

Clipp and George (1993) found an interesting component of these different perceptions of caregiver burden. Their study assessing caregivers of spouses with dementia or cancer found that younger spouses reported lower levels of well-being than did older spouses.

The authors speculate that this finding could be related to competing responsibilities, such as raising children and/or increased financial debt. This finding is significant in regard to caregivers of PLAs since they are primarily identified as friends, partners, and siblings who are young and have competing responsibilities similar to the younger caregivers identified in the Clipp and George study.

A recent study by Turner and Catania (1997) sought to describe and compare characteristics and caregiving experiences of persons caring for PLAs and burden experienced in the caregiving role. The definition of burden proposed by the investigators for this study was the caregiver's subjective experience of problems or strains directly linked to the caregiving role. Their study was conducted as a result of a larger project, the National AIDS Behavior Study (NABS). The authors collected information from 18 to 49-year-old participants from the Random Digit Dial central city sample of the larger survey. Data were from 260 men and women and included sociodemographics, HIV status, caregiving relationship, perceived vulnerability, caregiving demands, prior caregiving, caregiver burden, caregiving support, and the occurrence of informal caregiving.

The primary finding in the study suggests that caregiver burden varies with the characteristics of the caregiver and his or her relationship to the PLA. Specifically, the investigators found that greater burden was experienced by caregivers who: 1) were male; 2) reported lower incomes; and 3) were unaware of their own HIV status. The authors also found that social support for AIDS caregivers was effective in buffering the impact of objective demands on perceived burden.

An investigation by Folkman, Chesney, and Christopher-Richards (1994) identified differences among AIDS caregivers versus traditional caregivers. Caregivers for persons with AIDS were found to conform to a distinct profile: they were primarily male; young and middle-aged; at risk for contracting HIV/AIDS; had decreased familial support; and frequently had stigmatized relationships. The investigators found that many of the men caring for a person living with AIDS are infected with HIV/AIDS themselves. They also found that persons with HIV who were also caregivers exhibited significantly more depressive symptoms than infected persons who were not caregivers.

A study performed by Pakenham, Dadds, and Terry (1995) investigated caregiver burden and caregiver adjustment to HIV-infection. Variables of interest in this study included demographics, relationship characteristics, disease stage, health status, and caregiver coping. These researchers contended that caregivers of symptomatic persons with HIV would have increased burden and poorer adjustment than caregivers of asymptomatic persons with HIV; problem-focused coping would enhance adjustment and lower burden; and patients would be less adjusted to HIV than caregivers.

The study was conducted in Australia with a sample size of 34 caregivers and 30 persons with HIV infection. The sample was recruited via advertising within the gay community. All HIV-infected persons were male and identified themselves as gay. The caregiver study sample consisted of 14 family members, 7 friends and 13 partners. Measurement instruments included various checklists, surveys, and health status indices to identify information regarding sample demographics, patient HIV testing and health history, and aspects of the caregiving role. As a result of the data analysis, the most

outstanding finding is related to patient and caregiver coping. Correlational analysis supported the finding that "both patient and caregiver cope well together or have many problems together" (Pakenham et al., 1995, p. 198).

Due to the cross-sectional design of the study, causal relationships cannot be established. However, results from this study support previous research which found correlations of distress and adjustment in populations of patients with chronic illnesses, as well as their caregivers.

An unexpected finding related to caregivers is the lack of significance that illness stage played on caregiver adjustment or burden. This suggests the possibility that the psychological issues facing caregivers of persons with HIV may be more burdensome or distressing than the physical or practical issues of caring for PLAs. Fear, stigma, and prejudice surrounding this disease may create more difficulties for caregivers than practical care issues. This is plausible since caring for PLAs seems to place physical requirements on caregivers that are not unlike other chronic or disabling illnesses. These findings also support Linn et al. (1993) in reporting that stage of illness may not be a predictor of psychological well-being.

It is still unknown how these issues will be impacted through the discovery and use of improved treatment regimens that may increase longevity. The support systems of PLAs and caregivers may become overwhelmed as a result of more lengthy involvement and long-term effects of this chronic, life-threatening disease and its social stigma.

The AIDS Care Study was conducted in the San Francisco Bay area and part of Los Angeles County in California (Wardlaw, 1994). The purpose of the study was to identify

informal caregivers for people with AIDS and issues surrounding the caregiving role. The AIDS Care Study enrolled persons who were primary caregivers for a person living with AIDS. The study participants were recruited from various sites, including service agencies and medical sites, through advertisements, etc. The high incidence of people living with AIDS in San Francisco is not consistent with other metropolitan areas or smaller urban and rural communities.

Type of caregiver was divided into two categories for purposes of this study. One hundred-seventy caregivers were identified as traditional, meaning blood relative, usually a parent; 472 non-traditional caregivers were also included in the study, identified as being primarily gay males caring for male partners or friends.

Wardlaw found several significant differences between the two caregiver groups. Traditional caregivers tended to be older and predominantly female. Almost half of the non-traditional caregivers reported having provided care in the past for at least one person with AIDS, while only 11 percent of the traditional caregivers reported this occurrence.

The information collected in this study came from face-to-face interviews with caregivers. Data were collected regarding stress and coping, type of informal care provided, use of formal services, and sociodemographic variables. Specific measurement instruments or data analysis techniques were not delineated. Research findings suggest caregivers of persons living with AIDS have many issues facing them, including cost of care, resource needs, employment, relocation, and severity of illness, to name a few. Wardlaw found that "75 % of study participants stated they think of the impending death of the person living with AIDS frequently" (Wardlaw, 1994, p. 378). This study presents

initial information regarding the influence AIDS has on the lives of informal caregivers, but does not explain the significance of these influences or how these factors work together.

Turner, Catania, and Gagnon (1994) administered a study to identify the prevalence of informal AIDS caregiving in the United States, including the social and demographic characteristics of caregivers and the types of caregiving tasks caregivers typically perform. These investigators used a different sampling technique than has been used in most of the reported AIDS research. A national Random Digit Dial (RDD) sample and a central city RDD sample were generated. Approximately 70 percent of the national sample contacted and 65 percent of the central city sample agreed to participate in the study. Total sample numbers equaled 10,630 participants, 2,673 from the national sample, and 8,263 from the central city sample.

Study results indicated that 15 percent of the national sample and 23.5 percent of the central city sample participants know or have known someone with AIDS (Turner et al., 1994). "Of the respondents who indicated having known someone with AIDS, 24.4 percent of those in the central city sample and 20.2 percent of those in the national sample have provided care for or assisted a friend, lover, or relative with AIDS" (Turner, et al., 1994, p. 1546).

Significant results of the study by Turner et al. include the age of caregivers and the types of caregiving tasks performed. Both samples contained a majority of caregivers under 40 years of age. Caregivers for other chronic illnesses tend to be older spouses. Caregiving tasks were found to be labor intensive, involving such activities as cooking and

housekeeping and personal tasks such as bathing and dressing the PLA. These are activities similar to those performed for persons with other types of chronic illnesses.

Caregivers of PLAs face a number of challenges in fulfilling the caregiver role. The physical and psychological consequences of caregiving responsibilities are the most obvious factors involved. In addition, competing responsibilities such as employment, caring for children, establishing and maintaining relationships, and/or caring for elderly relatives may also face persons most likely to provide care for PLAs.

Previous studies have found that caregivers for persons with chronic illnesses tend to be older spouses or adult daughters. Persons living with AIDS, however, may rely upon friends, siblings, partners, or elderly parents for their care. In addition, caregivers of PLAs may fluctuate, especially in situations where sickness and disability are lengthy or when caregiving partners or friends are also HIV infected.

A compounding issue related to caregiver burden in response to HIV/AIDS is the stigma and prejudice identified with the disease and affected persons. PLAs may be at risk for possible repercussions associated with judgmental attitudes when receiving care from family members. Similarly, isolation from friends may occur if changing residences is necessary when PLAs become unable to continue living on their own. One purpose of the current study is to compare caregivers of PLAs level of perceived social support and burden for caregivers living in rural versus urban areas.

Types of Need and Service Utilization

The delivery of health and social services is influenced by multiple factors. Public need and equitable resources become an issue when specific groups of vulnerable persons are

found to fall significantly behind others in health status and access to healthcare-related services (Monroe, Ricketts, and Savitz, 1992). Understanding patterns of service utilization and perceived need for services for persons with HIV/AIDS is essential because of the nature of the disease and the complex factors involved with care and treatment. "Access to health-related services can decrease pain and suffering, delay the progression of illness, sustain higher levels of functioning and increase quality of life for PLAs" (Bonuck, 1994, p. 6).

The use of services by PLAs is impacted by the needs of the individual, availability of services, and the acceptance of service delivery mechanisms. Understanding characteristics of PLAs in communities outside the large epicenters of this disease allows planning for service delivery specific to the needs of individuals within these communities. Access to services in small and rural areas is especially significant for PLAs due to their specialized healthcare needs, social stigma, and discrimination associated with HIV/AIDS.

The current study proposes that psychological and cultural factors influence the perception of need for services, as well as use of services for PLAs, and that these will be impacted by rural and urban residential differences. This section of the literature review describes past studies that have attempted to measure service utilization and need patterns. The first three studies reviewed are based upon the Anderson and Newman Model for describing healthcare utilization. This model "asserts that individuals with different demographic characteristics have different types and amounts of illness, resulting in different patterns of health services usage" (Havir, 1995, p. 84). The Anderson and Newman Model prescribes three primary characteristics believed to influence health

services utilization: predisposing (demographic, social structure, and beliefs); enabling (family and community); and need (illness level) characteristics. While this model has been predominant in the literature, additional studies have approached service utilization research with a different focus for studying the relationships involved in utilization of health and social services.

Havir (1995) examined the relationship between rural-urban residence and the use of social services by an older population. The data used in this study were gathered "as part of a nine-county needs assessment telephone survey of the age 60 and older population living in east Central Minnesota" (Havir, 1995, p. 189).

In this study the reluctance to use services had a significant relationship to service utilization across most of the counties sampled in both rural and urban areas.

Interestingly, greater availability of services did not explain variation in service use. Thus, persons living in counties with increased service availability did not necessarily access these services more frequently than persons residing in counties with fewer service options. One possible explanation for this lack of variation could be the previously identified reluctance to use services by some members of the sample population.

Study limitations resulted in mixed findings related to the hypotheses, and the overall model of service utilization explained only 21 percent of the variation in number of services used. In conclusion, Havir suggests that additional measures of disabilities and chronic illnesses may be useful for future research (1995, p. 193). Informal support systems were not investigated in this study, and the relationship of families and caregivers to service utilization is left unexplained. The study findings provide support for the

proposition that social support and caregiver characteristics are important variables for examination in how they relate to populations at risk, such as the HIV/AIDS population and other populations suffering from chronic or life-threatening illnesses.

West, Delisle, Simard, and Drouin (1996) examined the use of health and social services in the patterns of leisure activities in an elderly population. Their study found that the subjects' marital status was significant to use of services. Persons in the sample who were not married were more likely to use formal social service programs for support. This finding supports the relevancy of close relationships on perceived need for social support and willingness to use formal services.

This study also supports findings from previous investigations that have found relationships between social isolation or social support and the use of health-related services. Their study did provide general support for the Anderson and Newman Model as explaining part of the variation in use of services.

A study completed by King (1980) focused on determining differential social service use by the elderly in the Commonwealth of Pennsylvania. She followed the Anderson and Newman framework for describing service utilization. Factors examined included age, gender, race, physical mobility, and other demographic variables in relationship to use of services. King found that regardless of race, the most commonly requested services were those she identified as less "ego-threatening" (King, 1980). This finding implies that service use in this population may be related more to the acceptance of the service rather than service need.

The study conducted by King offered partial support for the Anderson and Newman Model, yet the results were inconsistent. An important limitation to the study was that the study population included only users of services. Persons who had not accessed at least one service were not sampled, hence comparisons cannot be made to non-users. The author suggests recommendations for future research, which include measures of psychological, physiological, and social characteristics to identify needs and service use in sample populations.

Guadagnoli, Rice, and Mor (1991) conducted an investigation that followed a less frequently identified model for predicting use of services. They based their study on the transtheoretical model of behavioral change. They put forth this model as having the potential for “motivating patients to use formal resources to meet their daily living needs” (Guadagnoli et al., 1991, p. 3). Their study examined the knowledge of and willingness to use agency-based services in a sample of cancer patients, a population with similar issues to PLAs, including a life-threatening prognosis and complex treatment patterns.

Results from the study found that almost half of the 412 patients sampled had no knowledge regarding available services. Of that sample, 19 percent expressed the need for more help with activities such as meal preparation, homemaker services, shopping, and transportation. Ten percent of the sample expressed a need for additional help with tasks such as financial and legal counseling, paperwork, or treatment-related information; yet, over half of the sample did not know the services existed. Results also indicated that lack of such knowledge was a primary barrier in some instances, while unwillingness to use services was significant for others.

The aim of the investigation conducted by Mawby, Clark, Kalucy, and Andrews (1996) was to estimate the use of formal services by an aged population and to identify variables associated with formal service use. This study was conducted as a part of the Australian Longitudinal Study of Ageing. The purpose of the study was to determine whether specific sociodemographic indicators would be associated with formal service use in this population. Several factors were related to the use of formal community services: increased age, living alone, limited assets, and increased health and functional problems. The variables included in the study are similar to those prescribed in the Anderson and Newman Model.

The investigators used measures in the study for collecting primarily objective information. The single subjective measure in the study was a personal rating of self-health status. Access to services and availability of services were apparent in these communities, therefore results cannot be generalized to communities that may experience problems in these areas. This study also reflects differences existing in other countries where health and social services are valued and allocated differently than in the United States.

A study by Charles, Sellick, Montesanto, and Mohide (1996) also exposes differences related to countries outside the United States. The researchers studied priorities of cancer survivors in Ontario, Canada. In their sample of 270 cancer survivors, the authors found that "the level of unmet need was consistent across geographic demography" (Charles et al., 1996, p. 71). No significant differences were found based on residential area. Data collected in the study included variables measuring information needs, disease/treatment

problems, travel/distance, psychosocial support, finances, relationships, and medical care, as well as sociodemographic variables.

Several factors may relate to the lack of differences across regions. Availability of services was not clearly defined and measured. Rural Canada may have different issues than do rural areas in the United States. Insurance and healthcare coverage differences were not explained. The majority of the sample population were living with a partner and had also expressed their own health as good to excellent. Persons who rated their health as fair to poor were not well represented in the study nor were persons identified as living alone or without a partner.

Scant research has been conducted on service utilization by PLAs. As with most studies regarding PLAs, service utilization research has focused primarily on the large, urban epicenters with the greatest rate of HIV infection, transmission, and prevalence of AIDS cases. The following studies are representative of the research on service utilization and unmet need for PLAs.

Bonuck's (1994) study of the unmet health service needs of persons with HIV and AIDS adapted the Anderson and Newman Model to propose a model of Unmet Need appropriate to the HIV/AIDS population. In this study, Bonuck predicted that unmet needs of the HIV/AIDS population would be explained through sample characteristics such as gender, race, and functional status and through environmental characteristics such as provider availability, travel, and living arrangements. This study was conducted as part of a larger national research project. The data were from ten cities throughout the United

States, eight of which were identified as having a high prevalence of AIDS cases and two with a lower prevalence of AIDS cases.

Persons sampled were already identified as service users; as a result, no comparison could be made to non-users of services. Respondents were reimbursed for participation, and the overall study was longitudinal in nature with a private research firm directing the larger project which utilized trained, professional interviewers to collect the data.

Although study findings suggest themes found in similar research, the results differed in the different cities included in the study. Yet, findings did show a generally higher level of unmet need in areas with a lower prevalence of people living with AIDS.

An unusual and significant finding was the report from one city that had a managed care method for providing services for persons under Medicaid. This city registered the highest level of unmet need out of the entire sample. This finding is important to PLAs since most receive healthcare coverage from the Medicaid system across the United States.

Bonuck's study does not include measures of psychosocial variables that may influence health and social service use. As in the previous studies, how these variables relate to service use and unmet need is still unknown.

Marx, Katz, Park, and Gurley (1997) conducted a needs assessment to evaluate the success of the Ryan White CARE Act in meeting HIV-related service needs. The Ryan White CARE Act is a federal act providing funding for services to PLAs in communities considered to have a high prevalence of AIDS cases and limited financial support for needs specific to PLAs.

Marx et al. (1997) sampled clients for this needs assessment who were accessing services in the cities of San Francisco and Los Angeles, CA. Surveys were self-administered and anonymous. The population of 1,056 participants were predominantly males in their 30's identified as gay or bisexual. Primary factors identified as related to unmet needs included not trying to get services; being put on a waiting list; unavailability of services; not knowing where to go for services; and being too sick to get services.

Bias in this study is similar to that mentioned in the previous literature, i.e., persons selected as participants in this study were already seeking and accessing some type of service while non-users were not part of the sample utilized in this study. Perceived need for services was measured in this study, yet variables related to social support and caregiver involvement were not included. In fact, no data were collected regarding significant relationships for PLAs in this study.

The purpose of the study completed by Wight and Aneshensel (1995) was to identify factors related to the use and non-use of emotional and practical support by persons with AIDS and their informal caregivers. Data collected in this study were from the informal caregivers of PLAs living in the greater Los Angeles and the San Francisco Bay area. The investigation was cross-sectional in nature and included questions about service use by the PLA and the caregiver, as well as questions regarding stress, coping, and health. The interviews were conducted in the homes of the caregivers and they were reimbursed for their efforts.

Key barriers to service utilization were found to be unwillingness to use services and lack of access to services. The health status of the PLA was found to have little

relationship to actual service use, i.e., identified need for service was not followed by use of service. As supported in previous research, when the caregiver who lived in the home of the PLA was a partner, fewer needs were identified for emotional and practical support services.

Perhaps the most significant finding for this study was the high rate of reported unmet need. The study was conducted in cities with a high prevalence rate for AIDS, yet this did not ensure that needs for this population were met. This effect is expected to be magnified in geographic areas with a lower prevalence of AIDS since services specific to PLAs rarely exist outside of the disease epicenters. A limitation to this study involves the characteristics of the caregivers and PLAs. Parents or other family members were not identified as being caregivers for any of the PLAs in this population. In addition, the majority of the PLAs in the study were white, gay males from a large metropolitan area, which limits the extension of these findings to other groups of PLAs, including heterosexuals, females, minorities, injecting drug users, and those infected persons living in less urban communities. As a result, this finding is not expected to represent the population of PLAs and caregivers across the United States.

Identified needs and service utilization for PLAs are important to quality of life as well as longevity for this population. The previously mentioned studies have revealed numerous factors that have impacted access to formal services and availability and use of these services.

Surprisingly, availability of and access to services were not found to predict increased use or knowledge of services. However, caregiver status was found to influence use of

services. Additionally, attitudes toward and willingness to use services were also found to be linked to service use.

PLAs have health and social service needs throughout the continuum of the disease. Identifying factors related to service use and PLA need fulfillment are essential to understanding current and future health and social service concerns facing these individuals and their caregivers, especially regarding differences in populations from diverse backgrounds.

Rural and Urban Residence

Much has been learned about HIV/AIDS in the large metropolitan areas of the United States, including San Francisco, Los Angeles, Miami, and New York City. Yet rarely has the impact of HIV/AIDS been followed in smaller communities where the disease incidence may seem minor in comparison. Although reports suggest that "approximately 20 percent of AIDS cases in the United States have been located in rural areas" (Wisner, 1992, p. 71) and the AIDS rate of growth in rural areas rose 80 percent between 1991 and 1995, while only 47 percent in large urban areas, and 64 percent in small urban areas (American Medical News [AMN], 1996). One recent study found that most cases of AIDS in rural communities can be traced to gay men returning home to their family of origin, usually at the end stage of illness to be cared for until their death (AIDS/STD News Report, 1996, p. 11).

Characteristics specific to rural communities impact the treatment of PLAs and their caregivers. These include, but are not limited to, the tendency toward lower socioeconomic levels of living, increases in substandard housing, lack of personnel

available to care for PLAs, and limited access to healthcare (Aday, 1985; Holt, 1990; Kenkel, 1986). As a result of these limitations, rural residents may have to travel a greater distance to receive health-related services. Persons with HIV/AIDS are especially at risk due to limited rural resources regarding medical treatment and other health and social services.

Research has found that persons living in rural areas generally have more conservative values, place a high importance on religion, are less tolerant of diversity, and expect others to adhere to these community standards (Wisner, 1992). As a result of their characteristics and beliefs, many rural Americans are inclined to seek health services (formal support) less frequently than their urban counterparts and tend to rely more on family and neighbors (informal support) (Sowell et al., 1996, p. 109; Fisher, 1982). Rural Americans may also have a greater fear of being stigmatized due to the conservative values and frequent suspicion of formal mental health and social service providers (Kenkel, 1986).

Social relations in rural areas tend to be less formal and more intimate, inhibiting the privacy needs of PLAs and prohibiting formal help-seeking behavior due to fear of ostracism, stigma, and loss of confidentiality. As a result, PLAs and their families living in rural communities are at a higher risk of experiencing prejudice and discrimination than are those in large metropolitan areas. This difference results in special concerns regarding access to health and social services in rural areas.

Various methodological concerns arise surrounding the investigations of rural-urban differences. Definitions of rural-urban may differ according to the use of the terms. Such

differences in use may include public policy issues; service delivery and access; research studies and investigations; and local, state, or national concerns. Criteria which seem to improve the guidance used to classify rural-urban areas consist of the following typologies: population size and density; proximity to and relationship with urban areas; degree of urbanization; and principal economic activity (Hewitt, 1989). The following studies use a variety of defining criteria in comparing rural-urban differences.

Strickland and Strickland (1996) conducted a study to examine barriers to preventive health services for lower-income black households in rural communities. The methodological approach was a combined use of household, community leader, and focus group interviews. The study was performed in five rural communities in Georgia. The authors proposed that the existence of structural and nonstructural barriers resulted in a lack of use of preventive health services. Structural barriers identified pertained to tangible resources such as adequacy and availability of services, ability to pay, transportation, etc. Nonstructural barriers pertained to cognitive, attitudinal, and behavioral processes such as dissemination of information, awareness of programs, treatment of the individual, and need for services. The authors stated that “. . . identifying the complex of structural and nonstructural barriers that deter special populations from receiving services and addressing these barriers at the community, programmatic, and individual levels is essential to enhancing the use of services” (1996, p. 216).

Cohn, Klein, Mohr, van der Horst, and Weber (1994) sought to describe the migration patterns of patients infected with HIV seeking health services in North Carolina. They found that more than half of the 340 study participants were currently living in rural

communities (population < 50,000). Many of the participants reported receiving their initial HIV diagnosis prior to moving to North Carolina. Popular reasons given by participants for migrating to North Carolina included social support, health reasons, and better work or educational opportunities. These findings suggest that while rural areas are less likely to have formal support available to meet the health and community service needs of PLAs, PLAs are more likely to have access to informal sources of support, especially from family.

Bozovich, Cianelli, Johnson, Wagner, Chrash, and Mallory (1992) surveyed specific resources in a rural community to identify services that might benefit PLAs. The primary objective of the survey was to identify professionals in the rural community willing to provide services to PLAs. Questionnaires were mailed to local physicians, dentists, and funeral directors. The return rate from all three groups was less than 50 percent. Fifty-six percent of participating physicians were either unwilling to treat PLAs or undecided. Only 1 of 13 dentists sent questionnaires responded with a willingness to treat PLAs. Ten dentists did not respond to the questionnaire. Three of seven funeral directors responded to the questionnaire and reported a willingness to provide services to PLAs.

The implications of the study conducted by Bozovich et al. are extremely limited. The study does appear to support the idea that fear and prejudice toward PLAs may be influencing the behaviors of healthcare professionals as well as other providers of formal services. It also highlights the issue of stigma toward HIV/AIDS within the rural community in general. Reasons for non-participation in the study are not explained and may be significant to understand for planning future HIV/AIDS research in rural areas.

A qualitative study of AIDS in rural areas was conducted to examine the development and provision of services to PLAs and their families and barriers to the delivery of care (Rounds, 1988). The study took place in a southeastern state with a 48 percent rural population. Fifteen persons were interviewed for the study. These individuals were responsible for coordinating or delivering services to persons with AIDS and their families (Rounds, 1988). The total sample included social workers, nurses, health educators, administrators, and volunteers. Interview questions focused on geographic isolation, social networks, religion, stigma, and support systems.

Several themes emerged from these interviews. First, distance to healthcare services was found to hinder healthcare provision to PLAs in rural areas. A second theme was confidentiality and fear of disclosure of HIV status. A number of study respondents described incidents that involved breach of confidentiality (Rounds, 1988). Fear of AIDS contagion and homophobia were also found to be significant themes in the interviews. Some hospices and home care agencies reportedly would not accept referrals for PLAs. In addition, several respondents "identified incidents in which homophobia clearly interfered with persons with AIDS receiving support" (Rounds, 1988, p. 259). In fact, professionals willing to risk treating PLAs in this study were themselves found to be at risk for ostracism and stigma.

The study by Rounds was conducted early in the AIDS epidemic, especially for rural populations. The study has several limitations, including sample size, sampling technique, and lack of clarity in interview techniques. The study does not allow for generalizations to be made regarding other rural communities, nor does it discuss the characteristics of study

participants and community demographics. Rounds offers a general idea of what may be facing the health and well-being of PLAs and families in rural areas. The author suggests that further research is necessary to identify the significance of support and services in relation to PLAs and their families in rural communities.

Results of studies related to the social and psychological effects of living in small and rural communities suggest the existence of conservative beliefs and attitudes of persons living within these communities. Residents of small and rural communities tend to rely on informal sources of support and care such as extended family members, neighbors, and church affiliation. As a result of characteristics specific to rural communities, informal sources of support are likely to be more available and accessible than formal sources of support. It appears that rural PLAs may be more at risk for unmet needs (low levels of formal support) with potentially higher levels of informal social support. Rural caregivers may have fewer formal service needs than PLAs and as a result may have better adaptation to rural environments.

Findings are inconsistent concerning the effect of living in rural versus urban areas on levels of social support for PLAs and similar populations. While rural areas tend to be identified as having a reputation for being friendly and ready to help those in need, this readiness may only apply to those residents viewed as similar to most residing in rural communities (Kenkel, 1986). Individuals identified as exhibiting deviant behaviors, such as homosexuality and injecting drug use may not be considered similar, thus not deserving of help and support (Smith, Landau, and Bahr, 1990).

Other research has suggested it is not the size of the place that is important to an individual's attachment to a community, but rather the length of residence in a place that makes a difference (O'Brien, Hassinger, and Denshem, 1996; Haines, Hulbert, and Beggs, 1996). Community attachment may also be a factor in migration patterns of PLAs. PLAs returning to their hometown to live may have a stronger attachment to that community, in which case they may expect to have greater access to and levels of social support.

PLAs may be at risk for isolation, stigmatization, and discrimination while residing in these communities due to conservative values and judgments regarding HIV/AIDS infection. This may be especially true for persons moving back to these communities to be cared for by family members after being absent for many years, as they become unable to continue caring for themselves and no other alternatives are available to them. The impact of caring for a PLA in rural areas is unknown. Since rural areas tend to focus less on use of services in general, caregivers of PLAs may actually have better access and a greater willingness to use sources of informal support than caregivers in urban areas, due to the traditional belief that caring for a family member is expected and possibly less likely to be perceived as a burden.

The impact of HIV/AIDS in small and rural communities is generally still unknown. Large urban areas have a higher incidence of HIV/AIDS infection, a more immediate response to needs through formalized services and support, and a lower incidence of stigma and discrimination. These resources may not be available, accessible, or appropriate to those HIV/AIDS populations in smaller and rural communities. It is vital to understand what needs and gaps exist in these communities and where and how to

address these issues when necessary. Further research will assist in better understanding the impact of this disease epidemic in smaller and rural communities, including the reactions of persons affected and infected.

Statement of the Research Problem

Persons living with HIV/AIDS and their caregivers have a heightened need for physical and psychosocial support and service in response to the impact of this disease on their lives. The main purpose of the current study was to examine differences between people living with AIDS and their caregivers living in rural versus urban areas regarding social support, PLA identified need, and caregiver burden.

The questions to be examined in this analysis are:

- 1) What are the characteristics of PLAs and caregivers living in rural and urban areas?
- 2) Do differences exist in social support for PLAs and caregivers living in rural versus urban areas?
- 3) Do differences exist in caregiver burden for caregivers living in rural versus urban areas?
- 4) What are the types of needs of PLAs living in rural versus urban areas, and do they differ based upon area of residence?

CHAPTER 3

METHODOLOGY

This chapter describes the research design, sampling and data collection procedures, variables and measurement, procedures for protecting human subjects, and limitations. The chapter concludes with the research hypotheses and the data analysis procedures used for hypothesis testing.

Research Design

The research design is a cross-sectional survey of a convenience sample of PLAs and their caregivers living in rural and urban areas. PLAs and caregivers supplied data on the impact of HIV/AIDS on their lives. Study participants completed one in-person structured interview. Results of the study are based on data collected from 83 PLAs and 25 caregivers who volunteered for the research study. Figure 1 represents the geographic location of the PLA and caregiver study participants. Figure 2 displays the distance to the AIDS service organization from the counties included in the study.

Sampling and Data Collection Procedures

Obtaining the Sample

The sample of PLAs was selected from among the clients of an AIDS service organization (ASO) serving a sixteen-county area in East Tennessee. Four criteria were used for selection into the sample: (1) age 18 or older; (2) ability to speak and read English; (3) physical and cognitive ability to complete the research interview; and (4) inclusion of name on the confidential mailing list of the ASO (by client's permission). All clients meeting these criteria were eligible for participation in the study. The final sample

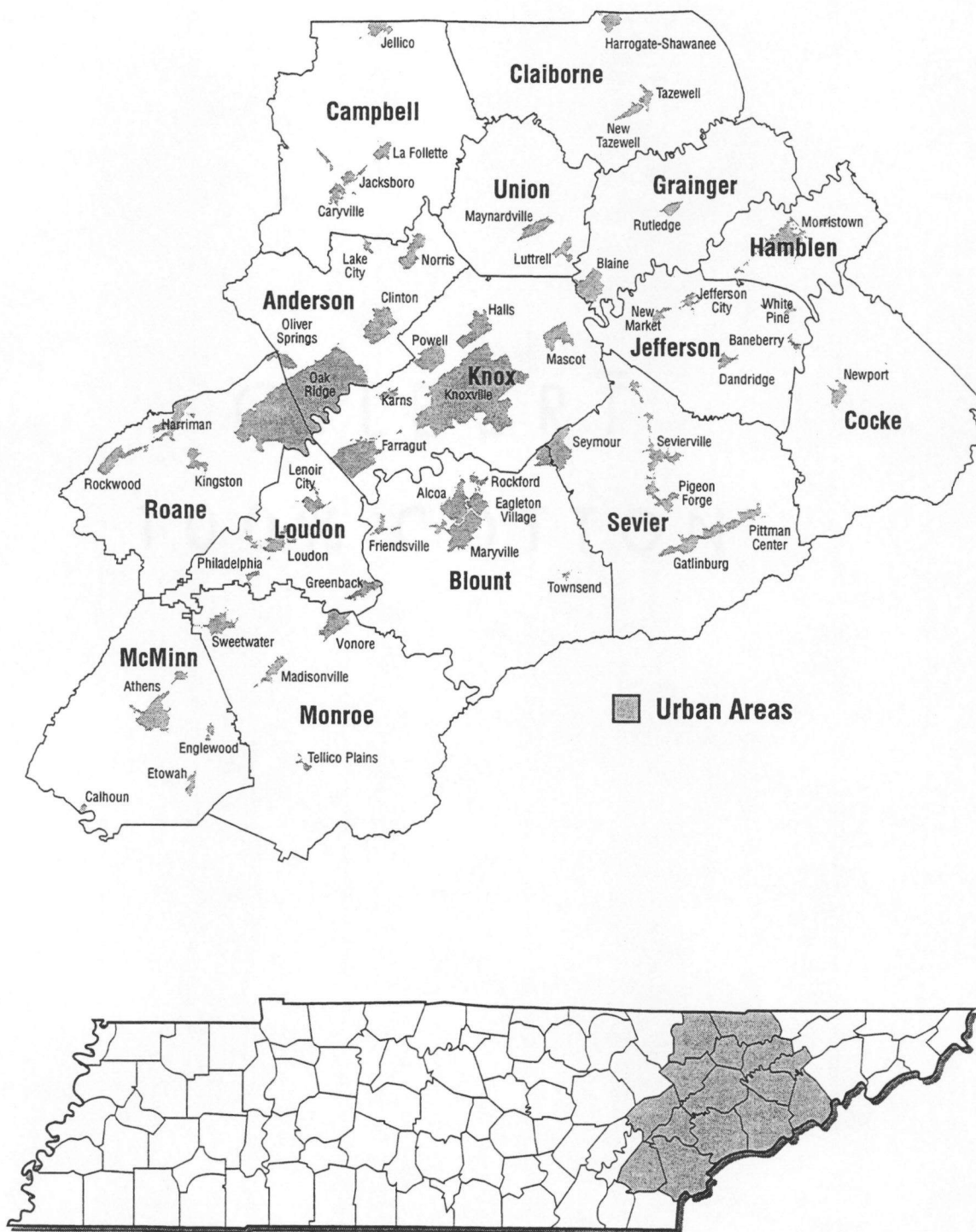


Figure 1. Geographic Location of Study Participants: Rural and Urban Areas

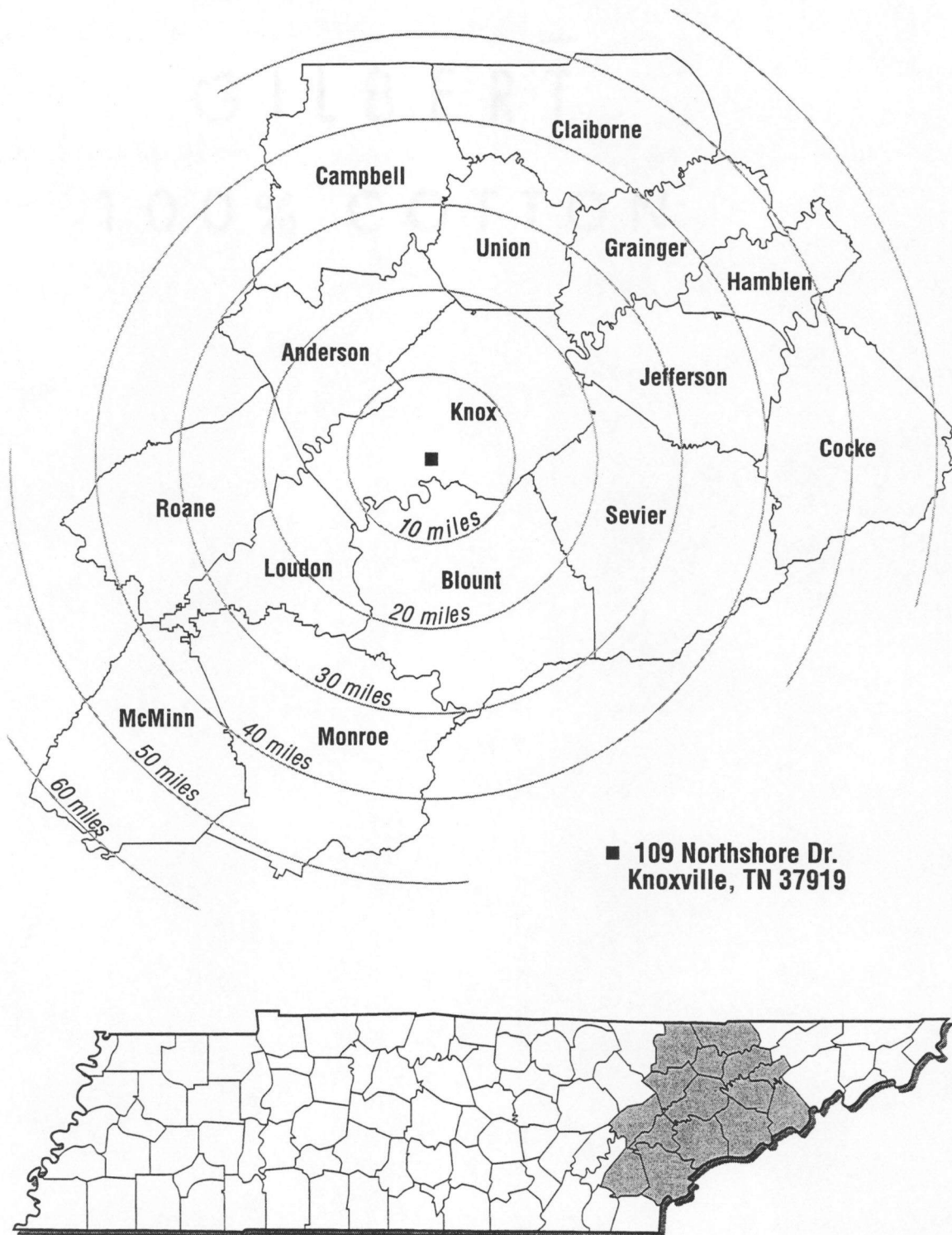


Figure 2. Location of AIDS Service Organization for Study Region (AIDS Response Knoxville)

consisted of the clients/PLAs meeting these criteria who were successfully contacted and agreed to participate in the study.

The caregiver sample consisted of primary caregivers identified by PLA study participants. The researcher asked each PLA to identify his or her primary caregiver (if any) and to give permission to contact the caregiver. The researcher attempted to contact each caregiver so identified. The final sample consisted of the caregivers who were successfully contacted and agreed to participate in the study.

The sample of potential PLA study participants consisted of 220 clients identified by the AIDS service organization case management staff as meeting criteria for study participation. The researcher found that after the initial invitation for study participation was sent through the mail, a group of 31 PLAs/clients were inaccessible for the following reasons: 30 had incorrect addresses or no forwarding address, and one chose not to participate.

From the remaining 189 possible PLA study participants, 93 responded to the initial study invitation for participation. A sample of 51 urban PLAs and 32 rural PLAs completed the PLA study interview. Ten PLAs did not participate in the study due to the following: eight could not be contacted after their initial response, one moved and left no forwarding address, and one changed his mind. No response was received from the 96 additional PLAs in the potential study sample.

Forty-three PLA study participants reported having a primary caregiver. Twenty-eight PLA study participants gave the researcher permission to contact their caregivers. A sample of 16 urban caregivers and 9 rural caregivers completed the caregiver study

interview. Eighteen caregivers did not participate in the study for the following reasons: 15 PLAs did not give permission to the researcher to contact their caregivers and three caregivers contacted by the researcher chose not to participate. The remaining sample of PLAs (n = 40) reported having no primary caregiver at this time.

Data Collection

The researcher obtained permission and cooperation to recruit PLA participants from AIDS Response Knoxville (ARK), using their client population. ARK is the only AIDS service organization (ASO) serving the entire 16-county area included in the study. The ASO case management staff administered the selection criteria to enter PLAs for potential study participation through their assessment of clients. Data collection began in November 1997 and ended in April 1998.

Each PLA had the opportunity to identify whether or not he or she had a primary caregiver. PLAs who did not identify a caregiver or whose caregiver did not participate in the study continued to be included in the PLA study sample. No caregivers were contacted without permission from the PLA. The next section describes the data collection procedure for the PLA group and the caregiver group, respectively.

PLA Group

The ASO mailed study information to clients who were potential study participants (Appendix 1). A "Call for Participation" was also posted in a public area at the ASO. The ASO gave the researcher a list of clients who volunteered for study participation. This client list included only the following information: name, address, gender, and telephone number. The researcher attempted to contact only clients/PLAs on this list.

The researcher mailed a study packet to PLAs who agreed to participate in the research study (Appendix 2). The researcher requested that the participant return one signed copy of the informed consent statement in the mail and to expect a telephone call from the researcher or a trained interviewer. Potential subjects were informed in the introductory mailing and follow-up contact that they would be given a \$15.00 cash gift for study participation.

The researcher or interviewer contacted the PLA upon receiving the signed informed consent statement and an appointment was scheduled to conduct a face-to-face structured interview at a time and location convenient to the PLA to protect confidentiality. Completion of the research interview required approximately 30-45 minutes of the participant's time.

During the study interview the researcher/trained interviewer asked PLAs to identify the person they defined as their primary caregiver. The PLA was asked for permission to contact this person for study participation. If the PLA gave permission to contact the caregiver, the PLA was asked to provide the name of the caregiver, relationship to the PLA, telephone number, address, and whether or not the caregiver has been informed of PLA diagnosis.

The \$15.00 cash gift was given to the PLA immediately after the completion of the structured interview. No personally identifying information was included on the survey.

Caregiver Group

The researcher sent caregivers initial notification of the study through the mail or delivered it in person during the PLA interview with permission from the PLA for those

caregivers residing with the PLA (Appendix 3). In the introductory letter or initial contact, the researcher/interviewer explained that the caregiver had been identified as being the primary caregiver by (PLA Name _____) and asked the caregiver to sign one copy of the informed consent statement if he or she was willing to participate in the study.

The researcher/interviewer contacted the caregiver upon receipt of the signed informed consent statement and an appointment was scheduled to conduct an in-person structured interview at a time and location convenient to the caregiver to protect confidentiality. Potential subjects were informed during the introductory mailing and follow-up contact that they would be given a \$15.00 cash gift for study participation.

Completion of the research interview required approximately 30-45 minutes of the participant's time. The \$15.00 cash gift was given to caregivers immediately after the completion of the structured interview. No personally identifying information is included on the survey.

Variables and Measures

This section describes how the variables in this study were measured. Measures used in both PLA and caregiver survey instruments are identified. The survey instrument for the PLA sample is displayed in Appendix 4 and the survey for the caregiver sample can be found in Appendix 5.

The research instruments are: (1) Multidimensional Scale of Perceived Social Support (MSPSS) and the Network Orientation Scale (NOS) for the PLA and caregiver groups, (2) the Caregiver Burden Interview (CBI) for the caregiver group, (3) a Needs

Assessment for the PLA sample, and (4) a separate demographic data form for both the PLA and caregiver groups. The three standardized instruments chosen for this study (MSPSS, NOS, CBI) have been used successfully in previous research with documented reliability and validity. The combined use of all measures provided a balance between relatively little effort to complete while generating a high degree of information on clinically relevant variables. The format of the instruments is reviewed in the following section.

Social Support

For the purposes of this study, social support is defined as an individual's perception of social support (Zimet, Dahlem, and Zimet, 1988), his or her unwillingness to maintain, nurture, or utilize those supports (Vaux et al., 1994), and the network of spouse or significant other, family, friends, and formal services providing these supports (Carlson and Robertson, 1994). This definition implies that individuals perceive social support from each of these sources and that a negative social network orientation would reflect beliefs that it would be useless, inadvisable, or dangerous to draw on these supportive resources (Vaux et al., 1994). Dimensions of social support were measured by two instruments: the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1988) and the Network Orientation Scale (NOS) (Vaux et al., 1986).

The 12 items in the MSPSS provide a measure of perceived social support from three sources: family, friends, and a significant other. The MSPSS assesses the extent to which respondents perceive social support from each of those sources. The differences in

perceived social support from these three sources has been confirmed (Cecil, Stanley, Carrion, and Swann, 1995, p. 600).

Scoring for the MSPSS is based upon a seven-point Likert-type scale with 1 = very strongly disagree and 7 = very strongly agree. The minimum possible total mean score is 1 and the maximum possible total mean score is 7. Higher mean scores reflect higher perceived levels of social support.

Research (Zimet, Powell, Farley, Werkman, and Berkoff, 1990; Dahlem, Zimet, and Walker, 1991; Zimet et al., 1988; Kazarian and McCabe, 1991; and Cecil et al., 1995) demonstrates satisfactory reliability for the MSPSS. Cronbach's alpha calculated in these studies ranged from .84 to .94 for the MSPSS total score. In this study Cronbach's alpha scores for the PLA group are .86 for the overall scale and Cronbach's alpha scores for the caregiver group are .81 for the overall scale. Permission to use the MSPSS was obtained from Gregory D. Zimet, its developer.

The NOS is a 20-item instrument used to measure a person's propensity to use his or her social support network (network orientation) in a time of need. The items in the NOS are based on social support theory and measure the individual's unwillingness to maintain, nurture, or utilize those supports he or she has (Vaux et al., 1994). It has been asserted that socially disadvantaged and oppressed persons are less willing to use the informal resources available given the extent to which negative or harmful societal and personal conditions may have influenced their effectiveness (Pretorius, 1993; Stokes, 1983).

The NOS is a four-point Likert-type scale that involves reverse scoring of some of the items, 1 = strongly agree and 4 = strongly disagree. All items are summed for a total

score; 20 is the minimum total score and 80 is the maximum total score. Higher total scores are indicative of a more negative social-network orientation, and a lower total score indicates a more positive social-network orientation (Tata and Leong, 1994).

The NOS has been found to have reasonable internal consistency for the total scale ($\alpha = .75$) (Pretorius, 1993) and ($\alpha = .74$) (Tata and Leong, 1994). In this study Cronbach's alpha for the PLA group is .77 and for the caregiver group is .39. Permission to use the NOS was obtained from Alan Vaux, its developer.

Caregiver Burden

In the current study, caregiver burden is defined as the subjective and objective stresses experienced by caregivers of persons living with HIV/AIDS, including personal strain and role strain (Vitaliano, Young, and Russo, 1991; Zarit, 1990). The study focuses on the consequences of caregiving on the caregiver (Reinhard, Gubman, Horwitz, and Minsky, 1994).

In this study the Caregiver Burden Interview (CBI) was used to measure burden for caregivers of PLAs (Zarit, 1990). The CBI is a 22-item instrument developed by Zarit and Zarit (1990) and designed as a composite measure, combining different aspects or dimensions of caregivers' reactions to their involvement with elderly or disabled persons. The CBI focuses on the consequences of caregiving associated with functional/behavioral impairments and the home care situation (Vitaliano et al., 1991, p. 69).

Scoring the CBI is based upon a five-item Likert-type scale, 0 = never and 4 = nearly always. Responses for the last item differ from the previous 21 items. The last item responses include: 0 = not at all, 1 = a little, 2 = moderately, 3 = quite a bit, and 4 =

extremely. The caregiver burden score is the sum of all responses across the 22 items; higher scores indicate greater caregiving distress, ranging from 0 (low burden) to 88 (high burden).

The CBI has been found to have high internal consistency ($\alpha = .91$) and test-retest reliability ($\alpha = .71$) (Gallagher, Rappaport, Benedict, Lovett, and Silven, 1985).

Internal reliability for the CBI has been estimated with Chronbach's alpha at .88 (Hassinger, 1985) and .91 (Gallagher et al., 1985). In this study Cronbach's alpha for the CBI is .84 for the total scale. Permission to use the CBI in this study was obtained from Stephen Zarit, its developer.

Types of Need

For the purposes of this study, the researcher developed a needs assessment instrument to collect appropriate and relevant information unique to the formal service needs of PLAs. The needs assessment was used to identify PLA types of need and satisfaction with services accessed to meet these needs. Assessing community and health service need and unmet need has become an important aspect of identifying gaps in these services for disadvantaged populations (Piette et al., 1993, p. 11; McGuire et al., 1996, p. 218; Witol et al., 1996, p. 176).

Types of need have been defined as factors associated with self-perceived met and unmet health, social, and emotional needs among persons living with HIV/AIDS and other disadvantaged populations (Bonuck, Arno, Green, Fleishman, Bennett, Fahs, and Maffeo, 1996; Piette, Fleishman, Stein, Mor, and Mayer, 1993; McGuire, Gerber, and Clemen-Stone, 1996; Witol, Sander, and Kreutzer, 1996). Unmet need may be a result of many

factors, including: lack of availability, lack of knowledge of services, inadequate transportation, unwillingness to use services, and fear of discrimination.

The survey needs assessment measured PLA self-reported types of met and unmet need and satisfaction with met need. Respondents were presented with a list of community and health services. For each service, the respondent indicated whether he or she needed the service in the previous six months. Those who reported a need were asked if they had received services. Respondents who either did not receive a needed service or were dissatisfied with a service received were classified as having an unmet need.

Type of need is a dichotomous variable indicating whether one of nine listed service needs was identified. Self-reported unmet need is a dichotomous variable indicating whether any unmet service need was reported. Satisfaction with service for met need was assessed by a four-point Likert-type scale. Scores of 1 (very dissatisfied) and 2 (somewhat dissatisfied) were considered inadequately met needs; scores of 3 (somewhat satisfied) and 4 (very satisfied) were considered adequately met needs.

Demographics

The researcher developed a demographic data form for the PLA and caregiver groups in order to collect appropriate and relevant information unique to these populations. The demographic data form for the PLA group is a 35-item instrument and the caregiver data form is a 22-item instrument because not all items pertained to both groups.

The following variables were used to describe the sample of PLAs: age, gender, relationship status, education, race, employment status, religion, income, relationship to caregiver, living situation, location of residence, residential history, HIV information, and

current physical condition. Also, PLAs were asked to provide descriptive information about persons with whom they have contact (quality and quantity of social interaction), residential proximity to family and friends, as well as activities performed by an identified primary caregiver.

Variables used to describe caregivers include: age, gender, relationship status, education, race, employment status, religion, income, relationship to PLA, living situation, location of residence, and self-reported health status. Caregivers were also asked to provide descriptive information about persons with whom they have contact, length of time in caregiver role, average number of hours per day spent on caregiving, caregiving activities, and average number of days per week spent on caregiving.

Procedures for Protection of Human Subjects

This study was reviewed and approved by the institutional review boards of the College of Social Work at the University of Tennessee, Knoxville and the Office of Research Administration at the University of Tennessee, Knoxville.

One of the most pressing concerns related to this study is the confidentiality of each PLA and caregiver who chose to participate. Every attempt has been made to protect the confidentiality of the participants.

Potential Risks and Safeguards for Confidentiality

The primary risk to the participants was breach of confidentiality, particularly of being identified as having HIV/AIDS or as being a caregiver for someone who has HIV/AIDS. Strict procedures were followed to minimize these risks. The master list of participant information, written informed consent statements, and ID numbers were kept by the

researcher in a locked cabinet. Only the researcher had access to this information. All materials were held in the strictest confidence and remained in locked files. All identifying information of the study participants was stored in a locked cabinet separate from the survey instruments. Only the researcher had keys to the separate locked cabinets. The risk for breach of confidentiality through the survey instruments was unlikely since the instruments were stored separately from identifying information of study participants.

The researcher and three trained interviewers signed a statement of complete confidentiality (Appendix 6) of the study data. All interviewers were trained by the researcher to ensure uniformity and accuracy. All training was done in person. Individual follow-up meetings and telephone contacts were conducted as needed. Since the interview was a structured survey and no open-ended questions were included, problems with individual interpretation of responses were minimized.

The researcher reviewed the instruments as the surveys were completed to ensure completion and consistency by all interviewers. Interviewers did not have access to the master list of study participant names, and completed surveys and study participant information were returned to the researcher daily.

The researcher was the sole data entry person for the study, which prevented breach of confidentiality at that level. Data for analysis did not include any personal identifiers. The informed consent statements will be maintained for the length of time required by the institutional review board at the University of Tennessee, Knoxville and then destroyed. (At completion of the study, all completed participant surveys were destroyed.)

Procedures for Minimizing Risk

Above all, the PLA survey instruments were non-threatening and did not solicit sensitive information not already required of the PLA to be a client of the AIDS service organization. There was no forced participation, and most participants were likely to have had similar experiences in relation to working with a case manager or in healthcare-related environments. Caregiver survey instruments were non-threatening and did not solicit sensitive information.

In general, PLA study participants were open and sharing about themselves during the interview. In fact, most of the interviews took place at the PLA's home. The primary information that PLAs seemed to protect was in reference to their caregiver. Not all PLAs felt comfortable providing the researcher with information necessary to contact their caregivers.

Caregiver study participants were very cooperative and also somewhat more careful regarding participation than PLAs. Caregivers seemed protective of the PLA for whom they were providing care.

None of the PLA or caregiver participants complained about discomfort or expressed a desire to stop the interview, and all participant interviews were complete. All participants had the researcher's telephone number and address for follow-up questions or assistance. The researcher received no follow-up contact by any participants for problems related to study participation. Caregivers and PLAs both seemed interested in the idea of furthering research on and the understanding of HIV/AIDS.

Procedures for Obtaining Consent

Participation in the study was voluntary. The researcher mailed a packet to PLAs and caregivers including two copies of the informed consent statement for study participation (Appendices 2 and 3). The letters requested that participants return one signed copy of the informed consent statement and to expect a telephone call from the researcher or trained interviewer if a telephone was available. Each participant signed an appropriate informed consent statement and mailed it to the researcher or presented it to the researcher in person, whichever was more convenient for the study participant. The informed consent statement for all participants and the documents mailed to caregivers did not include information regarding HIV/AIDS, in order to protect participants. This procedure prevented possible exposure of this sensitive issue.

Potential Benefits

There were no direct benefits for individual study participants, other than the opportunity for PLAs and caregivers to discuss their needs in a safe, confidential manner without fear of personal repercussions or losses. Respondents received \$15.00 cash as a small gift for allowing the time necessary to participate in the study.

Study findings may offer a significant contribution to knowledge in the field of social work and HIV/AIDS research. Little is known about the HIV/AIDS population in rural communities, especially in the Southeast. Small towns and rural communities tend to have less social diversity and may have greater levels of stigma, prejudice, and discrimination. Therefore, it is critical to identify the unique problems and needs of PLAs and caregivers in rural communities in order to develop appropriate programs and services. As stated

above, there were no foreseeable risks except breach of confidentiality. The procedures described in the previous section were followed to ensure strict confidentiality: thus the study's benefits offset this risk.

Limitations

This study has certain limitations, including those associated with pilot testing, sampling, and the temporal considerations of a cross-sectional study. The study design included a combination of survey measures drawn from various other surveys, as well as standardized measurement instruments.

The cross-sectional design of the study does not allow for changes over time for individual study participants as they may have changing experiences regarding HIV/AIDS physically and emotionally. The study did allow the researcher to investigate individuals at different stages of illness, hence the data were enhanced regarding the impact of HIV/AIDS from early- to late-stage disease.

The study was not piloted, due to budget and time constraints; consequently, it was not possible to determine the applicability of the survey prior to conducting the research project. Nonetheless, most items are drawn from reliable and valid surveys and measurement scales. The advisability of applying items from different population surveys and instruments to PLAs and their caregivers is unknown and the lack of a pilot test for the instrument(s) is a methodology limitation.

There is a sampling limitation in that the study enrolled PLAs from one AIDS service organization, and only those PLAs who are included on their confidential mailing list. PLAs who are not clients of this organization did not have the opportunity to participate

in the study. Accordingly, it is biased toward persons already seeking services and support, specifically from an organization focused on HIV/AIDS services. Persons experiencing difficulty or obstacles that prevent them from accessing HIV/AIDS services were less likely to be included in the sample, as well as persons who do not currently have a need for HIV/AIDS services. In addition, persons not included on the ASO mailing list may have had characteristics that differed from the study population.

Caregiver sampling is also a limitation. In order to gain access to caregivers, initial permission to contact the caregiver was granted by the PLA study participant and no caregivers could be accessed unless the PLA was a study participant who was willing to involve his or her caregiver in the study.

Data Analysis

The data were analyzed using SPSS-X PC version 7.5. Descriptive statistics were used to summarize data collected from the PLA and caregiver demographic data forms. Means, frequency distributions, and percentages were used to describe the PLA and caregiver samples. The demographic information gathered is used as descriptive data to enrich the understanding of PLAs and caregiver relationships through their social network, patterns of social interaction, quality and satisfaction of relationships, residential characteristics, and additional group attributes.

PLA Social Support

To examine whether or not rural and urban residential differences exist in PLA social support, the following hypothesis will be tested:

Hypothesis 1: Rural PLAs report less social support than urban PLAs.

Part of the first aim of the study was to analyze the relationship between PLA levels of social support and personal and environmental variables. Multiple regression techniques were employed to predict the value of the criterion variables from the values of the predictor variables.

While it is recommended that variables used for multiple regression analysis should be measured on an interval or ratio scale, for this study all predictor variables inserted into the regression equation were nominal level. As a result, a set of dummy variables was created for each predictor variable. Only the criterion variables were measured on an interval scale.

A correlation matrix was calculated to display the relationship among model variables. For testing the first hypothesis, a simultaneous multiple regression analysis was used to determine how much variation in the criterion variable is explained by the combination of predictor variables.

Through these statistical procedures the first research hypothesis was tested. From the results of the research it is possible to find the variables which affect social support for PLAs. The results of this study may be used to enhance the adjustment of persons with HIV infection, to identify areas possibly in need of intervention by helping professionals working with persons who are HIV infected, and to generally improve the understanding of the impact of HIV/AIDS on affected populations.

PLA Types of Need

In addition to the examination of social support for PLAs, an exploratory needs assessment was conducted to determine whether residential differences exist in PLA types

of need, met and unmet need, and satisfaction with met need. The literature does not hypothesize differences in formal service needs for PLAs living in rural compared to urban areas, thus this is an exploratory investigation. A needs assessment examining nine formal service needs was used to identify differences for PLAs living in rural versus urban areas.

Descriptive statistics were utilized to describe differences in need for PLAs living in rural versus urban areas. Through this preliminary analysis, it becomes possible to identify individual and environmental characteristics that may influence the types of PLA need and whether or not they are met. Therefore, this information can be used as a guide for future research to determine possible predictors of PLA need and unmet need, for professional guidance for practitioners working with persons with HIV/AIDS, and for persons conducting research on the impact of HIV/AIDS on infected persons.

Caregiver Social Support and Caregiver Burden

To examine whether or not rural and urban residential differences exist in caregiver social support and caregiver burden, the following hypotheses will be tested:

Hypothesis 2: Rural caregivers report more social support than urban caregivers.

Hypothesis 3: Rural caregivers report less burden than urban caregivers.

Due to the small caregiver sample size, independent-samples *t* tests were used to test the second and third hypotheses to evaluate the difference between means of rural and urban caregivers on two measures of social support and one measure of caregiver burden. From the results of this research, it becomes possible to discover whether differences in social support and burden exist for rural versus urban caregivers. Therefore, the study can be used to help explain the effect of HIV/AIDS on caregivers for PLAs. Study results

also offer the opportunity for social work practitioners to become aware of geographic and community characteristics that may impact the adjustment to caring for a PLA and for PLAs themselves.

CHAPTER 4

PERSONS LIVING WITH HIV/AIDS RESULTS

This study was designed to investigate the differences in social support for people living with HIV/AIDS (PLAs); to explore types of met and unmet need among PLAs; and to investigate differences in levels of social support and caregiver burden for PLAs and their caregivers in rural versus urban areas. This chapter reports the study findings for the PLA sample. Chapter 5 reports the study findings for the caregiver sample.

The results chapter for PLAs is divided into three sections. The first section provides a description of the PLA study sample. The second section reviews the results of the multiple regression equations to analyze predictors of PLA social support. The third section is an exploratory analysis of PLA types of need.

PLA Sample Characteristics

The PLA sample consisted of eighty-three persons living in rural ($n = 32$, 38.6%) and urban ($n = 51$, 61.4%) areas. Table 1 reports the gender, race, and age distribution of the PLA group. The distribution of the sample by race and gender was different for urban and rural areas. Slightly over 15 percent of PLA study participants were female and over 90 percent of the females lived in urban areas. Less than 15 percent of the entire sample was African American and they resided primarily in urban areas. The age of PLAs ranged from 21 to 58 years old, with a mean age of 36.4. Over half of the PLAs in both rural and urban areas were in the 29 to 38 year old age group.

The religious background of most PLAs was Protestant. Over half of the urban PLAs, and almost three-fourths of the rural PLAs are Protestant (Table 1). Slightly over one-

Table 1**Demographic Description of PLAs**

Variable	Group					
	(N = 32)		(N = 51)		(N = 83)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Age						
18-28	2	6.3	7	13.7	9	10.8
29-38	18	56.3	27	52.9	45	54.2
39-48	12	37.5	13	25.5	25	30.1
49 +	0	0.0	4	7.8	4	4.8
Mean Age in Years	36.8		36.2		36.4	
Race						
African American	2	6.3	9	17.6	11	13.3
White/Caucasian	30	93.8	42	82.4	72	86.7
Gender						
Male	31	96.9	38	74.5	69	83.1
Female	1	3.1	13	25.5	14	16.9
Religion						
Protestant	23	71.9	28	54.9	51	61.4
Roman Catholic	0	0.0	6	11.8	6	7.2
None	6	18.8	12	23.5	18	21.7
Other	3	9.4	5	9.8	8	9.6

fifth of the entire PLA sample stated no religious preference.

PLA sexual orientation varied in rural and urban areas (Table 2). Over four-fifths of rural PLAs reported being gay and almost half of urban PLAs reported to be gay. Less than 5 percent of PLAs responded as being bisexual, and all were living in urban areas.

Also, some variation existed in relationships for PLAs in rural and urban areas. Three-fifths of those living in rural areas, compared to only two-fifths of urban PLAs, were living with a spouse or partner.

Table 3 displays the education, employment status, and monthly income for PLAs. Over half of the PLA sample have either attended or completed vocational school or

Table 2

Relationship Characteristics of PLAs

Variable	Group					
	(N = 32)		(N = 51)		(N = 83)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Sexual Orientation						
Bisexual	0	0.0	4	7.8	4	4.8
Gay	27	84.4	24	47.1	51	61.4
Heterosexual	5	15.6	23	45.1	28	33.7
Relationship Status						
Living with partner/ spouse	19	59.4	21	41.2	40	48.2
Not living with partner/spouse	13	40.6	30	58.8	43	51.8

Table 3**Socioeconomic Description of PLAs**

Variable	Group					
	(N = 32)		(N = 51)		(N = 83)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Education						
No diploma/GED	2	6.3	9	17.6	11	13.3
Diploma/GED	12	37.5	12	23.5	24	28.9
Some vocational school/college	11	34.4	20	39.2	31	37.3
Completed vocational school/college	7	21.9	10	19.6	17	20.5
Employment						
Employed	2	6.3	11	21.6	13	15.7
Unemployed	4	12.5	5	9.8	9	10.8
Retired/disabled	25	78.1	35	68.6	60	72.3
Other	1	3.1	0	0.0	1	1.2
Monthly Income						
<\$500.00	10	31.3	17	33.3	27	32.5
\$500.00-\$999.99	12	37.5	22	43.1	34	41.0
\$1,000.00-\$1,499.99	3	9.4	7	13.7	10	12.0
\$1,500.00 +	7	21.9	5	9.8	12	14.5

college and only 13.3 percent, most of whom live in urban areas, have not earned a high school diploma or GED. Over 90 percent of rural PLAs and 78 percent of urban PLAs were not employed, most of the non-employed were disabled. Only one PLA was retired, and this case was combined with the disabled category because the PLA retired early due to HIV/AIDS. Monthly income varied according to rural and urban residence. Urban PLAs were more likely to be poorer than rural PLAs. Over one-fifth of rural PLAs reported a monthly income of \$1,500.00 or more, compared to one-tenth of urban PLAs.

Table 4 displays information related to HIV infection and the health status for the PLA sample. The entire PLA sample was distributed across three stages of infection: 41 percent are HIV positive and asymptomatic; 22.9 percent are HIV positive and symptomatic, and 36.1 percent have AIDS. Urban PLAs were somewhat more likely to be asymptomatic, while rural PLAs were more likely to have AIDS.

PLAs also reported their most recent T-cell count (Table 4). Lower T-cell counts (< 400) are usually indicative of a poorer health status for PLAs. About three-fifths of the entire PLA sample reported a T-cell count of 400 or less. Urban PLAs were more likely to have low T-cell counts (less than 200), while rural PLAs were more likely to have mid-range counts (200 - 400). This finding was somewhat unexpected since more rural PLAs were diagnosed with AIDS; nonetheless, it may indicate an improvement in PLA physical condition as a result of new and more effective treatment regimens. Three PLA study participants could not recall their most recent T-cell count, all being from an urban area. The number of years since the first positive test for HIV is the known period of infection for the PLA (Table 4). The average infection period for the sample is 5.37 years. Urban

Table 4**Disease and Health Status Information of PLAs**

Variable	Group					
	(N = 32)		(N = 51)		(N = 83)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Stage of Infection						
Asymptomatic	11	34.4	23	45.1	34	41.0
Symptomatic	8	25.0	11	21.6	19	22.9
AIDS	13	40.6	17	33.3	30	36.1
T-Cell Count						
<200	7	21.9	19	37.3	26	31.3
200-400	13	40.6	11	21.6	24	28.9
>400	12	37.5	18	35.3	30	36.1
Don't know	0	0.0	3	5.9	3	3.6
Known Period of Infection						
< one year	1	3.1	8	15.7	9	10.8
1-5 years	14	43.8	22	43.1	36	43.4
6-10 years	10	31.3	13	25.5	23	27.7
>10 years	7	21.9	7	13.7	14	16.9
Don't know	0	0.0	1	2.0	1	1.2
Mean Number of Years Infected with HIV	6.09		4.9		5.37	
HIV Transmission Category						
Sexual activity	29	90.6	37	72.5	66	79.5
Injecting drug use	1	3.1	1	2.0	2	2.4
Accidental exposure	0	0.0	1	2.0	1	1.2
Don't know	1	3.1	10	19.6	11	13.3
Other	1	3.1	2	3.9	3	3.6
Ambulatory Status						
Ambulatory	31	96.9	48	94.1	79	95.2
Ambulatory, with assistance	1	3.1	3	5.9	4	4.8

Table 4 cont.

Variable	Group					
	(N = 32)		(N = 51)		(N = 83)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Feeling in the Past Month						
Very poor	3	9.4	3	5.9	6	7.2
Poor	5	15.6	13	25.5	18	21.7
Average	10	31.3	17	33.3	27	32.5
Good	10	31.3	10	19.6	20	24.1
Very good	4	12.5	8	15.7	12	14.5

PLAs were more likely to have learned of their infection recently (within the past year), while rural PLAs were more likely to have known of their infection for more than ten years.

Almost four-fifths of the entire PLA sample reported sexual activity as the mode of HIV infection transmission (Table 4). About nine-tenths of the rural PLAs, compared to less than three-fourths of the urban PLAs, reported they contracted the HIV virus through sexual activity. However, it should be noted that almost a fifth of the urban group did not know their mode of infection transmission.

Few PLAs reported difficulty in walking or ambulating independently. Less than 5 percent of the entire PLA sample reported needing assistance with ambulation (Table 4).

PLAs were also asked to report how they had been feeling for the month prior to the study interview (Table 4). One-third of urban PLAs reported feeling very poor or poor, compared to only one-fourth of rural PLAs. A greater proportion of rural PLAs reported feeling good or very good than did urban PLAs.

Household composition varied slightly for PLAs in rural and urban areas (Table 5). Rural PLAs were most likely to live with only a partner or spouse, while urban PLAs were more likely to live either alone or with two or more people.

Table 6 indicates the characteristics of the living situation and residential history for PLAs. While most (almost nine-tenths) of the urban PLAs and almost two-thirds of the rural PLAs live in a house or apartment, over one-third of the rural PLAs live in a trailer or manufactured home.

Type of payment for housing also varied in rural versus urban areas (Table 6). Two-

Table 5**Household Composition of PLAs**

Variable	Group					
	(N = 32)		(N = 51)		(N = 83)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Living Situation						
Alone	7	21.9	18	35.3	25	30.1
Partner/spouse	19	59.4	20	39.2	39	47.0
Relatives	4	12.5	6	11.8	10	12.0
Friend	1	3.1	3	5.9	4	4.8
Other	1	3.1	4	7.8	5	6.0
Total Number of Persons in Household						
1	7	21.9	18	35.3	25	30.1
2	17	53.1	16	31.4	33	39.8
3	5	15.6	12	23.5	17	20.5
4 or more	3	9.4	5	9.8	8	9.6
Dependent Children in Household						
Yes	8	25	14	27.5	22	26.5
No	24	75	37	72.5	61	73.5

Table 6**Residential Information for PLA Study Sample**

Variable	Group					
	(N = 32)		(N = 51)		(N = 83)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Type of Housing						
House/apartment	20	62.5	45	88.2	65	78.3
Trailer/man. home	12	37.5	6	11.8	18	21.7
Housing Payment Status						
Rent	12	37.5	40	78.4	52	62.7
Mortgage	6	18.8	8	15.7	14	16.9
Own	7	21.9	2	3.9	9	10.8
Other	7	21.9	1	2.0	8	9.6
Currently Living in Hometown						
Yes	13	40.6	16	31.4	29	34.9
No	19	59.4	35	68.6	54	65.1
Location of Hometown						
Knoxville, TN	8	25.0	14	27.5	22	26.5
Other TN study counties	8	25.0	15	29.4	21	25.3
Non-study TN counties	3	9.4	4	7.8	9	10.8
Outside Tennessee	13	40.6	18	35.3	31	37.3
Length of Time at Current Residence						
< one month	1	3.1	3	5.9	4	4.8
1-6 months	2	6.3	13	25.5	15	18.1
6 months to a year	7	21.9	6	11.8	13	15.7
1-3 years	4	12.5	15	29.4	19	22.9
three years +	18	56.3	14	27.5	32	38.6

fifths of the rural PLAs, compared to one-fifth of the urban PLAs, own or have a mortgage on their home. Most (over three-fourths) of the urban PLAs are renting their place of residence.

Rural PLAs were more likely than urban PLAs to be living in their hometown (40% versus 31%). For the entire sample of PLAs, about two-thirds reported that their hometown was in Tennessee, including slightly over one-fourth whose hometown is Knoxville, the main metropolitan area for this study.

Compared to urban PLAs, rural PLAs were twice as likely to have lived at their current residence for three or more years (56% versus 28%); conversely, urban PLAs were over three times as likely to have lived at their current residence for six months or less (31% versus 9%).

Almost three-fifths of rural PLAs, but less than half of the urban PLA group have a caregiver (Table 7). In both rural and urban areas, about two-thirds of caregivers were the partner or spouse of the PLA. Having a parent as primary caregiver was reported more often for PLAs in rural areas (21.1% versus 4.2%) than for PLAs in urban areas. An adult daughter and an aunt were the only reported primary caregivers in the "other" category. Half of the caregivers identified by PLAs in rural areas did not participate in the study, compared to only 36 percent of caregivers for PLAs living in urban areas. Eighteen caregivers did not participate in the study: fifteen PLAs did not give the investigator permission to contact their caregiver and 3 caregivers chose not to participate.

Table 8 indicates the type of support received by all 43 PLAs who have a primary

Table 7**Caregiver Information for PLA Study Sample**

Variable	Group					
	(N = 32)		(N = 51)		(N = 83)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Caregiver Status						
Yes	19	59.4	24	47.1	43	51.8
No	13	40.6	27	52.9	40	48.2
Caregiver Relationship to PLA						
Partner/spouse	13	68.4	15	62.5	28	65.1
Parent	4	21.1	1	4.2	5	11.6
Sibling	1	5.3	2	8.3	3	7.0
Friend	1	5.3	4	16.7	5	11.6
Other	0	0.0	2	8.3	2	4.7
Caregiver Study Participation						
No	9	50.0	9	36.0	18	41.9
Yes	9	50.0	16	64.0	25	58.1

Table 8

Total PLA Support Received From Caregivers (n = 43) by PLA
Rural and Urban Residence

Variable	Group					
	(N = 19)		(N = 24)		(N = 43)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Emotional support	16	84.2	22	91.7	38	88.4
Shopping assistance	14	73.7	18	75.0	32	74.4
Housecleaning	10	52.6	20	83.3	30	69.8
Cooking	12	63.2	16	66.7	28	65.1
Transportation	11	57.9	10	41.7	21	48.8
Physical care	1	5.3	2	8.3	3	7.0
Other	5	26.3	12	50.0	17	39.5

caregiver. The types of support PLAs received most frequently from their caregivers were emotional support, assistance with shopping, and assistance with housecleaning. Few PLAs received physical care from their caregiver. All 43 PLAs received at least one type of support from their caregiver. Overall, urban PLAs were more likely to receive assistance with housecleaning and rural PLAs were more likely to receive assistance with transportation.

Table 9 reflects the residential proximity of family members and friends to the PLA. Rural PLAs reported that one-fourth of fathers lived in close proximity (same city or closer), compared to about one-tenth of urban PLAs. Slightly less than one-third of rural PLAs and almost half of urban PLAs responded that residential proximity to his or her father was unknown, that the PLA did not know where or if his or her father was living, due to having no recent contact.

Slightly over two-fifths of rural PLAs compared to about one-third of urban PLAs reported their mother was living in the same city or closer. Less than 5 percent of all PLAs responded that the residential proximity to his or her mother was unknown. Most PLAs reported that their caregiver was living with them. Over 95 percent of all PLAs had caregivers who lived in the same city or closer.

Almost four-fifths of urban PLAs' close friend(s) were living in close proximity versus only two-fifths for rural PLAs. PLAs who reported "not applicable" to the close friend category responded that he or she did not have a relationship with a person to fit that category. Only six percent of the PLA sample did not have a close friend. Almost half of urban PLAs and two-fifths of rural PLAs had "other relatives" who lived in the same city

Table 9

PLA Living Proximity by Rural and Urban Residence

Variable	Group					
	(N = 32)		(N = 51)		(N = 83)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Father						
Same City or Closer	8	25.0	7	13.7	15	18.1
Different City in TN	4	12.5	10	19.6	14	16.9
Different State	5	15.6	3	5.9	8	9.6
Deceased	5	15.6	8	15.7	13	15.7
Don't Know	10	31.3	23	45.1	33	39.8
Mother						
Same City or Closer	13	40.1	17	33.3	30	36.1
Different City in TN	6	18.8	13	25.5	19	22.9
Different State	8	25.0	10	19.6	8	9.6
Deceased	4	12.5	9	17.6	13	15.7
Don't Know	1	3.1	2	3.9	3	3.6
Caregiver						
Same City or Closer	18	94.7	23	95.8	41	95.3
Different City in TN	1	5.3	1	4.2	2	4.7
Closest Friend(s)						
Same City or Closer	13	40.1	40	78.4	53	39.8
Different City in TN	13	40.1	3	5.9	16	19.3
Different State	4	12.5	5	9.8	9	10.8
Not Applicable	2	6.3	3	5.9	5	6.0
Other Relatives						
Same City or Closer	13	40.6	24	47.1	37	44.6
Different City in TN	10	31.3	14	27.5	24	28.9
Different State	7	21.9	13	25.5	20	24.1
Deceased	1	3.1	0	0.0	1	1.2
Don't Know	1	3.1	0	0.0	1	1.2

or closer (Table 9).

Frequency of social interaction was measured for specific PLA relationships (Table 10). PLAs were asked to respond to their frequency of social interaction for the following persons: parents, friends, relatives, case manager, and their caregiver. Responses to PLA frequency of social interaction were collected on a scale of six responses, from “nearly every day” to “hardly ever” (Appendix 5). If PLAs had no contact with any persons identified in these relationships, their response was marked “not applicable.” Table 10 shows the distribution for the frequency of PLA social interaction for specific relationships.

Less than one-third of the PLA sample saw or talked with their father once a month or more. Over half of the PLA sample stated they had no social interaction with their father. Over one-third of rural PLAs and one-fourth of urban PLAs had contact with their mother nearly every day. Less than one-fifth of the PLA sample reported having no social interaction with their mother. Forty-seven percent of PLAs have contact with other relatives at least more than once a week. Less than five percent of PLAs reported not having any contact with other relatives.

Almost three-fourths of all PLAs reported interacting with a close friend at least more than once a week. Nearly two-fifths of urban PLAs reported seeing or talking with their closest friend(s) nearly every day, compared to only one-fourth of rural PLAs. Only six percent of all PLAs responded “not applicable” to social interaction with closest friend(s). Over half of the PLA sample reported interacting with other friend(s) at least more than once a week. Approximately one-third of rural PLAs and over one-fifth of urban PLAs

Table 10

PLA Report of Social Interaction by Rural and Urban Residence

Variable	Group					
	(N = 32)		(N = 51)		(N = 83)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Father						
Nearly every day	3	9.4	4	7.8	7	8.4
1 + per week	5	15.6	5	9.8	10	12.0
2-3 x month	4	12.5	4	7.8	8	9.6
1 x month	1	3.1	0	0.0	1	1.2
Several times a year	2	6.3	2	3.9	4	4.8
Hardly ever	2	6.3	3	5.9	5	6.0
Not applicable	15	46.9	33	64.7	48	57.8
Mother						
Nearly every day	11	34.4	13	25.5	24	28.9
1 + per week	7	21.9	15	29.4	22	26.5
2-3 x month	5	15.6	6	11.8	11	13.3
1 x month	2	6.3	2	3.9	4	4.8
Several times a year	2	6.3	2	3.9	4	4.8
Hardly ever	0	0.0	3	5.9	3	3.6
Not applicable	5	15.6	10	19.6	15	18.1
Other Relatives						
Nearly every day	6	18.8	8	15.7	14	16.9
1 + per week	7	21.9	18	35.3	25	30.1
2-3 x month	4	12.5	9	17.6	13	15.7
1 x month	5	15.6	5	9.8	10	12.0
Several times a year	4	12.5	4	7.8	8	9.6
Hardly ever	4	12.5	7	13.7	11	13.3
Not applicable	2	6.3	0	0.0	2	2.4

Table 10 cont.

Variable	Group					
	(N = 32)		(N = 51)		(N = 83)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Close Friend(s)						
Nearly every day	8	25.0	19	37.3	27	32.5
1 + week	14	43.8	19	37.3	33	39.8
2-3 x month	2	6.3	3	5.9	5	6.0
1 x month	5	15.6	1	2.0	6	7.2
Several times a year	1	3.1	4	7.8	5	6.0
Hardly ever	0	0.0	2	3.9	2	2.4
Not applicable	2	6.3	3	5.9	5	6.0
Other Friends						
Nearly every day	8	25.0	8	15.7	16	19.3
1 + week	13	40.6	18	35.3	31	37.3
2-3 x month	3	9.4	8	15.7	11	13.3
1 x month	3	9.4	2	3.9	5	6.0
Several times a year	1	3.1	0	0.0	1	1.2
Hardly ever	2	6.3	7	13.7	9	10.8
Not applicable	2	6.3	8	15.7	10	12.0
Neighbors						
Nearly every day	10	31.3	11	21.6	21	25.3
1 + week	6	18.8	7	13.7	13	15.7
2-3 x month	3	9.4	11	21.6	14	16.9
1 x month	1	3.1	1	2.0	2	2.4
Several times a year	1	3.1	0	0.0	1	1.2
Hardly ever	10	31.3	21	41.2	31	37.3
Not applicable	1	3.1	0	0.0	1	1.2
Case Manager						
Nearly every day	2	6.3	0	0.0	2	2.4
1 + week	1	3.1	6	11.8	7	8.4
2-3 x month	4	12.5	7	13.7	11	13.3
1 x month	4	12.5	15	29.4	19	22.9
Several times a year	10	31.3	9	17.6	19	22.9
Hardly ever	11	34.4	14	27.5	25	30.1

interacted with neighbors nearly every day, yet almost one-third of rural PLAs and over two-fifths of urban PLAs hardly ever interacted with neighbors.

Almost one-fourth of PLAs had contact with their case manager at least two to three times a month. However, about one-third of the PLA sample reported hardly ever having contact with their case manager. PLAs who reported having a caregiver reported having frequent contact with their caregiver (Table 11). Over nine-tenths of all PLAs reported interacting with their caregiver nearly every day. Only one PLA reported having contact with their caregiver only once a month.

PLAs were generally satisfied with their relationships with family members and friends. Approximately four-fifths of all PLAs reported being somewhat or very satisfied with relationships with family members and almost nine-tenths of PLAs reported being somewhat or very satisfied with relationships with friends.

Table 11

PLA Report of Social Interaction with Caregivers (n = 43)
by Rural and Urban Residence

Variable	Group					
	(N = 19)		(N = 24)		(N = 43)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Caregiver						
Nearly every day	18	94.7	21	87.5	39	90.7
1 + week	0	0.0	3	12.5	3	7.0
1 x month	1	5.3	0	0.0	1	2.3

Social Support for Persons Living with HIV/AIDS in Rural versus Urban Areas

Part of the first aim of this study was to examine significant predictors of social support for PLAs living in rural versus urban areas. In order to use multiple regression methods, several procedures were used to test the assumptions of normality of PLA data from the Multidimensional Scale of Perceived Social Support (MSPSS) and the Network Orientation Scale (NOS).

Tests for the Assumption of Normality

First a histogram of unstandardized residuals was graphed on the normal curve for the MSPSS and the NOS (Figures 3 and 4). While the residuals are not perfectly fitted to the normal curve, the degree of variation within the data does not preclude the assumption of normality for both measures (Agresti and Finlay, 1997).

The second procedure conducted to determine normality was a P-P plot of the unstandardized residuals for the MSPSS and the NOS (Figures 5 and 6). According to the assumption of the P-P plot, if the sample is from a normal distribution, points will cluster around a straight line. The plots for the MSPSS and NOS are closely clustered around the straight line, while not lying exactly on the line. Thus, according to the plot of the data, the assumption of normality seems plausible (SPSS, 1997).

A third measure was used to test the assumption of homogeneity of variances. Plots of the standardized residuals against the standardized predicted values for the MSPSS and the NOS were generated (Figures 7 and 8). The plot shows that the observations are fairly well distributed around zero. Consequently, there is no strong evidence of any gross violation for the assumption of homogeneity of variance for the PLA data set for the

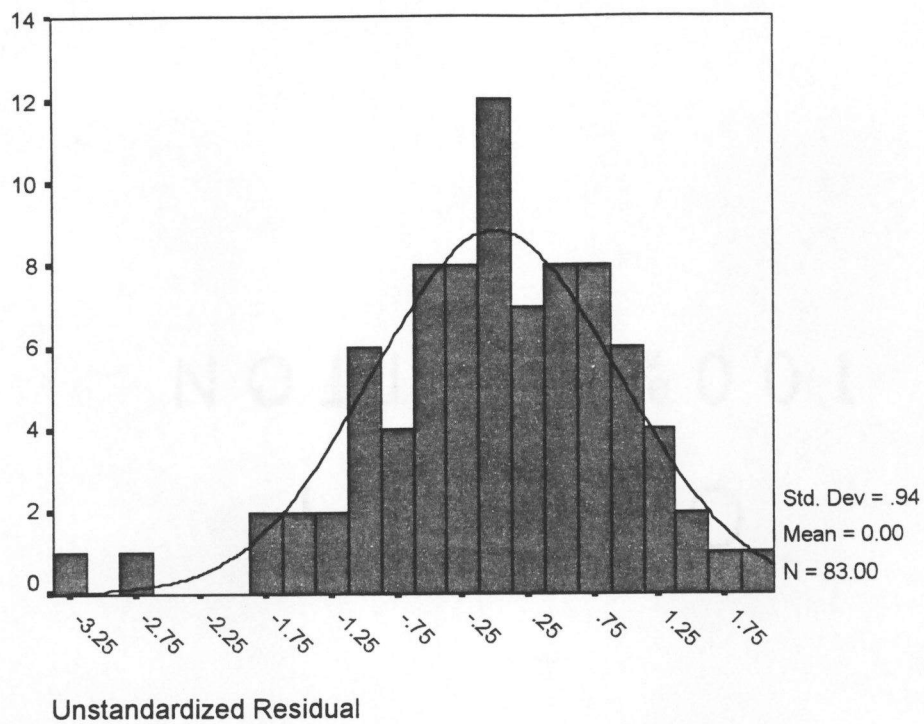


Figure 3. Frequency Distribution of Unstandardized Residuals for the MSPSS

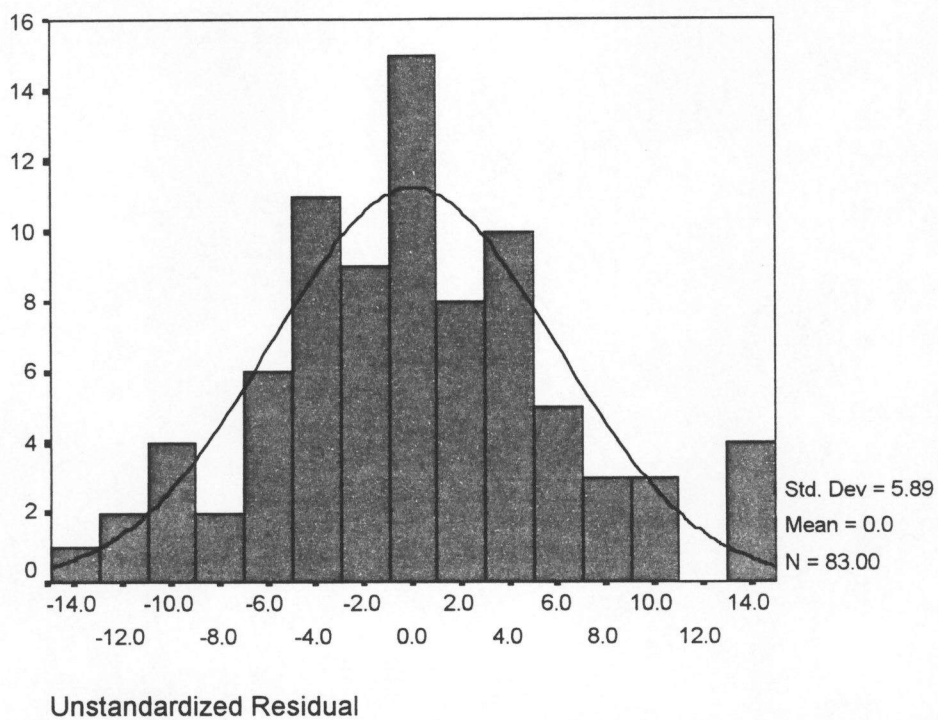


Figure 4. Frequency Distribution of Unstandardized Residuals for the NOS

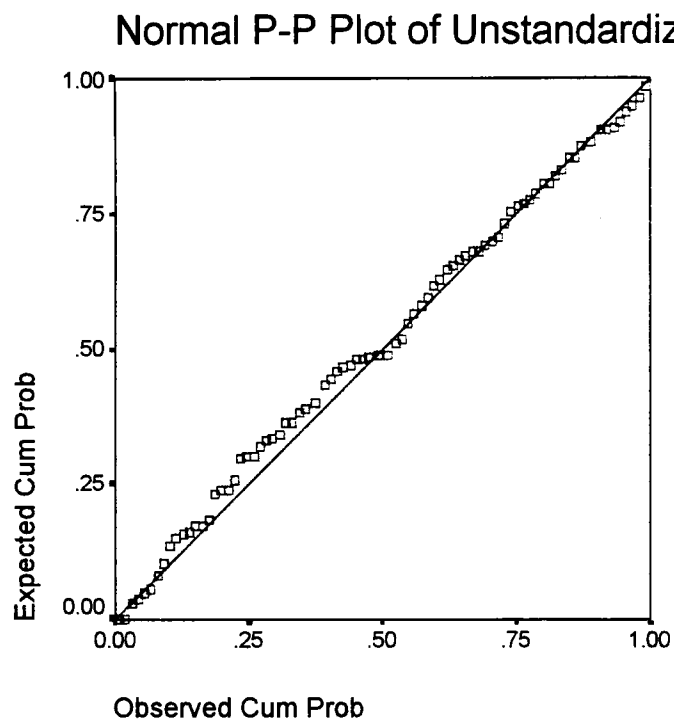


Figure 5. Normal Probability Plot of MSPSS Measure of Social Support

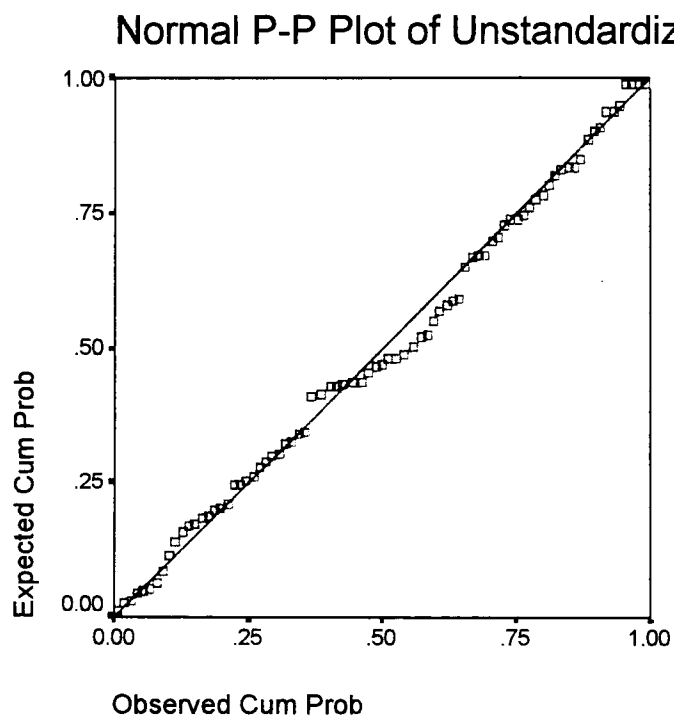


Figure 6. Normal Probability Plot of NOS Measure of Social Support

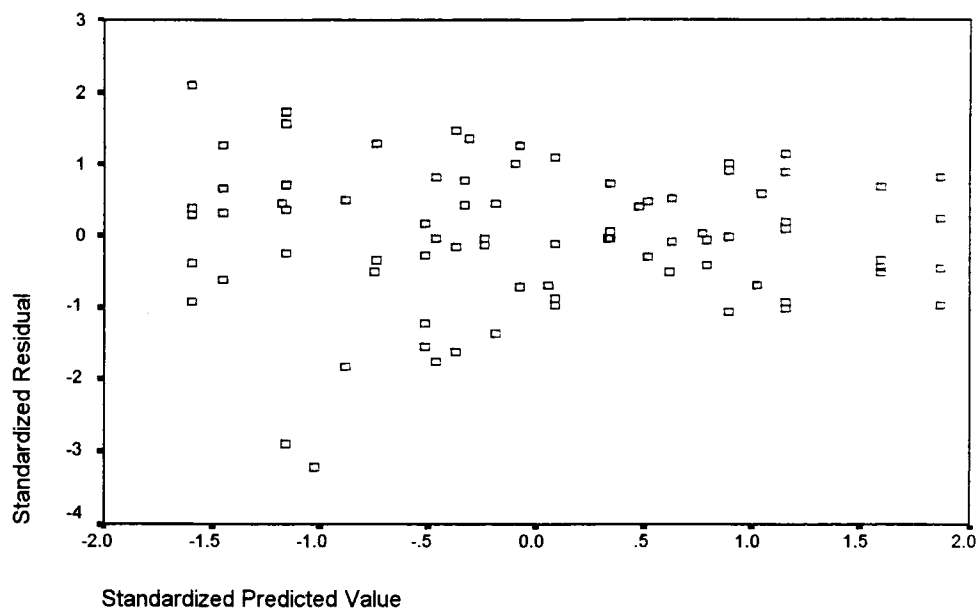


Figure 7. Residual Prediction Error Plot of the MSPSS Measure of Social Support

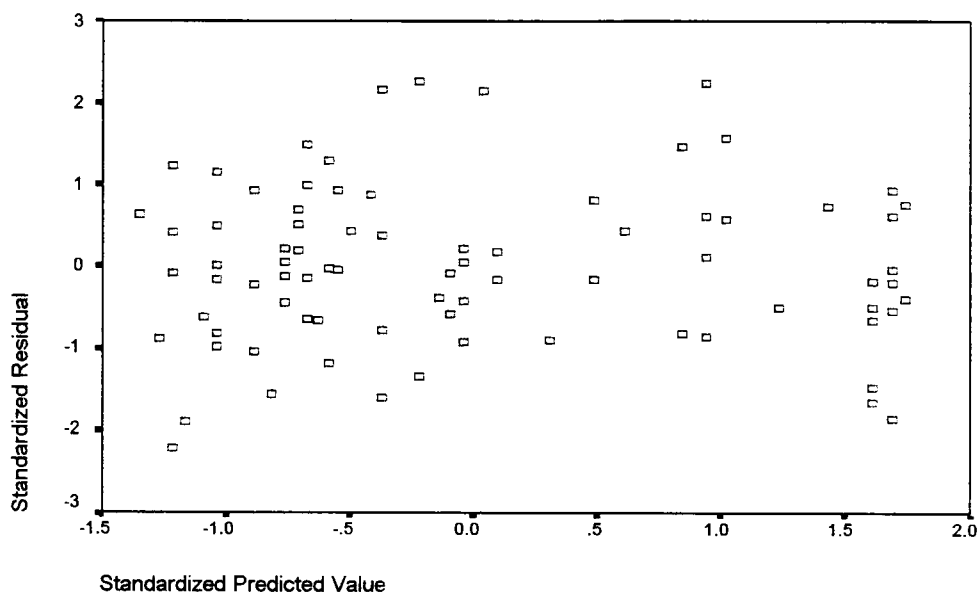


Figure 8. Residual Prediction Error Plot of the NOS Measure of Social Support

MSPSS and NOS measures of social support (Agresti and Finlay, 1997; Cohen and Cohen, 1983).

Finally, Cook's distance was used to determine if any data observations deviated from the rest, i.e., having relatively large values (Agresti and Finlay, 1997). All Cook's D values for the MSPSS and NOS are less than one; no case was expected to change the computation of the regression statistics upon exclusion (SPSS, 1997).

Predictor Variables

Predictor variables were chosen as a result of the review of the literature regarding characteristics of PLAs and caregivers living in rural versus urban areas. The five predictor variables were: rural versus urban residence, sexual orientation, caregiver status (whether or not the PLA had a caregiver), living in hometown (whether or not the PLA was living in his or her hometown), and length of time living at current residence.

Table 12 displays the proportion of the PLA sample in each category of the predictor variables as well as the dummy coding for the variables. All predictor variables were categorical in nature, thus dummy coded (Cohen and Cohen, 1983).

Table 13 presents the means, standard deviations, and range of scores for the Multidimensional Scale of Perceived Social Support and the Network Orientation Scale for PLAs. The data in Table 13 indicate that the overall mean score for the MSPSS among PLAs was 5.4 (SD = 1.0). This compares to a mean of 5.31 (SD = 1.46) for the MSPSS total norming sample (Zimet et al., 1988). Thus the overall MSPSS score for PLAs was very similar to that of the norming sample. Rural PLAs had a mean MSPSS score of 5.6 (SD = .81) and urban PLAs had a mean MSPSS score of 5.3 (SD = 1.1).

Table 12**Proportion of PLA Sample Per Predictor Variable and Dummy Coding**

Variable	PLA Sample	Dummy Coding	
	%	#	
Area of Residence			
Rural	38.6	0	
Urban	61.4	1	
Caregiver Status			
Yes	51.8	1	
No	48.2	0	
Sexual Orientation			
Heterosexual	33.7	0	
Gay/bisexual	66.3	1	
Living in Hometown			
Yes	34.9	1	
No	65.1	0	
Length of Time Living in Current Residence			
< one year	38.6	1	0
1 - 3 years	22.9	0	1
> 3 years	38.6	-1	-1

Table 13

PLA Means, Standard Deviations, and Ranges of Scores for Multidimensional Scale of Perceived Social Support and Network Orientation Scale by Rural versus Urban Area

Instrument	Group								
	Rural			Urban			Total		
	M	SD	Range	M	SD	Range	M	SD	Range
MSPSS	5.6	.81	3.5 - 7.0	5.3	1.1	1.8 - 6.8	5.4	1.0	1.8 - 7.0
NOS	45.0	6.4	30 - 59	47.8	6.3	35 - 63	46.7	6.5	30 - 63

Higher MSPSS scores reflect higher perceived social support. The difference in scores for rural versus urban PLAs on the MSPSS measure for social support was not statistically significant.

The overall mean score for the NOS among PLAs was 46.7 (SD = 6.5). Information regarding a norming sample was not available for the Network Orientation Scale. Rural PLAs had a slightly lower mean NOS score than urban PLAs. The mean NOS score for rural PLAs is 45 (SD = 6.4) and the mean NOS score for urban PLAs is 47.8 (SD = 6.3). Higher NOS scores indicate a more negative orientation toward maintaining, nurturing, or utilizing social support. The difference in scores for rural versus urban PLAs on the NOS measure for social support was not statistically significant. Table 14 presents a correlation matrix of the study variables.

Tests of the Hypothesis on Social Support for PLAs

To answer the first research question, simultaneous multiple regression analysis was performed to evaluate the relationship between social support and each predictor variable, while controlling for all other predictor variables. The first hypothesis to be tested was:

Hypothesis 1: Rural PLAs report less social support than urban PLAs.

Multiple Regression Results on the MSPSS Measure of Social Support for PLAs

The results of the regression analysis for the predictors of social support as measured by the MSPSS are presented in Table 15. The linear combination of predictor variables was significantly related to the Multidimensional Scale of Perceived Social Support [$F(6, 76) = 2.63, p = .023$]. The sample multiple correlation coefficient for the linear regression on the MSPSS was .415, indicating that approximately 17 percent ($R^2 = .17$; adjusted

Table 14

Zero-Order Correlation Matrix of Predictor and Criterion Variables

Variables	R/U	CS	CH	SO	T1	T2	MSPSS	NOS
R/U	1.000							
CS	-.120	1.000						
CH	-.094	.100	1.000					
SO	-.303(**)	.128	.309(**)	1.000				
T1	.226(*)	-.137	.000	-.290(**)	1.000			
T2	.290(**)	-.165	-.081	-.444(**)	.572(**)	1.000		
MSPSS	-.163	.285(**)	.181	.196	-.282(**)	-.237(*)	1.000	
NOS	.207	-.193	-.160	-.377(**)	.111	.186	-.485(**)	1.000

R/U = Rural or Urban; CS = Caregiver Status; CH = Currently Living in Hometown; SO = Sexual Orientation; T1 = Time In Current Residence 1; T2 = Time in Current Residence 2; MSPSS = Multidimensional Scale of Perceived Social Support; NOS = Network Orientation Scale.

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Table 15

Multiple Regression of MSPSS

n = 83

Model Predictor Variables	Unstandardized Coefficients		Standardized Coefficients		t	p	Partial Correlations
	B		Beta				
Constant	5.072				17.597	.000	
Rural or Urban Residence	-.117		-.056		-.497	.621	-.057
Caregiver Status	.461		.225		2.108	.038	.235
Sexual Orientation	.059		.028		.221	.825	.025
Living in Hometown	.304		.141		1.278	.205	.145
Time at Current Residence 1	-.240		-.206		-1.606	.112	-.181
Time at Current Residence 2	-.056		-.042		-.308	.759	-.035

Multiple R = .415 R square = .17 Adjusted R Square = .11

Dependent Variable: MSPSS/Social Support

R square = .11) of the variance in the level of perceived social support as measured by the MSPSS may be accounted for by the linear combination of the five predictor variables.

The relative strength of the individual predictors for the MSPSS is also presented in Table 15. Caregiver status was the only predictor variable that was significantly related to social support after controlling for the other predictor variables (Beta = .23, $p < .05$). On the basis of these correlational analyses, whether or not a person living with HIV/AIDS has a caregiver is significantly related to level of social support as measured by the MSPSS. The results show that PLAs who have caregivers are more likely to have higher levels of perceived social support.

Rural and urban PLAs did not significantly differ in the level of perceived social support as measured by the MSPSS. The results of the regression analysis do not support the first research hypothesis that rural versus urban residence is a predictor of perceived level of social support for PLAs as measured by the MSPSS.

Multiple Regression Results on the NOS Measure of Social Support for PLAs

The results of the regression analysis for the predictors of social support for the NOS measure of social support are presented in Table 16. The linear combination of predictor variables was significantly related to the Network Orientation Scale [$F(6, 76) = 2.64$, $p = .022$]. The sample multiple correlation coefficient for the linear regression on the NOS was .415, indicating that approximately 17 percent ($R^2 = .17$; adjusted $R^2 = .11$) of the variance in the level of perceived social support measured by the NOS may be accounted for by the linear combination of the five predictor variables. The relative strength of the individual predictor variables for the NOS is presented in Table 16.

Table 16

Multiple Regression of NOS

n = 83		Unstandardized Coefficients		Standardized Coefficients	t	p	Partial Correlation
Model Predictor Variables		B		Beta			
Constant		50.001			27.600	.000	
Rural or Urban Residence		1.225		.093	.829	.410	.095
Caregiver Status		-1.802		-.140	-1.312	.193	-.149
Sexual Orientation		-4.431		-.326	-2.608	.011	-.287
Living in Hometown		-.484		-.036	-.325	.746	-.037
Time at Current Residence 1		-.186		-.025	-.198	.844	-.023
Time at Current Residence 2		.024		.003	.021	.983	.002

Multiple R = .415 R square = .17 Adjusted R Square = .11

Dependent Variable: NOS/Social Support

Sexual orientation was the only predictor variable significantly related to social support after controlling for other predictor variables ($\text{Beta} = .33, p < .05$). On the basis of these correlational analyses, the only useful predictor of social support as measured by the NOS is the sexual orientation of the PLA. The results indicate that heterosexual PLAs are less likely to utilize their social support network and more likely to believe it may be hazardous or dangerous to seek assistance. The results of the second regression analysis do not support the research hypothesis that rural versus urban residence is a predictor of social support among PLAs as measured by the NOS.

PLA Types of Need

An exploratory examination of PLA types of need was conducted comparing PLAs in rural versus urban areas. This section provides the frequencies and distributions of nine types of need for PLAs living in rural versus urban areas and the mean number of met and unmet needs for rural and urban PLAs.

PLAs were asked to complete a needs assessment regarding four healthcare-related services and five social services (Appendix 4). PLAs were asked if they needed any of these services for the six months prior to the study interview. If the PLA reported a need, he or she was asked if the service was received and, if received, how satisfied he or she was with the service.

Over half of the entire PLA sample reported needing the following three services: case management, dental care, and medical care (Table 17). Urban PLAs reported a greater proportion of need than did rural PLAs for six of the nine services, including: financial assistance for rent/mortgage, financial assistance for food, transportation assistance, case

Table 17

PLA Types of Need Reported by Rural and Urban Residence
Percentage Distribution of Need and Met Need

Type of Need	Group					
	(N = 32)		(N = 51)		(N = 83)	
	Rural		Urban		Total	
	% Need (n)	% Met Need	% Need (n)	% Met Need	% Need (n)	% Met Need
Rent/Mortgage	28.1 (9)	66.7	35.3 (18)	88.9	32.5 (27)	81.5
Food	18.8 (6)	66.7	25.5 (13)	69.2	22.9 (19)	68.4
Transportation	12.5 (4)	75.0	21.6 (11)	91.0	18.1 (15)	86.7
Case Management	56.3 (18)	83.3	64.7 (33)	97.0	61.4 (51)	92.2
Dental Care	65.6 (21)	66.7	54.9 (28)	78.6	59.0 (49)	73.5
Housing	6.2 (2)	00.0	19.6 (10)	60.0	14.5 (12)	50.0
Medical Care	96.9 (31)	100.0	94.1 (48)	100.0	95.2 (79)	100.0
Financial Ass. for Medication	6.2 (2)	50.0	17.6 (9)	88.9	13.3 (11)	81.8
Mental Health/ Counseling	40.6 (13)	69.2	27.5 (14)	64.3	32.5 (27)	66.7

management services, housing assistance, and financial assistance for medication. Rural PLAs reported a greater proportion of need for two healthcare-related services: dental care and mental health/counseling services. Ninety-five percent of the entire PLA sample had a need for medical care.

Table 17 also presents the proportion of PLAs who reported that their needs were met. The lowest proportion of met need was also determined for the nine types of need. The following needs were identified as having the highest proportion on unmet need: mental health/counseling, dental care, financial assistance for food, and housing assistance. Mental health/counseling was the only service where urban PLAs reported a greater proportion of unmet need than rural PLAs. Distributions of met and unmet needs were conducted concerning specific characteristics of PLAs including: living situation, monthly income, and stage of illness. Two-fifths of PLAs living alone reported unmet needs, while less than one-third of PLAs living with others reported unmet needs (Table 18). Almost two-fifths of PLAs with an income of less than \$1,000.00 per month reported unmet needs and only slightly over one fifth of PLAs with incomes over \$1,000.00 per month reported unmet needs (Table 19). Little difference was found in unmet need by stage of illness (Table 20).

About one-third of the PLA sample had at least one unmet need. A greater proportion of rural PLAs reported having an unmet need than did urban PLAs (Table 21). Forty percent of the rural PLA group reported at least one unmet need and only 29 percent of the urban PLA group reported an unmet need.

PLAs reported that over four-fifths of the service needs listed in the assessment were

Table 18**PLA Met and Unmet Need by Living Situation (n = 83)**

Variable	Group					
	(N = 25)		(N = 58)		(N = 83)	
	Living Alone		Living w/ Others		Total	
	N	%	N	%	N	%
Need						
Met need	15	60	40	69	55	66.3
Unmet need	10	40	18	31	28	33.7
Total	25	100	58	100	83	100

Table 19**PLA Met and Unmet Need by Monthly Income (n = 83)**

Variable	Group					
	Under \$1,000.00		Over \$1,000.00		Total	
	N	%	N	%	N	%
Need						
Met need	38	62.3	17	77.3	55	66.3
Unmet need	23	37.7	5	22.7	28	33.7
Total	61	100	22	100	83	100

Table 20**PLA Met and Unmet Need by Stage of Illness (n = 83)**

Variable	Group							
	Asymptomatic		Symptomatic		AIDS		Total	
	N	%	N	%	N	%	N	%
Need								
Met need	23	67.6	13	68.4	19	63.3	55	66.3
Unmet need	11	32.4	6	31.6	11	36.7	28	33.7
Total	34	100	19	100	30	100	83	100

Table 21**PLAs (n = 83) with Unmet Need by Rural and Urban Residence**

Variable	Group					
	Rural		Urban		Total	
	N	%	N	%	N	%
Unmet Need						
Yes	13	40.6	15	29.4	28	33.7
No	19	59.4	36	70.6	55	66.3
Total	32	100	51	100	83	100

met for the entire sample (Table 22). Rural PLAs reported a greater proportion of unmet service needs than urban PLAs. Urban PLAs reported 87 percent of their service needs were met and rural PLAs reported 78 percent of their service needs were met.

A total of 290 needs were reported by the entire PLA sample (Table 22). The mean number of PLA needs was 3.5 (SD = 1.7). As anticipated, rural PLAs reported an overall greater proportion of unmet needs than did PLAs in urban areas. Rural PLAs reported that over one-fifth of their needs were unmet and urban PLAs reported only slightly over one-tenth of their needs were unmet. The mean number of unmet needs was .57 (SD = 1.1).

PLAs were asked to rate their level of satisfaction for needs they identified as being met. There was no significant difference for overall mean satisfaction of met needs for rural versus urban PLAs. Mean satisfaction was measured on a 4-point Likert-type scale, with a score of 1 = very dissatisfied to a score of 4 = very satisfied. Mean satisfaction with met needs for rural and urban PLAs was 3.6 (SD = .54).

Table 22Total Met and Unmet Needs for PLAs by Rural and Urban Residence

Variable	Group					
	Rural		Urban		Total	
	N	%	N	%	N	%
Need						
Met	83	78.3	160	87	243	83.8
Unmet	23	21.7	24	13	47	16.2
Total # of needs	106	100	184	100	290	100
Mean # of needs	3.3		3.6		3.5	
Mean # of unmet needs	0.72		0.47		0.57	

Eleven urban PLAs and five rural PLAs reported being somewhat or very dissatisfied with a total of 20 met needs. Adding the number of PLAs whose needs were not satisfactorily met to unmet needs changes the distribution for PLAs with unmet need (Table 23). Combining unsatisfactorily met needs with unmet needs led to over two-fifths of all PLAs reporting having close to at least one unmet need (Table 24). Total number of met and unmet need also changed as a result of unsatisfactorily met needs. One-fourth of urban PLA needs are now identified as being unmet and over one-fourth of rural PLA needs are now unmet. Combining needs that were not satisfactorily met as unmet needs changed the mean number of unmet needs to an average of almost one unmet need per rural PLA and to .73 unmet needs per urban PLA.

Summary

Social support for PLAs does show some relationship to individual characteristics of

Table 23

PLAs (n = 83) with Unmet Need by Rural and Urban Residence Including
PLAs Somewhat or Very Dissatisfied with Met Needs

Variable	Group					
	Rural		Urban		Total	
	N	%	N	%	N	%
Unmet Need						
Yes	16	50.0	21	41.2	37	44.6
No	16	50.0	30	58.8	46	45.4
Total	32	100	51	100	83	100

Table 24

Total Met and Unmet Needs for PLAs by Rural and Urban Residence Including
PLAs Somewhat or Very Dissatisfied with Met Needs

Variable	Group					
	Rural		Urban		Total	
	N	%	N	%	N	%
Need						
Met	76	71.7	147	79.9	223	76.9
Unmet	30	28.3	37	20.1	67	23.1
Total	106	100	184	100	290	100
Mean # of unmet needs		0.94		0.73		0.81

the PLAs for this study sample. Nevertheless, rural and urban residence was not a significant predictor for social support in the MSPSS or the NOS measures; consequently, there is no evidence to support the first research hypothesis.

Only two predictor variables were found to be significantly related to social support for PLAs: caregiver status and sexual orientation. Caregiver status was a significant predictor of PLA social support based on the regression analysis on the MSPSS measure. Sexual orientation was a significant predictor of PLA social support based on the regression analysis on the NOS measure. While only one predictor variable was significant for each regression equation, both equations were significant overall ($p < .05$).

The regression model for the MSPSS measure of social support explained 17 percent (11% adjusted) of the variation in perceived level of social support for PLAs living in rural and urban areas. The results indicate that whether or not a PLA has a caregiver is a predictor of how the PLA perceives the availability of social support from friends, family, and a significant other and that having a caregiver is likely to lead to higher levels of social support.

The regression model for the NOS measure of social support explained 17 percent (11% adjusted) of the variation in unwillingness to maintain or utilize social support for PLAs living in rural and urban areas. The results indicate that the sexual orientation of the PLA is a predictor of whether or not the PLA believes it is useless or inadvisable to access support from one's social network and that heterosexuals are more likely to be unwilling to utilize these supports.

Types of need varied among PLAs living in rural versus urban areas. Almost half of the PLA sample had at least one unmet need. Almost one-fifth of PLA needs were identified as being unmet, including needs that were unsatisfactorily met. PLAs living in rural areas had a greater proportion of unmet need than urban PLAs (28.3% vs. 20.1%). Most PLAs (76.9%) reported that their needs had been met.

CHAPTER 5

CAREGIVER RESULTS

This chapter reports the study findings for the caregiver sample. The results chapter for caregivers is divided into three sections. The first section provides a description of the caregiver study sample. The second section reports the results of the test on the second research hypothesis: t-tests for comparing caregiver means on two measures of social support, the Multidimensional Scale of Perceived Social Support and the Network Orientation Scale. The third section reports the results for the statistical test on the third hypothesis: a t-test for comparing means on one measure of caregiver burden, the Caregiver Burden Interview.

Caregiver Sample Characteristics

The caregiver sample consisted of twenty-five caregivers living in rural ($n = 9$, 36%) and urban ($n = 16$, 64%) areas. Table 25 reports the race, gender, and age distribution of the caregiver group. Ninety-six percent of caregivers were white/Caucasian. Slightly over three-fourths of the caregiver sample was male. The age of caregivers ranged from 21- 65 years old, with a mean age of 37.16. One-fourth of the caregivers in urban areas were in the 21-28 year-old age group, while no rural caregivers were 28 years of age or younger. Rural caregivers are older (mean age = 42) than urban caregivers (mean age = 34.4).

Four-fifths of the entire caregiver sample have a religious background and over half are of Protestant faith (Table 26). Almost one-third of the urban caregivers have no religious background, while all rural caregivers have a religious background. Over four-fifths of the caregiver sample live with a partner or spouse (Table 26).

Table 25**Demographic Description of Caregiver Study Sample**

Variable	Group					
	(N = 9)		(N = 16)		(N = 25)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Age						
21-28	0	0.0	4	25.0	4	16.0
29-38	3	33.3	8	50.0	11	44.0
39-48	4	44.4	3	18.8	7	28.0
49 +	2	22.2	1	6.2	3	12.0
Mean Age in Years	42		34.4		37.2	
Race						
African American	0	0.0	1	6.2	1	4.0
White/Caucasian	9	100.0	15	93.8	24	96.0
Gender						
Male	7	77.8	12	75.0	19	76.0
Female	2	22.2	4	25.0	6	24.0

Table 26**Socioeconomic Description of Caregiver Study Sample**

Variable	Group					
	(N = 9)		(N = 16)		(N = 25)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Religion						
Protestant	6	66.7	8	50.0	14	56.0
Other	3	33.3	3	18.8	6	24.0
None	0	0.0	5	31.2	5	20.0
Relationship Status						
Living with partner/spouse	7	77.8	14	87.5	21	84.0
Not living with partner/spouse	2	22.2	2	12.5	4	16.0
Relationship to PLA						
Partner/spouse	7	77.8	13	81.3	20	80.0
Parent	1	11.1	1	6.2	2	8.0
Friend	1	11.1	2	12.5	3	12.0
Education						
No high school diploma/GED	1	11.1	5	31.2	6	24.0
High school diploma/GED	2	22.2	2	12.5	4	16.0
Some vocational school or college	4	44.4	7	43.8	11	44.0
Completed voc. school/college	2	22.2	2	12.5	4	16.0
Employment						
Employed	4	44.4	6	37.5	10	40.0
Unemployed	1	11.1	4	25.0	5	20.0
Retired/disabled	4	44.4	5	31.3	9	36.0
Other	0	0.0	1	6.2	1	4.0

Table 26 cont.

Variable	Group					
	(N = 9)		(N = 16)		(N = 25)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Monthly Income						
<\$500.00	2	22.2	6	37.5	8	32.0
\$500.00-\$999.99	2	22.2	8	50.0	10	40.0
\$1,000.00-\$1,499.99	2	22.2	1	6.2	3	12.0
\$1,500 +	3	33.3	1	6.2	4	16.0

Four-fifths of caregivers reported that their partner or spouse was also the PLA care recipient. Three-fifths of the caregiver sample have either attended or completed vocational school or college (Table 26). Almost one-third of urban caregivers have not earned a high school diploma or GED, compared to only one-tenth of rural caregivers.

Forty percent of the caregiver sample are employed and of those working all but one were working full-time (Table 26). Rural caregivers were more likely to be disabled and urban caregivers were more likely to be unemployed.

Almost three-fourths of the caregiver sample have an income of less than \$1,000.00 per month (Table 26). One-third of rural caregivers had a monthly income of at least \$1,500.00, compared to only six percent of urban caregivers.

Table 27 reports the number of days per week caregivers reported providing support and assistance to PLAs. Slightly over three-fourths of the caregiver sample currently spend seven days per week assisting the PLA. The mean number of days per week spent caring for PLAs was 6.04. Rural caregivers averaged slightly fewer days caring for PLAs than urban caregivers.

Table 28 shows the length of time spent as a caregiver. Seventy-six percent of the caregiver sample have spent one to five years caring for PLAs. Slightly less than one-fifth of the urban caregiver sample have cared for PLAs for six or more years and no rural caregivers were in this group.

Household composition is reported in Table 29. Over four-fifths of the entire caregiver sample were currently living with the PLA care recipient. The remaining group of caregivers were living alone. Two-fifths of the caregiver sample have at least one child

Table 27**Number of Days Per Week Caring for PLA**

Variable	Group					
	Rural		Urban		Total	
	N	%	N	%	N	%
Days Per Week						
1	1	11.1	1	6.2	2	8.0
2	1	11.1	0	0.0	1	4.0
3	0	0.0	0	0.0	0	0.0
4	0	0.0	1	6.2	1	4.0
5	1	11.1	1	6.2	2	8.0
6	0	0.0	0	0.0	0	0.0
7	6	66.7	13	81.3	19	76.0
Total	9	100.0	16	100.0	25	100.0
Mean # of days per week caring for PLA	5.56 days		6.31 days		6.04 days	

Table 28**Length of Time as a Caregiver**

Variable	Group					
	(N = 9)		(N = 16)		(N = 25)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Time as Caregiver						
< one year	2	22.2	1	6.2	3	12.0
1-5 years	7	77.8	12	75.0	19	76.0
6-10 years	0	0.0	2	12.5	2	8.0
> ten years	0	0.0	1	6.2	1	4.0

Table 29**Household Composition of Caregiver Study Sample**

Variable	Group					
	(N = 9)		(N = 16)		(N = 25)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Living with PLA						
Yes	8	88.9	14	87.5	22	88.0
No	1	11.1	2	12.5	3	12.0
Dependent Children at Home (< age 18)						
Yes	4	44.4	6	37.5	10	40
No	5	55.6	10	62.5	15	60

under eighteen years old living in their home.

Table 30 indicates the caregiver report of the types of support provided to PLAs. The most frequently provided types of support reported by the caregivers to PLAs were emotional support, cooking assistance, shopping assistance, and housecleaning assistance. All caregivers reported providing at least some type of support for the PLA. No rural caregivers reported providing physical care for PLAs and only two urban caregivers were found to have provided physical support.

Caregivers were asked to respond to the frequency of social interaction regarding specific relationships (Table 31). All caregivers reported being in contact with the PLA care recipient nearly every day. Two-thirds of rural caregivers had contact with their closest relative nearly every day and this was true for less than half of urban caregivers. Slightly over two-fifths of rural caregivers and only one-fourth of urban caregivers

Table 30**Caregiver Report of Support Provided to PLAs by Rural and Urban Residence**

Variable	Group					
	(N = 9)		(N = 16)		(N = 25)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Emotional support	8	88.9	15	93.8	23	92.0
Shopping assistance	7	77.8	15	93.8	22	88.0
Housecleaning	8	88.9	14	87.5	22	88.0
Cooking	9	100.0	13	81.3	22	88.0
Transportation	7	77.8	10	62.5	17	68.0
Physical care	0	0.0	2	12.5	2	8.0
Other	5	55.6	12	75.0	17	68.0

Table 31

Caregiver Report of Social Interaction by Rural and Urban Residence

Variables	Group					
	(N = 9)		(N = 16)		(N = 25)	
	Rural		Urban		Total	
	N	%	N	%	N	%
PLA						
Nearly every day	9	100	16	100	25	100.0
Closest Relative						
Nearly every day	6	66.7	7	43.7	13	52.0
1 + week	1	11.1	6	37.5	7	28.0
2-3 x month	2	22.2	0	0.0	0	0.0
Hardly ever	0	0.0	3	18.8	3	12.0
Closest Friend						
Nearly every day	4	44.4	4	25.0	8	32.0
1 + week	2	22.2	7	43.8	9	36.0
2-3 x month	2	22.2	1	6.2	3	12.0
1 x month	1	11.1	0	0.0	1	4.0
Several times a year	0	0.0	1	6.2	1	4.0
Hardly ever	0	0.0	3	18.8	3	12.0
Other Relatives						
Nearly every day	3	33.3	3	18.8	6	24.0
1 + week	3	33.3	3	18.8	6	24.0
2-3 x month	1	11.1	4	25.0	5	20.0
1 x month	0	0.0	1	6.2	1	4.0
Several times a year	1	11.1	2	12.5	3	12.0
Hardly ever	1	11.1	3	18.8	4	16.0
Other Friends						
Nearly every day	3	33.3	3	18.8	6	24.0
1 + week	1	11.1	7	43.8	8	32.0
2-3 x month	2	22.2	2	12.5	4	16.0
1 x month	2	22.2	1	6.2	3	12.0
Several times a year	1	11.1	1	6.2	2	8.0
Hardly ever	0	0.0	2	12.5	2	8.0

Table 31 cont.

Variables	Group					
	(N = 9)		(N = 16)		(N = 25)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Neighbors						
Nearly every day	4	44.4	5	31.2	9	36.0
1 + week	1	11.1	3	18.8	4	16.0
2-3 x month	1	11.1	1	6.2	2	8.0
1 x Month	1	11.1	0	0.0	1	4.0
Several times a year	0	0.0	0	0.0	0	0.0
Hardly ever	2	22.2	7	43.8	9	36.0

reported social interaction nearly every day with close friends. Over one-third of rural caregivers and less than one-fourth of urban caregivers had social interaction with other relatives nearly every day. Over one-third of rural caregivers and less than one-fourth of urban caregivers had social interaction with other friends nearly every day. Over two-fifths of rural caregivers and almost one-third of urban caregivers reported social interaction with neighbors nearly every day. Over two-fifths of urban caregivers hardly ever had contact with neighbors and only slightly over one-fifth of rural caregivers hardly ever had social interaction with neighbors.

Caregivers were asked to rate how they had been feeling in the past month on a scale of 1 = very poor to 5 = very good (Table 32). Over two-fifths of all caregivers reported that they had been feeling good or very good in the past month. Almost one-third of urban PLAs felt poor or very poor versus only about one-tenth of rural caregivers.

Caregivers were also asked to rate their relationships with family and friends on a scale of 1 = very dissatisfied to 4 = very satisfied (Appendix 5). Over 90 percent of all caregivers were somewhat or very satisfied with their relationships with their family. Almost 90 percent of all caregivers were somewhat or very satisfied with relationships with their friends.

Social Support and Burden for Caregivers in Rural versus Urban Areas

The second aim of this study was to investigate rural and urban differences in levels of perceived social support and levels of burden for caregivers living in rural versus urban areas. Independent-samples *t* tests were used to determine whether significant differences exist in levels of social support and caregiver burden for caregivers living in rural versus

Table 32**Caregiver Report of Feeling in the Past Month by Rural and Urban Residence**

Variable	Group					
	(N = 9)		(N = 16)		(N = 25)	
	Rural		Urban		Total	
	N	%	N	%	N	%
Feeling in the Past Month						
Very poor	0	0.0	1	6.3	1	4.0
Poor	1	11.1	4	25.0	5	20.0
Average	4	44.4	4	25.0	8	32.0
Good	3	33.3	4	25.0	7	28.0
Very good	1	11.1	3	18.8	4	16.0

urban areas.

Social Support

Figures 9 and 10 display the distribution of scores for the caregiver sample on the MSPSS and the NOS measures of social support. Table 33 presents the means, standard deviations, and range of scores for the Multidimensional Scale of Perceived Social Support (MSPSS) and the Network Orientation Scale (NOS) for caregivers. The MSPSS is a 12 item instrument that provides a measure of perceived social support from three sources: family, friends, and a significant other. The MSPSS assesses the extent to which respondents perceive social support from each of those sources. The NOS is a 20-item instrument used to measure a person's propensity to use his or her social support network in a time of need. The items in the NOS are based on social support theory and measure

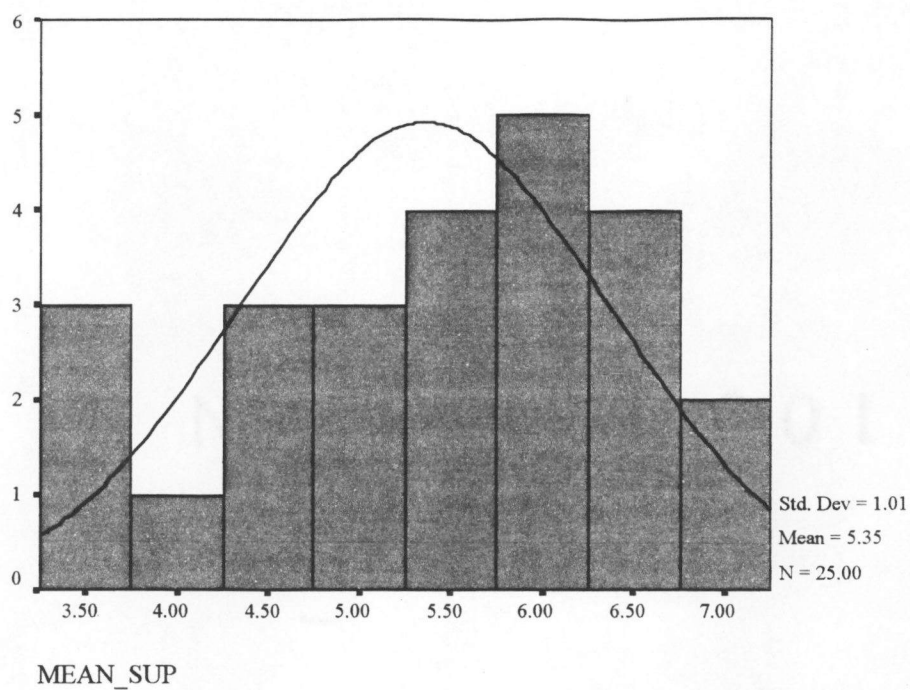


Figure 9. Frequency Distribution of the MSPSS Measure of Social Support for Caregivers

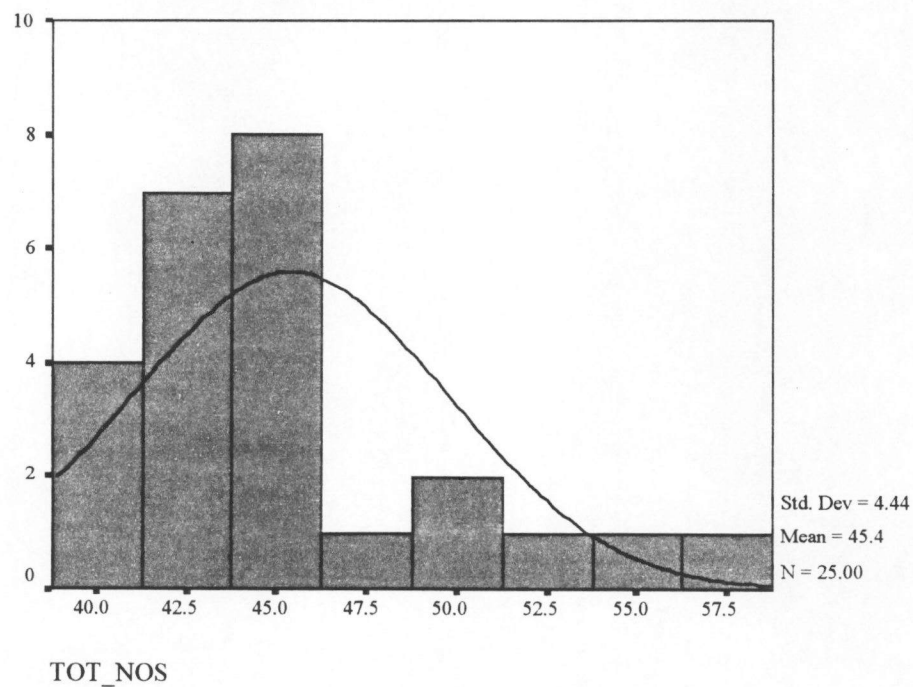


Figure 10. Frequency Distribution of the NOS Measure of Social Support for Caregivers

Table 33

Caregiver Means, Standard Deviations, and Ranges of Scores for Multidimensional Scale of Perceived Social Support and Network Orientation Scale by Rural versus Urban Area

<u>Instrument</u>	<u>Group</u>					
	<u>Rural</u>			<u>Urban</u>		
	<u>M</u>	<u>SD</u>	<u>Range</u>	<u>M</u>	<u>SD</u>	<u>Range</u>
MSPSS	5.4	.96	3.67 - 6.42	5.3	1.1	3.42 - 6.75
NOS	43.3	2.1	40 - 46	46.5	5.0	41 - 58
				45.4	4.4	40 - 58

the individual's unwillingness to maintain, nurture, or utilize those supports he or she has, which reflects a person's orientation toward his or her support network (Vaux et al., 1994). The data in Table 33 indicate that the overall mean score for the MSPSS among caregivers was 5.35 (SD = 1.0). This compares to a mean of 5.31 (SD = 1.46) for the MSPSS total norming sample (Zimet et al., 1988). Rural caregivers had a mean MSPSS score of 5.4 (SD = .96) and urban caregivers had a mean MSPSS score of 5.3 (SD = 1.1). Higher MSPSS scores reflect higher perceived social support.

The overall mean score for the NOS among caregivers was 45.4 (SD = 4.4). Information regarding a norming sample was not available for the Network Orientation Scale. The mean NOS score for rural caregivers is 43.3 (SD = 2.1) and the mean NOS score for urban caregivers is 46.5 (SD = 5.0). Higher NOS scores indicate a more negative perception toward maintaining, nurturing, or utilizing social support.

Tests of the Hypothesis on Social Support for Caregivers

Independent-samples *t* tests comparing MSPSS scores and NOS scores for caregivers in rural versus urban caregivers were conducted to evaluate the second hypothesis.

The second hypothesis to be examined was:

Hypothesis 2: Rural caregivers report more social support than urban caregivers.

Independent-Samples T Test for the MSPSS Measure of Social Support for Caregivers

The *t* test for the Multidimensional Scale of Perceived Social Support was statistically non-significant [$t(23) = .175, p = .863$]. The second hypothesis was not supported by the results of this test. Rural and urban caregivers were not found to differ significantly in perceived levels of social support as measured by the MSPSS.

Independent-Samples T Test for the NOS Measure of Social Support for Caregivers

A *t* test for unequal variances was used for the NOS measure of social support as a result of the finding that the Levene test of homogeneity-of-variances could not be assumed for these data (Agresti and Finlay, 1997; Leonard, 1976; Ott, 1988; SPSS, 1997).

The *t* test for unequal variances was statistically significant for the Network Orientation Scale [$t(23) = -2.19, p = .039$]. This significant result for the NOS indicates that urban caregivers on the average are less willing to maintain, nurture, or utilize their social support resources than are rural caregivers. Urban caregivers in this sample were more likely to perceive the use of their social support network as dangerous or undesirable for seeking aid and service from others. The result of the *t* test for social support measured by the NOS supports the research hypothesis that rural caregivers have higher levels of social support than urban caregivers.

Caregiver Burden

The last part of this study was an investigation of rural and urban differences in levels of burden for caregivers of PLAs. A *t* test was used to determine whether or not significant differences exist in levels of burden for caregivers in rural versus urban areas.

Figure 11 displays the distribution of caregiver scores for the CBI. Table 34 presents the means, standard deviations, and ranges of scores for the Caregiver Burden Interview (CBI). The data in Table 34 indicate that the mean score on the CBI among caregivers was 22.04 (SD = 11.07). Information regarding a norming sample was not available for the CBI. The mean CBI score for rural caregivers is 15.9 (SD = 10.0) and the mean CBI score for urban caregivers is 25.5 (SD = 10.4). Higher CBI scores indicate greater

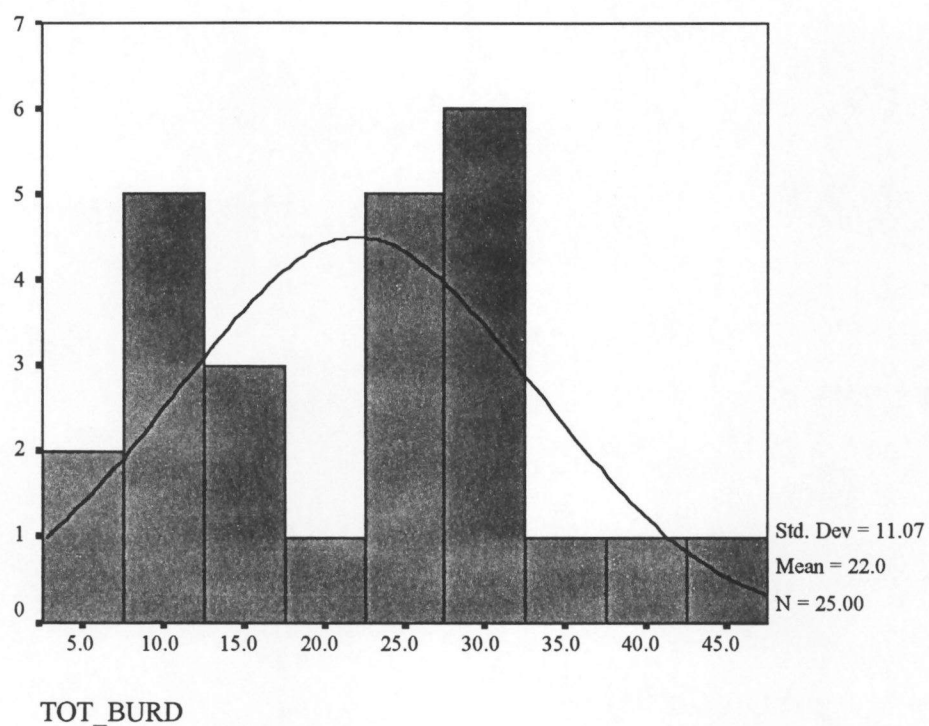


Figure 11. Frequency Distribution of the CBI Measure of Burden for Caregivers

Caregiver Means, Standard Deviations, and Ranges of Scores for the Caregiver Burden Interview by Rural versus Urban Area

134

caregiving distress (Zarit, 1990). It has been suggested that for the Caregiver Burden Interview, levels of burden can be differentiated according to the scale scores. Waller Snyder (1993) suggests that "estimates of the degree of burden for the CBI can be made according to the following scale: scores 0 - 20 = low or no burden, 21 - 40 = mild to moderate burden, 41 - 60 = moderate to severe burden, and 61 - 88 = severe burden" (p. 86).

Test of the Hypothesis on Burden for Caregivers

An independent-samples t-test comparing CBI scores for caregivers in rural versus urban caregivers was conducted to evaluate the third hypothesis. The third hypothesis to be examined was:

Hypothesis 3: Rural caregivers report less burden than urban caregivers.

Independent-Samples T Test for the Measure of Caregiver Burden

The results of the *t* test for the CBI measure of caregiver burden was significant [*t* (23) = -2.254, *p* = .034]. Rural caregivers on the average (*M* = 15.9, *SD* = 10.0) reported less caregiver burden than did caregivers from urban areas (*M* = 25.5, *SD* = 10.4). Study findings provide support for the third hypothesis that rural caregivers have lower levels of burden than urban caregivers.

Summary

Chapter 5 examined the results of the caregiver study sample. Statistical findings indicate that the level of social support on the Multidimensional Scale of Perceived Social Support was not significantly different for caregivers in rural versus urban areas. Results do show, however, that willingness to utilize or maintain social support as measured by

the Network Orientation Scale was significantly different for caregivers living in rural versus urban areas. Caregivers in urban areas have higher NOS scores. This finding indicates that urban caregivers were less willing to utilize or maintain their social network than rural caregivers.

Urban caregivers were also found to have higher levels of burden compared to rural caregivers as measured by the difference in scores on the Caregiver Burden Interview. The difference in caregiver scores on the CBI is statistically significant, indicating that caregivers living in an urban area have a higher level of burden than caregivers in rural areas. According to this scale, rural caregivers in this study are identified as having low burden ($M = 15.9$) and urban caregivers are identified as having mild to moderate burden ($M = 25.5$).

CHAPTER 6

DISCUSSION OF FINDINGS

The purpose of this study was to examine the differences in PLAs and their caregivers living in rural versus urban areas. This chapter includes a discussion of the results of the analyses reported in Chapters 4 and 5. The chapter begins with a summary of the study findings, a discussion of the findings, and study limitations. Following this, implications for research, policy, and practice will be discussed.

Summary of Study Findings

The first aim of this study was to examine differences in social support and to explore types of need for PLA study participants living in rural ($n = 32$) versus urban ($n = 51$) areas. The results of the regression analysis did not offer support for the first research hypothesis. Rural versus urban residence was not found to be a predictor of social support for PLAs in the current study. Rural versus urban residence was not found to be a predictor of social support on either measure of social support, the Multidimensional Scale of Perceived Social Support or the Network Orientation Scale.

Statistical analyses did find that the combination of predictor variables used in the regression analysis for both the MSPSS and the NOS measures was significant in predicting social support for PLAs. One independent variable was found to be a significant predictor of PLA social support for each measure of support: caregiver status was a significant predictor of social support as measured by the MSPSS and sexual orientation was a significant predictor of social support as measured by the NOS.

Exploratory results of PLA types of need found variation in met and unmet need for PLAs living in rural versus urban areas. Rural PLAs reported a greater proportion of unmet need than did urban PLAs for over three-fourths of services included in the needs assessment. Slightly over half of all PLAs were dissatisfied with service needs that had been met. Combining needs that were unsatisfactorily met with needs that were unmet resulted in approximately one-fourth of all PLA needs being unmet.

The second aim of this study was to examine differences in levels of social support and burden for the caregiver study participants living in rural ($n = 9$) versus urban ($n = 16$) areas. Statistical analysis on the NOS resulted in a significant difference in the level of social support between caregivers living in rural versus urban areas for the Network Orientation Scale measure of social support. Urban caregivers had significantly higher scores on the Network Orientation Scale compared to rural caregivers indicating that urban caregivers exhibited a greater unwillingness to access and maintain support from the support network (lower levels of social support). No significant difference in level of social support as measured by the MSPSS was found for caregivers living in rural versus urban areas. These findings provide partial support for the second study hypothesis that rural caregivers have higher levels of social support than urban caregivers.

Study findings offer support for the third research hypothesis that rural caregivers have lower levels of burden compared to urban caregivers. The statistical analysis determined that significant differences exist in levels of burden for caregivers living in rural versus urban areas as measured by the Caregiver Burden Interview. Rural caregivers had significantly lower scores for the Caregiver Burden Interview compared to urban

caregivers, demonstrating that the level of perceived burden for rural caregivers was lower than for urban caregivers. These findings are discussed below. In addition, limitations of this study and recommendations for policy, practice, and research are addressed.

Discussion of PLA Findings

The first hypothesis was not supported by the statistical analysis. No significant differences in levels of social support were found for PLAs living in rural versus urban areas.

Social Support for PLAs

The current study findings contradict the results of previous research (Bozovich et. al. 1992; Rounds, 1988). The current study found that conditions previously thought to negatively impact social support (rural residence and homosexuality) were either not significant or were positively related to social support for PLAs in the study sample. Previous research has indicated that HIV/AIDS is a highly stigmatized condition and that formal service providers in rural communities were likely to limit involvement with PLAs and treatment of PLAs. Consequently, it is surprising that the results indicated a finding of no significant difference in levels of support for PLAs in rural versus urban areas.

Previous findings have also indicated that PLAs are likely to fear prejudice and possible breach of confidentiality in rural areas and may be unwilling to pursue support from rural communities. Rural areas in general tend to lack services and support for persons with specialized healthcare needs, and frequently barriers exist regarding the use of available services (Strickland and Strickland, 1996; Wismer, 1992).

Nevertheless, Cohn et al. (1994) and Sowell (1996) found that popular reasons for PLAs to move to rural areas include social support (to be near family and friends) and that migration back to rural areas (home) may vary according to HIV mode of infection. Informal sources of support in rural areas may be perceived as more available and accessible than formal sources of support and urban areas may exhibit improved access to formal sources of support. Possible explanations for the finding of no meaningful differences in levels of perceived social support for PLAs in rural areas may include the possibility that: informal support buffers the lack of formal services accessible to rural PLAs; or that the use of formal services may have less importance for rural PLAs; or even that the distance to formal sources of support are not prohibitive to rural PLAs obtaining services.

In addition, the current study found that most PLAs (80%) believed they had been infected with HIV as a result of sexual activity. Injecting drug users may have different levels of social support compared to other HIV-infected populations (Crandall, 1991). This suggests that social support may vary according to HIV mode of infection, including the type of sexual behavior, i.e., gay/bisexual sex, heterosexual sex, and other risk-taking behavior such as injecting drug use.

Support measures in the current study focus on perception of support available and unwillingness to use support primarily directed at informal sources, i.e., family, friends, and partner/spouse. While there is not statistically significant support for the first research hypothesis, the results indicate that informal social support is available for PLAs in rural and urban areas. Future studies which focus on examining perceptions of formal sources

of support for PLAs may be more likely to indicate significant differences according to area of residence. For example, PLAs may migrate to rural areas to receive social support from friends and family (informal support). However, access to informal sources of support may not indicate availability and utilization of formal support services such as specialized healthcare services.

Informal social support may modify the need for some formal services, such as financial assistance and mental health services. The current study findings suggest that although rural PLAs are more likely to have a greater proportion of unmet need (formal support) than urban PLAs, levels of informal social support do not differ for PLAs living in rural versus urban areas.

Caregiver status (whether or not the PLA had an identified caregiver) was the only predictor variable in the regression equation that was statistically significant ($p < .05$) for the MSPSS measure of social support. Rural versus urban residence, sexual orientation, living in hometown, and length of time in current residence were not found to be statistically significant predictors for the MSPSS measure of social support for PLAs. The finding that caregiver status was predictive of social support for PLAs is congruent with the MSPSS. Caregivers in the study were primarily spouses/partners of PLAs, family members, or friends and the MSPSS measures perceived social support from these three specific sources: friends, family, and a significant other.

For the MSPSS regression equation, PLAs with caregivers were found to be more likely to have higher levels of perceived social support than PLAs without an identified caregiver. Several study findings indicate that persons suffering from chronic or life-

threatening illnesses such as cancer and HIV/AIDS prefer to receive informal support from family and friends and may expressly return to communities to receive this support if they have previously moved away. These results also suggest that having a partner or spouse is vital to HIV-infected persons. In this sample, most of the identified caregivers (65%) were a partner or a spouse to the PLA. Hence, the implications are that this one relationship may be the primary factor in the perception of social support by PLAs (Stokes, 1983; West et al., 1996). The existence of a primary caregiver may also enhance the PLAs' access to other sources of support or may lead to the belief that no additional support is necessary.

Sexual orientation (gay/bisexual versus heterosexual) was the only statistically significant social ($p < .05$) predictor variable in the regression analysis for the NOS measure of social support. In fact, gays/bisexuals were found to have lower NOS scores than heterosexuals. Therefore, heterosexuals were found to be less willing to utilize and maintain their social support network than gays/bisexuals. The other four predictor variables included in the regression equation were not found to be significantly related to the NOS measure of social support for PLAs.

The finding that heterosexuals had higher scores on the NOS than gays/bisexuals was surprising. Due to the stigmatization of persons who are gay in general, one would assume that a gay person with HIV/AIDS would receive less social support than heterosexual persons with HIV/AIDS. Yet higher levels of social support reported by gays/bisexuals may be a result of the proactive response of the gay community. This response began early in the HIV/AIDS epidemic and may continue to influence the

perception of social support for this population. It is also plausible that communities with a low incidence of HIV/AIDS may be less aware of the spread of HIV/AIDS in less stigmatized populations. Heterosexuals with HIV/AIDS may have a greater fear of the disease stigma than gay persons.

Persons with different modes of HIV infection may believe that they will be categorized as being gay or as being from populations traditionally less deserving of familial, social, and community care and concern due to behavior deemed as immoral or irresponsible (Beedham and Wilson-Barnett, 1995). As a result, heterosexuals may be less willing to confide in others regarding HIV infection and may also lack the motivation to maintain or access support, perceiving that it may be useless or even dangerous to do so.

Although the results of the regression analysis for both measures of social support were found to be statistically significant, 90 percent of the variation in social support for PLAs was left unexplained for the NOS and the MSPSS measures of social support. This result may indicate that the measures of social support used in this study were not appropriate for use with HIV-infected persons.

PLA Types of Need

Study findings revealed new information regarding the types of need for PLAs. An exploratory analysis was conducted comparing healthcare-related and social service needs of PLAs living in rural versus urban areas. Medical care (95.2%), case management (61.4%), and dental care (59.0%) were the services most likely to be needed by PLAs in the current study. Two-fifths of rural PLAs reported at least one unmet need, compared

to one-third of urban PLAs. PLAs who lived alone and had lower monthly incomes were more likely to have unmet needs.

In the current study, as has been true for previous research on PLAs, the study sample was obtained through an HIV/AIDS service agency. Information is not available for PLAs who have not utilized at least some type of service. As a result, level and type of unmet needs for PLAs in the current study are not necessarily representative of all PLAs in the study region.

Previous research recommendations for studying PLA needs have included the identification of satisfaction with services received (Bonuck, 1993). As a result, the current study included the investigation of satisfaction of met service needs for PLAs living in rural versus urban areas. Although rural PLAs were more likely to have unmet needs, urban PLAs were more likely to be dissatisfied with met needs.

Needs that were not satisfactorily met were classified as unmet needs. This classification resulted in an overall increase in unmet need as well as an increase in the proportion of PLAs who had unmet needs. As a result of this reclassification about 30 percent of rural PLAs needs and almost 20 percent of urban PLA needs were unmet and the proportion of rural PLAs with unmet increased from 41 to 50 percent and for urban PLAs from 29 to 41 percent.

The finding that a greater proportion of unmet need exists for PLAs in rural areas than for PLAs in urban areas was not surprising. Rural areas have been found to have limited resources, especially concerning access to healthcare, which may be especially true for PLAs who frequently require specialized care. Rural communities also frequently lack

public services such as transportation and tend to have increased levels of substandard housing (Holt, 1990).

Needs most likely to be unmet for rural PLAs were housing and financial assistance for medication. Urban PLAs expressed a greater likelihood for unmet needs related to housing and mental health/counseling services. In fact, mental health/counseling was the only need that was more likely to be unmet for urban PLAs than for rural PLAs. Previous research suggests that rural community residents are less likely to utilize mental health services and tend to be suspicious of these services (Kenkel, 1996). The overall proportion of unmet need for PLAs in the current study was similar to findings of unmet need in previous research (Bonuck, 1993; Marx et al., 1997; Wight et al., 1995).

The current study is unique in that it examines the difference in types of need for PLAs living in rural compared to urban areas. Additionally, the entire region of the current study has a low incidence for HIV infection, compared to the large, metropolitan areas of the previously mentioned studies. Therefore, information has been gathered for populations previously unexamined.

The needs assessment for this study referred to formal service needs that PLAs may have as a result of the effects of the disease. Results of the PLA needs assessment indicate that unmet needs related to social/community services and sometimes healthcare services are common for persons with HIV infection. While rural PLAs were found to have a greater proportion of unmet need, PLAs in general were likely to be at risk for unmet need or for being dissatisfied with services received.

Discussion of Caregiver Findings

Results of the data analysis for caregivers provide partial support for the second research hypothesis that caregivers in rural areas have higher levels of social support than urban caregivers. Study findings support the third research hypothesis that rural caregivers have lower levels of burden than urban caregivers.

Social Support for Caregivers

Surprisingly, there was not a statistically significant difference in caregiver scores on the MSPSS measure of social support for those living in rural versus urban areas.

However, results of the statistical analysis for the NOS measure of social support were statistically significant. Urban caregivers had significantly higher NOS scores than rural caregivers. Higher scores on the NOS suggest lower levels of social support, including an increased hesitancy to access existing support resources and a negative orientation toward the social network. Results of this study show that urban caregivers are more likely to be unwilling to maintain or utilize support from their social network than rural caregivers.

Social support for caregivers is vital to the social support of the PLA. A PLA's perception of social support and ability to cope with HIV/AIDS may fluctuate with caregiver support and coping ability (Pakenham, 1995). Previous research shows that better support for caregivers will result in better support for the PLA and that certain types of caregivers for PLAs (persons at risk for HIV, persons with lower incomes) may be more at risk for increased burden than others (Turner and Catania, 1997).

The lack of significant differences on the t-test for the MSPSS measure of social support for rural and urban caregivers is difficult to explain. Previous findings indicate

that the NOS and MSPSS are highly correlated (Cecil, 1995). As a result it was expected that the results of the statistical tests would be similar for both measures of social support. One problem regarding the NOS study results is the low alpha for reliability of this measure of social support ($\alpha = .39$). The result of the reliability analysis for the NOS in the current study is contradictory to the use of the instrument in previous research. It is not known if this is due to the small sample size, unequal variation in scores between urban and rural caregivers, or in the low reliability of the instrument. Therefore, there is limited support for the result of significant differences in social support for rural versus urban caregivers.

Caregiver Burden

Results of the statistical analysis for the CBI measure of caregiver burden were statistically significant: urban caregivers had higher scores on the CBI than rural caregivers. Higher scores on the CBI suggest higher levels of burden. Results provide support for the third research hypothesis that rural caregivers have lower levels of burden than urban caregivers.

While burden scores were significantly different for rural and urban caregivers, the mean scores for both groups were in the lower range according to the CBI measure and research on previous caregiver populations (Parker, 1994; Zarit, 1990). Previous research suggests that urban caregivers in the current study are mildly or moderately burdened, while rural caregivers have low or no burden (Waller Snyder, 1993; Zarit, 1990).

While the levels of caregiver burden for the rural and urban caregivers were surprisingly low, the findings do make a unique contribution to the field of caregiver

research. These findings are distinctive because research on caregivers of PLAs has been limited, and no previous research exists to describe rural versus urban differences in caregivers of PLAs.

Previous research findings indicate that who the caregiver is may also determine the level of burden experienced by the caregiver in the caregiving role. Turner and Catania (1997) found that greater burden was experienced by caregivers who were male, who had lower incomes, and who were unaware of their own HIV status. In addition, previous research on caregivers for PLAs has usually focused on large, metropolitan areas of primarily gay populations (Pakenham et al., 1995; Parker, 1994; Wardlaw, 1994; Sipes, 1998). The findings of the current research bring attention to the increasing occurrence of HIV/AIDS in varying communities, especially communities previously thought to be unaffected by the HIV/AIDS epidemic.

Current study findings support previous research that caregivers for PLAs are usually partners or spouses of PLAs. This has been a consistent finding throughout previous research, especially for PLAs in the gay community (Folkman et al., 1994; Pakenham et al., 1995).

Study Limitations

Due to various limitations of the current study, caution should be exercised when interpreting the results. The selection bias concerning the recruitment of participants also limits the generalizability of this study. First, because this is a convenience sample, PLA and caregiver sociodemographic characteristics are possibly a result of recruitment

strategies. Participants in the current study may not be representative of PLAs and caregivers who live in other parts of the country.

The only source of PLA study participation was the local AIDS service organization (ASO). And only PLAs on the ASO mailing list and persons visiting the agency received notice regarding study participation. In addition, AIDS service organizations have been traditionally viewed as predominantly designed for or used by gay men (Beedham and Wilson-Barnett, 1995). Heterosexuals, women, and minorities who access services from an ASO may be more distressed than those not accessing support from an ASO since these organizations are generally seen as stigmatizing.

The PLA sample was the source for the recruitment of caregiver study participants. Caregiver study participation was limited to PLA study participants who had a caregiver and who were willing to give the investigator permission to contact their caregiver. Caregivers of PLAs who were not informed of the opportunity to participate in the study were not able to be contacted by the investigator regarding study participation.

Also, the PLA and caregiver samples consist of participants who volunteered and were paid \$15.00 for their participation, activities that are potential sources of bias. PLA participants who were asymptomatic, who had been infected for shorter periods of time, or who were unwilling or unable to seek services may not access services or support from an ASO. Although these techniques are common practice in the field of social and behavioral research, a random sample of PLAs and caregivers would have resulted in a better representation of these populations.

The use of a cross-sectional design to examine relationships that are possibly causal, such as the effect of predictor variables on the dependent variable, is also a study limitation. Because of this design limitation, the predictor variables in this study cannot be assumed to occur prior to the experience of social support for PLAs. Consequently, it is not possible to definitely establish a causal connection between the predictor variables (sexual orientation and caregiver status) and the dependent variable (level of social support).

Another issue of concern was the use of categorical predictor variables in the regression analysis. Although nominal variables were dummy coded for use in regression analysis, quantitative measurement is typically recommended for this type of statistical technique. Future researchers may wish to determine if variables used in this study could be measured differently.

Also, the small sample size for the PLA group limited the number of predictor variables that can effectively be entered into the regression equation. This limitation may lead to an omission of important variables. If other relevant variables had been included in the regression model, the significance of sexual orientation or caregiver status in levels of social support for PLAs may not be maintained.

The very small caregiver sample prohibited the use of regression analysis and limited analysis of caregiver data to the use of independent-samples *t* tests of mean scores for comparing rural versus urban groups. As a result, it is not known if variables other than rural versus urban residence are related to level of social support and burden for caregivers.

Forty-four percent of PLAs who the investigator attempted to contact participated in the study and 89 percent of caregivers contacted by the completed study interviews. It is important to note that for PLAs this number represents the percentage of PLAs the investigator attempted to notify regarding study participation, which was also a limitation for the caregiver sample. It is not known how many PLAs did not receive this notification since the ASO was responsible for the initial contact of PLAs on their confidential client mailing list and the investigator may not know of PLA deaths or address changes, etc.

It is also not known what the social support levels are for PLAs who received study information but chose not to participate. It is possible that these PLAs were feeling such low levels of support that participating in a survey interview may have felt risky or dangerous. Thus, many of the PLAs who chose not to participate may be suffering from the lowest levels of support and were not represented in this study.

The current study also does not include PLAs in the study area who are not on the mailing list of the ASO and PLAs who are not clients of the ASO; therefore, PLAs unaware of AIDS services or fearful of accessing AIDS services are not represented. In addition, some caregivers may never have been notified of the opportunity to participate since the PLA was responsible for providing the researcher with information necessary to contact the caregiver for study participation.

Because the investigator could not conduct all the surveys personally, it was necessary to assume that the trained interviewers were consistent and conscientious in their interviewing method. This assumption seems plausible because the interviewers were

given specific instruction in the interview method and the interview format required minimal interpretation.

It is also not known what motivated PLAs and caregivers to participate in the study. However, PLAs and caregivers frequently responded that the opportunity to further the understanding of HIV/AIDS and to maintain interest and support surrounding HIV/AIDS were motivating factors. Other participants reported being appreciative of the interest of the investigator as someone who could be viewed as a safe source for listening to the discussion of personal issues regarding the impact of HIV/AIDS. Most of all, participants reported being motivated by the idea of assisting the investigator in completing her education and feeling some responsibility in helping that to happen.

PLA and caregiver sample sizes were small, but future research activities can be developed as a result of study findings. First, the study can be replicated in other areas of the United States. The findings of this study can be compared with those of PLAs and caregivers in other regions of the country to see if findings of the current study can be replicated and to determine if there are differences or similarities in PLA and caregiver social support, PLA types of need, and caregiver burden. Continued research with a more representative sample of PLAs and caregivers permits a greater likelihood of predicting whether or not having a caregiver and sexual orientation are significantly related to PLA social support. Another option for future research would be a follow-up study of the PLA and caregiver participants of the current study.

Implications for Research

Treatment innovations continue to improve outcomes for persons infected with HIV, resulting in increased longevity and usually an improved quality of life for PLAs. As a result, HIV/AIDS may be viewed as a more chronic condition that may offer a greater hope of a cure for PLAs prior to reaching the end-stage of the disease process.

Nevertheless, there is currently no cure for AIDS, and as PLAs live longer, the incidence of HIV/AIDS continues to increase and is becoming a growing concern for all persons. Even as the faces of people infected with HIV change, the stigma attached to the disease continues to impact all infected persons.

This study allowed for the examination of PLA and caregiver differences based on area of residence. It is vital for those who conduct HIV/AIDS research to further investigate the relationships of PLAs and caregivers in an attempt to understand the role of persons who are perceived as sources of support and to establish methods for maintaining and enhancing this support.

Previous studies examining the impact of living in rural versus urban areas have been inconsistent and tend to vary according to region and population being studied. For some, the closeness of rural communities and the increased conservative values have been reported as a source of comfort and security. For others, these characteristics of rural communities have been punishing or at least exclusionary.

Since the current study took place in a conservative region of the United States (East Tennessee), it was expected this would be true even moreso for rural communities within the study region. Nevertheless, the study did not find low levels of social support for

PLAs in general and no significant differences were found comparing social support for PLAs in rural and urban areas.

Though no significant relationship was found between social support and rural versus urban residence for PLAs, differences were found for caregivers. Further research is needed to determine the reliability of this finding, especially due to the small number of caregiver participants in the current study.

Results of this study indicate that differences in the perception of social support may exist for gays or bisexuals versus heterosexuals. Less research has been conducted with heterosexuals infected with HIV versus HIV-infected gay men, especially in rural areas and in communities with a lower incidence of HIV infection. Current study findings also point out the need to investigate gender differences as well, since only a small proportion (17%) of the current PLA sample were female; hence, this study offers guidance for future research.

The changing demographics of HIV/AIDS suggest that researchers must pursue more diverse populations infected with HIV to understand the impact of AIDS on these populations. As a result of the growing incidence of HIV infection in populations other than gay men, the role of the caregiver has also changed. An interesting topic of future research will be continued investigation of the role of caregivers for PLAs, including who the caregivers are, what they do, and the period of time required of the caregiving role.

Social support and burden are not necessarily stable conditions. As a result of the changes in demographics of PLAs, the source of and need for support by PLAs also

change, consequently affecting the support needs of caregivers and potentially the level of caregiver burden.

Finally, PLAs report a high level of need for health and social services. This study offered an exploratory analysis of PLA types of need. Variation was found in types of need by PLAs living in rural versus urban areas. Future research is necessary to determine the significance of these residential differences and to also determine what contributes to unmet need for PLAs.

Implications for Policy

Attitudes of PLAs and their caregivers toward the use of formal and informal sources of support may influence their desire to use these resources. AIDS service organizations have traditionally focused on HIV-infected gay male populations living in metropolitan areas. Current study findings indicate the need to acknowledge the increasing occurrence of HIV/AIDS in other populations and to adjust programs and services accordingly. Heterosexuals, women, and minorities may be not be accepted or feel accepted within traditional AIDS organizations and their needs may vary from those traditionally expressed by gay men.

Public health departments exist within every county in the state of Tennessee. These organizations tend to be viewed as less stigmatizing than an ASO since they provide services concerning all relevant public health issues. These departments are unique in that they exist in every county, thus are viewed as accessible even in the most rural areas. The opportunity exists for services needed by HIV-infected populations to be offered through these departments, possibly in conjunction with ASOs.

The state health department in Tennessee collects information about the spread of HIV/AIDS throughout the state. It is vital that this information is successfully disseminated to health and human services practitioners as well as to persons at risk for infection. Developing community involvement of institutions and organizations such as local governments, health departments, hospitals, medical clinics, mental health centers, churches, and schools may be an effective means of promoting HIV-preventive behavior and educating persons about the rapidly changing demographics of disease prevalence.

Study findings also indicate the possible need for new or different programs and services to address the needs of caregivers, especially in urban areas. Formal services need to be promoted or developed which provide social and emotional support for AIDS caregivers. Caregiver support groups and telephone networks could function as support for caregivers and may be organized according to the personal characteristics of caregivers. For example, implementing separate caregiver support groups for gay partners, heterosexual partners, and parents and family may be more effective at meeting the needs of these different groups of caregivers.

Services and support programs may be directed toward PLAs who do not have a primary caregiver. Buddy programs, support groups, etc., may benefit those PLAs with decreased access to informal sources of support. Programs specific to the characteristics of the PLA may improve the PLA's willingness to use services. Heterosexuals, women, and minorities may be more willing to use services they believe are better addressed to meet their needs.

Federal policy also impacts the availability and accessibility of formal and informal sources of support for PLAs and their caregivers. Currently the Family and Medical Leave Act of 1993 applies only to persons who are legally married to the person who is ill or who are biological family members. Since most caregivers of PLAs are same sex partners, they are at risk for losing their job or having to quit their job in order to maintain their caregiver role. The inclusion of any person who is a designated caregiver to be eligible for benefits under this policy is vital to the well-being of the caregiver and the PLA.

Previous federal policy has limited HIV/AIDS funding to areas with the greatest incidence of HIV/AIDS. This limitation leaves communities with low incidence at risk for increased problems when trying to serve PLAs. These policies encourage PLAs to live in areas where HIV/AIDS funding is available, which in return may lead to an overwhelming number of critically ill persons with HIV/AIDS residing in metropolitan communities. The burgeoning occurrence of PLAs in metropolitan areas is likely to lead to overburdened resources, such as hospitals, individual health care providers, housing services, and mental health services. Current legislation is being proposed to filter funds to more communities in an attempt to alleviate the burden placed on metropolitan areas with the greatest incidence of HIV/AIDS.

Implications for Practice

The results of this study point out the relationship between PLA sociodemographic characteristics and social support for PLAs. Study findings also suggest that living in a rural versus urban residence may have a more significant impact on caregivers than on

PLAs. These findings at least support the idea that different variables may affect levels of social support for PLAs and caregivers.

Social work professionals should be aware that the perception of social support may be affected by several factors. For example, heterosexuals infected with HIV may be more likely to report lower levels of social support than gays or bisexuals.

PLAs reporting to have a primary caregiver are likely to have higher levels of social support. As a result, identifying whether or not PLAs have a caregiver and understanding the effect of the relationship for PLAs and caregivers is important for human services professionals when working with these populations.

Rural versus urban residence may have a stronger effect on social support for caregivers than for PLAs. Social support may in turn may affect caregiver feelings of burden. Levels of caregiver burden were surprisingly low in the current study. Social work providers should be alert to the long-term effect of caregiving on caregivers. In the current study, most caregivers reported filling this role for five years or less. In fact, only 12 percent of the caregiver sample had been caregivers six or more years, and all resided in an urban area. Improved treatment for HIV/AIDS may result in a change in the length of time required to be a caregiver of an HIV-infected person as well as a change in the role of the caregiver. Examining the role of caregivers over time will provide helpful information regarding the relationship of PLAs to caregivers and their effect on each other.

Results obtained in this study suggest that the following implications should be considered by the professionals working with PLAs. Health and social service workers

need to be aware of the psychosocial characteristics of PLAs, especially regarding the support network of PLAs and basic personal characteristics of PLAs, such as whether or not they have a partner/spouse or a caregiver, their sexual orientation, and even how they were infected with HIV/AIDS.

As the spread of HIV/AIDS continues, the characteristics of persons infected and affected change. Gay men, injecting drug users, and prostitutes are no longer the only persons suffering from the effects of this disease epidemic. In order to develop or enhance informal support as well as formal support resources for PLAs, it is important to recognize specific characteristics of PLAs and to understand how these characteristics impact the PLA response to HIV/AIDS to ensure the fit of services and interventions to better meet their changing needs.

Conclusion

In summary, the present study found that PLAs and caregivers have a need for informal support. The only significant differences in level of social support in rural versus urban areas was for caregivers, measured by mean differences on the Network Orientation Scale measure of social support. For the NOS measure, rural caregivers reported significantly higher levels of social support than did caregivers in urban areas. However, these results must be reviewed with caution due to the small sample size and problems with reliability of the instrument for this sample.

In the current study, level of burden was found to be significantly different for caregivers in rural versus urban areas. Urban caregivers had higher levels of burden than rural caregivers. This finding may reflect an increasing reliance on formal versus informal

sources of support for caregivers in urban areas, less satisfaction with formal support, and less perceived availability of informal social support.

Further research is necessary to understand the relationship between caregiver burden and area of residence. Nevertheless, while levels of burden differed in rural versus urban areas, neither caregiver group reported high levels of burden. Urban caregivers reported mild to moderate burden and rural caregivers reported low or no burden. This finding is unusual compared to the reports of caregiver burden for other populations of caregivers. Further research is vital to examine the accuracy of these findings and to determine factors that influence these outcomes.

Finally, it is important to note that a major change in the medical treatment of PLAs occurred prior to this study. Beginning in mid-1996, a new class of drugs appeared for the treatment of AIDS, which has offered many HIV-infected persons the opportunity for a more extended period of life and improved quality of life. This new treatment regimen has altered the perception of HIV/AIDS and, although no cure has been discovered, PLAs are now more likely to have a lengthy (chronic) period of illness. This change and the hope for continued improvements in the treatment of HIV/AIDS may result in the perception that a cure may be discovered prior to persons reaching the terminal stage of disease.

Long-term effects of these new drug treatments are unknown, and in the short-term many infected persons may experience a remarkable change in their health status as a result of these improvements in treatment of the disease. An improvement in PLA health status will undoubtedly change the perspective of caregivers. As a result, caregivers may

be unsure of their role and the changes in long-term care needs of PLAs. As treatment regimens change, PLA and caregiver needs will change. Social work research and practice with these populations must adjust to these changes accordingly.

REFERENCES

Aday, L. A. (1985). Hospital Sponsored Medical Groups: Their Impact on Access to Primary Care in Rural Communities. Journal of Community Health, 10(3), 180-194.

Adelman, M. (1989). Social Support and AIDS. AIDS and Public Policy, 4(1), 32-39.

Agresti, A. F., Barbara. (1997). Statistical Methods for the Social Sciences. (Third ed.). Upper Saddle River: Prentice Hall.

AIDS/STD News Report. (1996). AIDS in Rural Communities Traced to Gay Men Returning From City Life. Silver Spring: CD Publications.

Albrecht, T. L. & Adelman, M. B. (1987). Dilemmas of Supportive Communication. In T. L. Albrecht and M. B. Adelman, M. B. (Eds.), Communicating Social Support (pp. 240-254). Newbury Park: Sage.

Funding Renewed for Rural AIDS Center. (1997). American Medical News, 39(35), 18.

Baker, N. T., & Seager, Robert, D. (1991). A Comparison of the Psychosocial Needs of Hospice Patients with AIDS and Those with Other Diagnoses. In M. A. O'Rawe, and Tehan, Clare B. (Ed.), AIDS and the Hospice Community (pp. 61-70). Binghamton: Harrington Park Press.

Barber, C. E. (1988). Correlates of Subjective Burden Among Sons and Daughters Caring for Aged Parents. Journal of Aging Studies, 2(2), 133-144.

Barrera, M. J., Jr, & Baca, Louise M. (1990). Recipient Reactions to Social Support: Contributions of Enacted Support, Conflicted Support and Network Orientation. Journal of Social and Personal Relationships, 7, 541-551.

Barrera, M. J., Jr, Sandler, I. N., & Ramsay, T. B. (1981). Preliminary Development of a Scale of Social Support: Studies on College Students. American Journal of Community Psychology 11, 435-447.

Bechtel, G. A., & Swartzberg, Barbara B. (1993). Social Support Among Gay Men with AIDS or at High Risk for AIDS. AIDS Patient Care, 7(4), 213-215.

Beedham, H. & Wilson-Barnett J. (1995). HIV and AIDS Care: Consumers' Views on Needs and Services. Journal of Advanced Nursing, 22, 677-686.

Berkman, L. F. (1984). Assessing the Physical Health Effects of Social Networks and Social Support. Annual Review of Public Health, 5, 413-432.

Birkel, R. C. & Repucci, N. D. (1983). Social Networks, Information-Seeking, and the Utilization of Services. American Journal of Community of Psychology, 11(2), 1983.

Bloom, J. R., Fobair, Pat, Spiegel, David, Cox, Rick S., Varghese, Anna, & Hoppe, Richard. (1991). Social Supports and the Social Well-Being of Cancer Survivors. Advances in Medical Sociology, 2, 95-114.

Bonuck, K. A. (1993). AIDS and Families: Cultural, Psychosocial, and Functional Impacts. Social Work in Health Care, 18(2), 75-89.

Bonuck, K. A. (1994). The Unmet Health Service Needs of Persons with HIV and AIDS, and Factors Associated with Them. Unpublished Ph.D., Rutgers, New Brunswick.

Bonuck, K. A., Arno, Peter, Green, Jesse, Fleishman, John, Bennett, Charles L., Fahs, Marianne C., and Maffeo, Carla. (1996). Self-Perceived Unmet Health Care Needs of Persons Enrolled in HIV Care. Journal of Community Health, 21(3), 183-198.

Bor, R., Miller, Riva, & Goldman, Eleanor. (1993). HIV/AIDS and the Family: A Review of Research in the First Decade. Journal of Family Therapy, 15, 187-204.

Bozovich, A., Cianelli, Lori, Johnson, Jannel, Wagner, Lynne, Chrash, Melany, & Mallory, Gail. (1992). Assessing Community Resources for PWAs. AIDS Patient Care, 6(5), 229-231.

Braithwaite, V. (1996). Understanding Stress in Informal Caregiving. Research on Aging, 18(2), 139-174.

Cantor, M. H. (1983). Strain Among Caregivers: A Study of Experience in the United States. The Gerontologist, 23(6), 597-604.

Carlson, K. W. & Robertson, S. E. (1994). Social Networks of Spouse Caregivers of Partners with Dementia. Canadian Journal of Rehabilitation, 7(4), 239-249.

Casey, K. M. (1995). Pathophysiology of HIV-1, Clinical Course, and Treatment. In J. U. Flaskerud, Peter J. (Ed.), HIV/AIDS A Guide to Nursing Care (Third ed., pp. 64-80). Philadelphia: W. B. Saunders Company.

Cecil, H., Stanley, M. A., Carrion, P. G., & Swann, A. (1995). Psychometric Properties of the MSPSS and NOS in Psychiatric Outpatients. Journal of Clinical Psychology, 51(5), 593-602.

Charles, K., Sellick, Scott M., Montesanto, B. A., & Mohide, E. Ann. (1996). Priorities of Cancer Survivors Regarding Psychosocial Needs. Journal of Psychosocial Oncology, 14(2), 57-72.

Clair, J. M., Fitzpatrick, Kevin M., & La Gory, Mark E. (1995). The Impact of Psychosocial Resources on Caregiver Burden and Depression: Sociological Variations on a Gerontological Theme. Sociological Perspectives, 38(2), 195-215.

Clipp, E. C., & George, Linda K. (1993). Dementia and Cancer: A Comparison of Spouse and Caregivers. The Gerontologist, 33(4), 534-541.

Cobb, S. (1976). Social Support as a Moderator of Life Stress. Psychosomatic Medicine, 38(5), 300-314.

Cohen, J. C. & Cohen, Patricia. (1983). Applied Multiple Regression/Correlation Analysis for the Behavioral Sciences. (Second ed.). Hillsdale: Lawrence Erlbaum Associates.

Cohen, S. (1988). Psychosocial models of the role of social support in the etiology of physical disease. Health Psychology, 7, 269-297.

Cohen, S. T. & Wells, T. A. (1985). Stress, social support, and the buffering hypothesis. Psychological Bulletin, 2, 310-357.

Cohn, S. E., Klein, Jonathan D., Mohr, Jack E., van der Horst, Charles, M., & Weber, David J. (1994). The Geography of AIDS: Patterns of Urban and Rural Migration. Southern Medical Journal, 87(6), 599-606.

Crandall, C. S. (1991). Multiple Stigma and AIDS: Illness Stigma and Attitudes Toward Homosexuals and IV Drug Users in AIDS-related Stigmatization. Journal of Community and Applied Social Psychology, 1, 165-172.

Currey, C., Johnson, M., & Ogden, B. (1990). Willingness of Health-professions Students to Treat Patients with AIDS. Academic Medicine, 65, 472-474.

Dahlem, N. W., Zimet, G. D., & Walker, R. R. (1991). The Multidimensional Scale of Perceived Social Support: A Confirmation Study. Journal of Clinical Psychology, 47(6), 756-761.

Day, P. J. (1989). A New History of Social Welfare. Englewood Cliffs: Prentice Hall.

Depner, C. E. and Wethington, Elaine. (1984). Social Support: Methodological Issues in Design and Measurement. Journal of Social Issues, 40(4), 37-54.

Dimatteo, M. R. & Hays, R. (1981). Social Support and Serious Illness. In B. H. Gottlieb (Ed.), Social Networks and Social Support. Beverly Hills: Sage.

Dunkel-Schetter, C. (1984). Social Support and Cancer: Findings Based on Patient Interviews and Their Implications. Journal of Social Issues, 40(4), 77-98.

Etzion, D. (1984). Moderating effect of social support on the stress-burnout relationship. Journal of Applied Psychology, 69(November), 615-622.

Fengler, A. P. & Goodrich, Nancy. (1979). Wives of Elderly Disabled Men: The Hidden Patients. The Gerontologist, 19(2), 175-183.

Fiore, J. D., Becker, J., & Coppel, D. B. (1983). Social Network Interactions: A buffer or at stress? American Journal of Community Psychology, 11, 423-429.

Fiore, J., Coppel, J. B., & Cox, Gary, B. (1986). Social Support as a Multifaceted Concept: Examination of Important Dimensions for Adjustment. American Journal of Community Psychology, 14(1), 93-111.

Folkman, Susan, Chesney, Margaret A. & Christopher-Richards, Anne. (1994). Stress and Coping in Caregiving Partners of Men with AIDS. Psychiatric Clinics of North America, 17(1), 35-53.

Gallagher, D., Rappaport, M., Benedict, A., Lovett, S., & Silven, D. (1985) Reliability of Selected Interview and Self-report Measures with Family Caregivers. Paper presented at the meetings of the Gerontological Society of America, New Orleans, LA.

George, L. K. & Gwyther, L. (1986). Caregiver Well-Being: A Multidimensional Examination of Caregivers of Demented Adults. The Gerontologist, 26, 253-259.

Germain, C. B. & Gitterman., Alex. (1980). The Life Model of Social Work Practice. New York: Columbia University Press.

Germain, C. B. & Gitterman., Alex. (1996). The Life Model of Social Work Practice. (Second ed.). New York: Columbia University Press.

Gilbar, O. (1994). The Elderly Patient and His Spouse: Two Perceptions of the Burden of Caregiving. Journal of Gerontological Social Work, 21(3/4), 149-158.

Given, C. W., Collins, Clare E., & Given, Barbara A. (1988). Sources of Stress Among Families Caring for Relatives with Alzheimer's Disease. Nursing Clinics of North America, 23(1), 69-82.

Green, G. (1993). Editorial Review: Social Support and HIV. AIDS Care, 5(1), 87-104.

Guadagnoli, E., Rice, Christopher., & Mor, Vincent. (1991). Cancer Patients' Knowledge of and Willingness to Use Agency-Based Services: Toward Application of a Model of Behavioral Change. Journal of Psychosocial Oncology, 9(3), 1-21.

Haines, V. A., Hurlbert, Jeanne S., & Beggs, John J. (1996). Exploring the Determinants of Support Provision: Provider Characteristics, Personal Networks, Community Contexts, and Support Following Life Events. Journal of Health and Social Behavior, 37(September), 252-264.

Hart, Graham, Fitzpatrick, R., & McLean, J. (1990) Gay men, social support, and HIV Disease: A study of social integration in the gay community. AIDS Care, 2(2), 163-170.

Hassinger, M. J. (1985). Community-dwelling Dementia Patients Whose Relatives Sought Counseling Services Regarding Patient Care: Predictors of Institutionalization Over a One-year Follow-up Period. Unpublished Ph.D. University of Southern California.

Havir, L. M. (1995). But Will They Use It? Social Service Utilization by Rural Elderly. In S. Bruchey (Ed.), Garland Studies on the Elderly in America. New York: Garland Publishing, Inc.

Hays, R. B., Turner, Heather, & Coates, Thomas J. (1992). Social Support, AIDS-Related Symptoms, and Depression Among Gay Men. Journal of Consulting and Clinical Psychology, 60(3), 463-469.

Henderson, S., Byrne, D. G., & Duncan-Jones, P. (1981). Neurosis and the social environment. North Ryde: Academic Press.

Herek, G. M. & Capitanio, J. P. (1997). AIDS Stigma and Contact with Persons with AIDS: Effects of Direct and Vicarious Contact. Journal of Applied Social Psychology, 27(1), 1-36.

Herek, G., M. & Capitanio, J. P. (1994). Conspiracies, contagion, and corrosion: Trust and public reactions to AIDS. AIDS Education and Prevention, 6, 367-377.

Herek, G., M. & Glunt, E. K. (1988). An epidemic of stigma: Public reactions to AIDS. American Psychologist, 43, 886-891.

Hewitt, M. (1989). Defining Rural Areas: Impact on health care policy and research (Staff paper Y3 T22/2:2R88). Washington, DC: Office Of Technology Assessment.

Holt, S. (1990). AIDS in Rural America: Research and Educational Issues. Chapel Hill: The University of North Carolina.

Kaplan, B. H., Cassel, J. C. & Gore, S. (1977). Social Support and Health. Medical Care, 15(Supplement), 47-58.

Kazarian, S. & McCabe, S. B. (1991). Dimensions of Social Support in the MSPSS: Factorial Structure, Reliability, and Theoretical Implications. Journal of Community Psychology, 19(April), 150-160.

Kenkel, M. B. (1986). Stress-Coping-Support in Rural Communities: A Model for Primary Prevention. American Journal of Community Psychology, 14(5), 457-478.

King, S. W. (1980). Select Factors Related to Social Service Utilization by Black and White Elderly in Pennsylvania. Unpublished Ph.D., Washington University, St. Louis.

Koski, M. J. (1998). Burnout in Gay Men Caring For a Partner with AIDS: The Relationship Between Social Support, Coping with HIV, and Level of Intimacy. Unpublished Ph.D., Columbia, New York.

Lazarus, R. S. & Folkman, Susan. (1984). Stress, Appraisal, and Coping. New York: Springer Publishing Company.

Leonard, W. M. (1976). Basic Social Statistics. New York: West.

Lieberman, M. A. & Fisher, Lawrence. (1995). The Impact of Chronic Illness on the Health and Well-Being of Family Members. The Gerontologist, 35(1), 94-102.

Linn, J. G., Lewis, Frances Marcus, Cain, Van A., & Kimbrough, Gwenelle A. (1993). HIV-Illness, Social Support, Sense of Coherence, and Psychosocial Well-Being in a Sample of Help-Seeking Adults. AIDS Education and Prevention, 5(3), 254-262.

Marx, R., Katz, Mitchell H., Park, Min-Sun., & Gurley, R. Jan. (1997). Meeting the Service Needs of HIV-Infected Persons: Is the Ryan White CARE Act Succeeding? Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology, 14(1), 44-55.

Mawby, L., Clark, M. S., Kalucy, E. R., & Andrews, G. R. (1996). Determinants of Formal Services Use in an Aged Population. Australian Journal on Ageing, 15(4), 177-181.

McGuire, S. L., Gerber, D. E. & Clemen-Stone, S. (1996). Meeting the Diverse Needs of Clients in the Community: Effective Use of the Referral Process. Nursing Outlook, 44(5), 218-222.

Monroe, A. C., Ricketts, Thomas C., & Savitz, L. A. (1992). Cancer in Rural Versus Urban Populations: A Review. The Journal of Rural Health, 8(3), 212-220.

Murphy, P. & Perry, Kathleen. (1988). Hidden Grievors. Death Studies, 12(5-6), 451-462.

Namir, S., Wolcott, D. L., Fawzy, F. I., & Alumbaugh, M. J. (1987). Coping with AIDS: Psychological and Health Implications. Journal of Applied Social Psychology, 17(3), 309-328.

NASW. (1979). Code of Ethics of the National Association of Social Workers. Washington: NASW.

Nieto, D. (1989). AIDS and the Rural Family: Some Systems Considerations and Intervention Implications for the Human Services Practitioner. Human Services in the Rural Environment, 13(1), 34-38.

Norbeck, J. S., Lindsey, Ada M., & Carrieri, Virginia, L. (1983). The Development of an Instrument to Measure Support. Nursing Research, 30(5), 264-269.

O'Brien, D. J., Hassinger, Edward W., & Dershem, Larry. (1996). Size of Place, Residential Stability, and Personal Social Networks. Sociological Focus, 29(1), 61-72.

Ott, L. (1988). An Introduction to Statistical Methods and Data Analysis. (Third ed.). Boston: PWS-Kent.

Pakenham, K. I., Dadds, M. R., & Terry, D. J. (1995). Carers' Burden and Adjustment to HIV. AIDS Care, 7(2), 189-203.

Parker, D. R. (1994). Caregivers of Persons with HIV Dementia: Factors Associated with Psychological Distress. Unpublished Ph.D., The Wright Institute.

Patterson, T. L., Shaw, William S., Semple, Shirley J., Cherner, Mariana, McCutchan, J. Allen, Atkinson, J. Hampton, Grant, Igor, & Nannis, Ellen. (1996). Relationship of Psychosocial Factors to HIV Disease Progression. Annals of Behavioral Medicine, 18(1), 30-39.

Persson, L., Hanson, Bertil, S., Moestrup, Torkil., & Ostergren, Per-Olof. (1994). HIV infection: social network, social support, and CD4 lymphocyte values in infected homosexual men in Malmo, Sweden. Journal of Epidemiology and Community Health, 48, 580-585.

Peterson, K. J. (1991). Social Workers' Knowledge about AIDS: A National Survey. Social Work, 36(1), 31-37.

Phillips, K. D. (1994). Testing Biobehavioral Adaptation in Persons Living with AIDS Using Roy's Theory of the Person as an Adaptive System. Unpublished Dissertation, University of Tennessee, Knoxville.

Piette, J. D., Fleishman, J. A., Stein, M. D., Mor, V. & Mayer, K. (1993). Perceived Needs and Unmet Needs for Formal Services Among People with HIV Disease. Journal of Community Health, 18(1), 11-23.

Pratt, C. C., Schmell, Vicki L., Wright, Scott, & Cleland, Marilyn. (1985). Burden and Coping Strategies of Caregivers to Alzheimer's Patients: Special Issue: The Family and Health Care. Family Relations Journal of Applied Family and Child Studies, 34(1), 27-33.

Pretorius, T. B. (1993). Willingness To Use Social Support: Use of the Network Orientation Scale With Black South African Students. Psychological Reports, 73, 1011-1017.

Prevention, Centers for Disease Control, (1992). Morbidity and Mortality Weekly Report (1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults 41(RR-17)). Atlanta: U.S. Department of Health and Human Services.

Prevention, Centers for Disease Control, (1995). HIV/AIDS Surveillance Report (7(no.2)). Atlanta: Centers for Disease Control and Prevention.

Prevention, Centers for Disease Control, (1995). Morbidity and Mortality Weekly Report (Update: AIDS Among Women—United States, 1994 44(5)). Atlanta: U.S. Department of Health and Human Services.

Prevention, Centers for Disease Control, (1997). HIV/AIDS Surveillance Report. Atlanta: Department of Health and Human Services.

Reinhard, S. C., Gubman, G. D., Horwitz, A. V. & Minsky, S. (1994). Burden Assessment Scale for Families of the Seriously Mentally Ill. Evaluation and Program Planning, 17, 261-269.

Rook, K. S. (1984). The Negative Side of Social Interaction. Journal of Personality and Social Psychology, 46, 1097-1108.

Rounds, K. (1988). Responding to AIDS: Rural Community Strategies. Social Casework, 360-370.

Ryan, C. C. (1991). Where Do We Go From Here? Social Work, 36(1), 3-4.

Sarason, B. R., Shearing, Edward, N., Pierce, Gregory R., & Sarason, Irwin, G. (1987). Interrelations of Social Support Measures: Theoretical and Practical Implications. Journal of Personality and Social Psychology, 52(4), 813-832.

Shinn, M., Lehmann, S., & Wong, N. W. (1984). Social Interaction and Social Support. Journal of Social Issues, 40(4), 55-76.

Sipes, C. S. (1998). The Experiences of Gay Male Caregivers Who Provided Care for Their Partners with AIDS. Unpublished D.S.N., Rush University, Chicago.

Smith, J. E., Landau, Jeremy, & Bahr, G. Richard. (1990). AIDS in Rural and Small Town America. AIDS Patient Care, 4(3), 17-21.

Sowell, R. L. & Christensen, Pat. (1996). HIV Infection in Rural Communities. Nursing Clinics of North America, 31(1), 107-123.

SPSS 7.5 for Windows [Computer software]. (1996). Chicago, IL: SPSS Inc.

Stokes, J. P. (1983). Predicting Satisfaction with Social Support from Social Network Structure. American Journal of Community Psychology, 11(2), 141-152.

Strickland, J. & Strickland, David L. (1996). Barriers to Preventive Health Services for Minority Households in the Rural South. The Journal of Rural Health, 12(3), 206-217.

Tata, S. P. & Leong, F. T. L. (1994). Individualism-Collectivism, Social Network Orientation, Acculturation as Predictors of Attitudes Toward Seeking Professional Psychological Help Among Chinese Americans. Journal of Counseling Psychology, 41(3), 280-287.

Thoits, P. A. (1985). Social Support and Psychological Well-Being: Theoretical Possibilities. In I. G. Sarason, and Sarason, Barbara R. (Ed.), Social Support: Theory, Research, and Applications (pp. 51-72). Boston: Martinus Nijhoff Publishers.

Thompson, E. H. & Doll, William. (1982). The Burden of Families Coping with the Mentally Ill: An Invisable Crisis. Family Relations, 31(3), 379-388.

Turner, H. A. & Catania, Joseph A. (1997). Informal Caregiving to Persons with AIDS in the United States: Caregiver Burden Among Central Cities Residents Eighteen to Forty-Nine Years Old. American Journal of Community Psychology, 25(1), 35-59.

Turner, H. A., Catania, Joseph A., & Gagnon, John. (1994). The Prevalence of Informal Caregiving to Persons with AIDS in the United States: Caregiver Characteristics and Their Implications. Social Science Medicine, 38(11), 1543-1552.

Turner, H., A., & Pearlin, Leonard I. (1989). Issues of Age, Stress, and Caregiving: Informal Support of People with AIDS. Generations, 13(4), 56-59.

Vaux, A., Burda, Philip, & Stewart, Doreen. (1994). Network Orientation Scale. In Joel Fischer. & Kevin Corcoran (Ed.), Measures for Clinical Practice: A Sourcebook (Second ed., Vol. 2,). New York: The Free Press.

Vaux, A., Phillips, J., Holly, L., Thomson, B., Williams, D., & Stewart, D. (1986). The Social Support Appraisals (SS-A) Scale: Studies of Reliability & Validity. American Journal of Community Psychology, 14(2), 195-219.

Vitaliano, P. P., Young, H. M. and Russo, J. (1991). Burden: A Review of Measures Used Among Caregivers of Individuals with Dementia. The Gerontologist, 31(1), 67-75.

Wallace, R. (1991). Social Disintegration and the Spread of AIDS: Thresholds for Propagation Along 'Sociogeographic' Networks. Social Science and Medicine, 33(10), 1155-1162.

Waller Snyder, J. R. (1993). Caregiving and Carereceiving: An Investigation of Burdens and Satisfaction. Unpublished Ph.D, University of Illinois at Urbana-Champaign, Urbana.

Wardlaw, L. (1994). Sustaining Informal Caregivers for Persons with AIDS. Families in Society, 373-384.

Weiner, B., Perry, R. P., & Magnusson, J. (1988). An attributional analysis of reactions to stigmas. Journal of Personality and Social Psychology, 55, 738-748.

West, G. E., Delisle, Marc-Andre, Simard, Clermont, & Denis Drouin. (1996). Leisure Activities and Service Knowledge Use Among the Rural Elderly. Journal of Aging and Health, 8(2), 254-279.

Wicklund, B., M. & Jackson, Mary Anne. (1992). Coping with AIDS Hemophilia. In Ahmed, P. and Ahmed, Nancy (Ed.), Living and Dying with AIDS (pp. 255-268). New York: Plenum Press.

Wight, R. G., Leblanc, J. & Aneshensel, C. S. (1995). Support Service Use by Persons with AIDS and their Caregivers. AIDS Care, 7(4), 509-520.

Wisner, J. (1992). AIDS Rural America. Imprint, 39(4), 71-75.

Witol, A. D., Sander, A. M., & Kreutzer, J. S. (1996). A Longitudinal Analysis of Family Needs Following Traumatic Brain Injury. NeuroRehabilitation, 7, 175-187.

Zarit, S. H. (1990). Concepts and Measures in Family Caregiving Research. Paper presented at the Invitational Conference on Family Caregiving Research, Toronto, Ontario.

Zarit, S. H. and Whitlatch, Carol J. (1992). Institutional Placement: Phases of the Transition. The Gerontologist, 32(5), 665-672.

Zarit, S. H. (1990). The Memory and Behavior Problems Checklist and the Burden Interview. In J. M. Zarit (Ed.) (pp. 1-13): Penn State Gerontology Center.

Zich, J. & Temoshok, Lydia. (1987). Perceptions of Social Support in Men with AIDS and ARC: Relationships with Distress and Hardiness. Journal of Applied Social Psychology, 17(3), 193-215.

Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The Multidimensional Scale of Perceived Social Support. Journal of Personality Assessment, 52(1), 30-41.

Zimet, G. D., Powell, S. S., Farley, G. K., Werkman, S., & Berkoff, K. A. (1990). Psychometric characteristics of the Multidimensional Scale of Perceived Social Support. Journal of Personality Assessment, 55(3 & 4), 610-617.

APPENDICES

Appendix 1

PURPOSE AND DESCRIPTION OF THE STUDY

Rural and Urban Differences in Seriously Ill Persons and their Caregivers

Persons Living with HIV/AIDS

I am a Licensed Clinical Social Worker and a doctoral candidate in the College of Social Work at the University of Tennessee, Knoxville. I am conducting a study to seek to understand differences in persons living with HIV/AIDS and their caregivers in rural vs. urban communities. This information will be collected from persons who are HIV positive or have AIDS and their caregivers.

This letter is a invitation for you to participate in the study. As mentioned in the previous mailout, participation will consist of an interview to complete a survey. During the interview you will be asked questions about your experiences living with HIV or AIDS. You may withdraw from participation at any time and if you are uncomfortable at any time during the interview you may end the interview or skip any questions that you do not wish to answer. You will receive \$15.00 upon completion of the survey interview.

Your name will not be on the survey. I and trained interviewers have signed a statement agreeing to hold all information confidential. Your name will not be reported or included in published results. The survey instruments will be stored in the private office of the investigator until completion of the study, at which time they will be destroyed. The signed informed consent statement will be stored and maintained for a period of 3 years past the completion of the study at the University of Tennessee, Knoxville, College of Social Work.

This study has no direct benefits for you, although I hope you will enjoy talking to an interested listener about your experiences. You will also be contributing to our understanding of the differences in persons living with a serious illness and their caregivers in rural vs. urban communities.

You may keep this information statement and a copy of the informed consent statement for your records. You are free to change your mind about participating at any time. If you have questions or concerns about the study, either now or later, please call me at the phone number shown below. Thank you for your participation.

Principal Investigator: Maureen Newton, M.S.W., L.C.S.W. Phone: (423) 981-1773
Ph.D. Candidate
P.O. Box 10804
Knoxville, TN 37939-0804

INTRODUCTORY LETTER FROM ARK TO CLIENTS

Dear _____:

A "Call for Participation" is enclosed asking for your voluntary participation in a study which involves completing a survey regarding your experiences living in East Tennessee. The study is being conducted by Maureen Newton, Doctoral Student at the University of Tennessee, College of Social Work. Ms. Newton is conducting the study as part of the requirements necessary for the completion of her education.

Ms. Newton has insured strict monitoring of the confidentiality of the data. Ms. Newton and the trained interviewers who will assist in data collection will follow the confidentiality guidelines of ARK and the University of Tennessee, Knoxville and have signed confidentiality pledges expressing this agreement. Only Ms. Newton will have access to survey data. All participant information and survey instruments will be kept in locked cabinets in separate locations to prevent breach of confidentiality.

Your decision to participate is completely voluntary and has no affect on services provided by ARK. If you do not wish to be contacted for study participation please return the enclosed postcard to ARK or contact your case manager directly.

If you have any questions or concerns regarding the study you may contact your ARK case manager or Ms. Newton directly. Thank you.

Sincerely,

AIDS Response Knoxville

INFORMED CONSENT STATEMENT FOR STUDY PARTICIPATION

I understand the description and purpose of the study "Rural and Urban Differences in Seriously Ill People and their Caregivers" and by signing this statement give my consent to an interview to complete the necessary research survey. I am aware that this information is treated in a highly confidential manner and that it is part of a doctoral study conducted by Maureen Newton, a student at the University of Tennessee, Knoxville, College of Social Work. I have been informed that none of the surveys will include my real name or any other identifying information. I understand that all study materials will be held in the strictest confidence, in locked files, and only Maureen Newton, Principal Investigator will have access to this information. I have been informed that all study participant identifying information will be stored separately from the survey instruments. I understand that upon completion of the study, survey instruments will be destroyed and that informed consent statements will be safely stored for at least three years at the University of Tennessee, Knoxville, College of Social Work. If any portion of the research findings are selected for publication I have been insured that my privacy will be protected. I understand that my responses will be kept confidential and that the names of those who complete the survey interview will not be reported in any manner. I have received information which describes more specifically the purpose of the research project and how to contact the principal investigator if necessary. I understand that participation in the study will involve approximately 30-45 minutes of my time. If I choose, I may omit answering any questions that I do not wish to answer and I may discontinue participation at any time. My participation is entirely voluntary and will not effect receipt of services.

Name(print)

Participant's Signature

Date

Signature of Interviewer

Principal Investigator-Maureen Newton, M.S.W., L.C.S.W.
Ph.D. Candidate
P.O. Box 10804
Knoxville, TN 37939-0804

Phone: (423) 981-1773

CALL FOR PARTICIPATION

Rural and Urban Differences in Seriously Ill People and their Caregivers

Persons Living with HIV or AIDS

I am a Licensed Clinical Social Worker and a doctoral candidate in the College of Social Work at the University of Tennessee, Knoxville. I am conducting a study to seek to understand differences in Persons Living with HIV/AIDS and their caregivers in rural vs. urban communities.

I am seeking respondents who are HIV positive or have AIDS living in East Tennessee.

Participation in the study involves an interview to complete a survey requiring approximately 30-45 minutes. The information will be held strictly confidential and respondents will not be identified in the report of the study. You will receive a \$15.00 gift for study participation.

I and trained interviewers will be contacting persons to interview. Please return the enclosed participation response card in the self-addressed, stamped envelope to ARK or contact your ARK case manager directly about study participation. You are not obligated to participate in the survey and your decision to participate may be withdrawn at any time. If you have any questions or concerns about the study you may contact your ARK case manager or me directly. Thank you.

Maureen Newton, M.S.W., L.C.S.W.
Principal Investigator
Ph.D. Candidate
P.O. Box 10804
Knoxville, TN 37939-0804

Phone: (423) 981-1773

Appendix 3

INTRODUCTORY LETTER TO PLAS

Dear _____:

I am a Licensed Clinical Social Worker and doctoral candidate at the University of Tennessee, Knoxville, College of Social Work. I am seeking respondents who are HIV positive or have AIDS living in rural and urban communities in East Tennessee. Participation in the study involves completing a survey about your experiences regarding HIV/AIDS in East Tennessee.

Enclosed you will find the purpose and description of the study, two copies of a written statement of informed consent, and a stamped return envelope addressed to me. Please read the information and if you are willing to participate please sign and complete one copy of the informed consent statement and return it in the enclosed envelope.

When I receive your informed consent statement, I or a trained interviewer will contact you to schedule a time and location convenient for you to complete the survey interview. The survey will take approximately 30-45 minutes to complete. Your participation is completely voluntary. Upon completion of the study you will receive a \$15.00 gift.

Please contact me at (423) 981-1773, if you have any questions or would like additional information. Thank you for your cooperation in this important project.

Sincerely,

Maureen Newton
Principal Investigator

INFORMED CONSENT STATEMENT FOR STUDY PARTICIPATION

I understand the description and purpose of the study "Rural and Urban Differences in Seriously Ill People and their Caregivers" and by signing this statement give my consent to an interview to complete the necessary research survey. I am aware that this information is treated in a highly confidential manner and that it is part of a doctoral study conducted by Maureen Newton, a student at the University of Tennessee, Knoxville, College of Social Work. I have been informed that none of the surveys will include my real name or any other identifying information. I understand that all study materials will be held in the strictest confidence, in locked files, and only Maureen Newton, Principal Investigator will have access to this information. I have been informed that all study participant identifying information will be stored separately from the survey instruments. I understand that upon completion of the study, survey instruments will be destroyed and that informed consent statements will be safely stored for at least three years at the University of Tennessee, Knoxville, College of Social Work. If any portion of the research findings are selected for publication I have been insured that my privacy will be protected. I understand that my responses will be kept confidential and that the names of those who complete the survey interview will not be reported in any manner. I have received information which describes more specifically the purpose of the research project and how to contact the principal investigator if necessary. I understand that participation in the study will involve approximately 30-45 minutes of my time. If I choose, I may omit answering any questions that I do not wish to answer and I may discontinue participation at any time. My participation is entirely voluntary and will not effect receipt of services.

Name(print)

Participant's Signature

Date

Signature of Interviewer

Principal Investigator-Maureen Newton, M.S.W., L.C.S.W.
Ph.D. Candidate
P.O. Box 10804
Knoxville, TN 37939-0804

Phone: (423) 981-1773

PURPOSE AND DESCRIPTION OF THE STUDY

Rural and Urban Differences in Seriously Ill Persons and their Caregivers

Persons Living with HIV/AIDS

I am a Licensed Clinical Social Worker and a doctoral candidate in the College of Social Work at the University of Tennessee, Knoxville. I am conducting a study to seek to understand differences in persons living with HIV/AIDS and their caregivers in rural vs. urban communities. This information will be collected from persons who are HIV positive or have AIDS and their caregivers.

This letter is a invitation for you to participate in the study. As mentioned in the previous mailout, participation will consist of an interview to complete a survey. During the interview you will be asked questions about your experiences living with HIV or AIDS. You may withdraw from participation at any time and if you are uncomfortable at any time during the interview you may end the interview or skip any questions that you do not wish to answer. You will receive \$15.00 upon completion of the survey interview.

Your name will not be on the survey. I and trained interviewers have signed a statement agreeing to hold all information confidential. Your name will not be reported or included in published results. The survey instruments will be stored in the private office of the investigator until completion of the study, at which time they will be destroyed. The signed informed consent statement will be stored and maintained for a period of 3 years past the completion of the study at the University of Tennessee, Knoxville, College of Social Work.

This study has no direct benefits for you, although I hope you will enjoy talking to an interested listener about your experiences. You will also be contributing to our understanding of the differences in persons living with a serious illness and their caregivers in rural vs. urban communities.

You may keep this information statement and a copy of the informed consent statement for your records. You are free to change your mind about participating at any time. If you have questions or concerns about the study, either now or later, please call me at the phone number shown below. Thank you for your participation.

Principal Investigator: Maureen Newton, M.S.W., L.C.S.W. Phone: (423) 981-1773
Ph.D. Candidate
P.O. Box 1080
Knoxville, TN 37939-0804

Appendix 4

INTRODUCTORY LETTER TO CAREGIVERS

Dear _____:

I am a Licensed Clinical Social Worker and doctoral candidate at the University of Tennessee, Knoxville, College of Social Work. I am seeking respondents who have been identified as caregivers for persons with a serious illness living in rural and urban communities in East Tennessee.

Your name was given to me by _____, who identified you as his/her primary caregiver. Participation in the study involves completing a survey about your experiences as a caregiver.

Enclosed you will find the purpose and description of the study, two copies of a written statement of informed consent, a postcard to decline study, and a stamped return envelope addressed to me. Please read the information and if you are willing to participate please sign and complete one copy of the informed consent statement and return it in the enclosed envelope. If you do not wish to participate please return the postcard in the enclosed envelope.

When I receive your informed consent statement, I or a trained interviewer will contact you to schedule a time and location convenient for you to complete the survey interview. The survey will take approximately 30-45 minutes to complete. Your participation is completely voluntary. Upon completion of the study you will receive a \$15.00 gift.

Please contact me at (423) 981-1773, if you have any questions or would like additional information. Thank you for your cooperation in this important project.

Sincerely,

Maureen Newton
Principal Investigator

PURPOSE AND DESCRIPTION OF THE STUDY

Rural and Urban Differences in Seriously Ill People and their Caregivers

Caregivers

I am a Licensed Clinical Social Worker and a doctoral candidate in the College of Social Work at the University of Tennessee, Knoxville. I am conducting a study to seek to understand differences in seriously ill persons and their caregivers in rural vs. urban communities. This information will be collected from persons who have a chronic and/or life-threatening illness and their caregivers.

This letter is an invitation for you to participate in the study. Participation will consist of an interview to complete a survey. During the interview you will be asked questions about your experiences as a caregiver. You can withdraw from participation at any time and if you are uncomfortable at any time during the interview you can end the interview or you may skip any questions that you do not wish to answer.

Your name will not be on the survey. I and the trained interviewers have signed a statement agreeing to hold all information confidential. Your name will not be reported or included in published results. The survey instruments will be stored in the private office of the investigator until completion of the study, at which time they will be destroyed. The signed informed consent statement will be stored and maintained for a period of 3 years past the completion of the study at the University of Tennessee College of Social Work.

This study has no direct benefits for you, although I hope you will enjoy talking to an interested listener about your experiences. You will also be contributing to our understanding of the differences in persons living with chronic and/or life-threatening illness and their caregivers in rural vs. urban communities.

You may keep this information statement and a copy of the informed consent statement for your records. You are free to change your mind about participating at any time. If you have questions or concerns regarding the study, either now or later, please call me at the phone number shown below. Thank you for your participation.

Investigator: Maureen Newton, M.S.W., L.C.S.W.
Ph.D. Candidate
P.O. Box 10804
Knoxville, TN 37939-0804

Phone: (423) 981-1773

INFORMED CONSENT STATEMENT FOR STUDY PARTICIPATION

I understand the description and purpose of the study "Rural and Urban Differences in Seriously Ill People and their Caregivers" and by signing this statement give my consent to an interview to complete the necessary research survey. I am aware that this information is treated in a highly confidential manner and that it is part of a doctoral study conducted by Maureen Newton, a student at the University of Tennessee, Knoxville, College of Social Work. I have been informed that none of the surveys will include my real name or any other identifying information. I understand that all study materials will be held in the strictest confidence, in locked files, and only Maureen Newton, Principal Investigator will have access to this information. I have been informed that all study participant identifying information will be stored separately from the survey instruments. I understand that upon completion of the study, survey instruments will be destroyed and that informed consent statements will be safely stored for at least three years at the University of Tennessee, Knoxville, College of Social Work. If any portion of the research findings are selected for publication I have been insured that my privacy will be protected. I understand that my responses will be kept confidential and that the names of those who complete the survey interview will not be reported in any manner. I have received information which describes more specifically the purpose of the research project and how to contact the principal investigator if necessary. I understand that participation in the study will involve approximately 30-45 minutes of my time. If I choose, I may omit answering any questions that I do not wish to answer and I may discontinue participation at any time. My participation is entirely voluntary and will not effect receipt of services.

Name(print)

Participant's Signature

Date

Signature of Interviewer

Principal Investigator-Maureen Newton, M.S.W., L.C.S.W.
Ph.D. Candidate
P.O. Box 10804
Knoxville, TN 37939-0804

Phone: (423) 981-1773

1. Date of Birth? / /
MO DA YR
2. Gender: Male Female Other(explain)
3. Race/ethnicity: Please circle: Asian, Black/African American, American Indian, Hispanic, White/Caucasian, Other[Specify]
4. Education (in years): (Please circle the appropriate year).
Elementary School 1 2 3 4 5 6 7 8
High School 9 10 11 12
GED 13 (taken and passed)
Vocational Training (Beyond high school): 1, 2, 3, 4+ Year(s)
College 1, 2, 3, 4, 5+ Year(s)
5. Religious Preference: Protestant(Please specify) Roman Catholic
 Jewish None Other (Please specify)
6. What is your total monthly income? A= Under \$500.00 D= \$1,500.00 - \$1,999.99
(circle letter) B= \$500 - \$999.99 E= \$2,000.00 - \$2,499.99
C= \$1,000.00- \$1,499.99 F= Over \$2,500.00

7. Employment Status

____ Employed, (please circle): Part-time Full-time : How many hours per week? ____
____ Unemployed ____ Retired ____ Disabled
____ Other (Please specify _____)

8. Relationship Status:

____ Unmarried, not living with a partner ____ Married, but not living with spouse
____ Unmarried, but living with a partner ____ Married and living with spouse
____ Divorced, not living with a partner ____ Widowed
____ Other (Please specify _____)

9. What is your relationship to your primary caregiver? (Please check one)

____ Spouse ____ Parent
____ Partner ____ Friend
____ Sibling ____ Other (Please specify _____)

10. How would you describe your current living situation?

____ Homeless ____ Trailer/Manufactured home(permanent)
____ House or apartment(permanent) ____ Other (Please specify _____)

11. Which of the following applies to your home?

_____ Rent _____ Mortgage _____ Own

_____ Other (Please specify _____)

12. Number of persons living in your residence(including self _____)

Number of adults _____, children under 18 years old _____

13. What best describes your current living situation?

_____ Live alone

_____ Live with parents, siblings, or adult children

_____ Live with other relatives

_____ Live with a friend

_____ Live with spouse

_____ Live with partner

_____ Other (Please specify _____)

14. County of residence _____ City of residence _____

Residential History (circle response or fill in blanks)

15. How long have you lived in your current residence?

Less than one month	1-6 months	6 months to a year	1-3 years	Three or more years
------------------------	---------------	-----------------------	--------------	------------------------

16. How satisfied are you with your current living environment?

Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
-------------------	-----------------------	--------------------	----------------

17. Where did you live prior to your current residence?

City _____ State _____

18. How long did you live at your prior residence?

Less than one month	1-6 months	6 months to a year	Over a year
------------------------	---------------	-----------------------	----------------

19. Where do you consider your home town, that is, the place you spent most of your childhood, ages infancy to 17 years old?

City _____ State _____

20. How long did you live there?

Under a year	1-3 years	4-6 years	Over 7 years
-----------------	--------------	--------------	-----------------

Residential Proximity (circle response and fill in blanks)

21. Approximately how close do you live to the following persons?

A. Primary Caregiver:

Same Household	Next Door	Same Building	Same Neighborhood	Same City	Different City Same State	Different State
			#miles _____	#miles _____	#miles _____	#miles _____

B. Your Mother or Father:

Same Household	Next Door	Same Building	Same Neighborhood	Same City	Different City Same State	Different State
			#miles _____	#miles _____	#miles _____	#miles _____

C. Your Closest Friend or Friends:

Same Household	Next Door	Same Building	Same Neighborhood	Same City	Different City Same State	Different State
			#miles _____	#miles _____	#miles _____	#miles _____

D. Other Relatives(brothers, sisters, children):

Same Household	Next Door	Same Building	Same Neighborhood	Same City	Different City Same State	Different State
			#miles _____	#miles _____	#miles _____	#miles _____

Instrumental Support (check all that apply)

22. Which of the following things does your primary caregiver help you with?

_____ emotional support

_____ transportation

_____ cooking

_____ housecleaning

_____ shopping

_____ physical care (bathing, dressing)

_____ other _____

23. Is there anyone else who can help you if your primary caregiver is away?

_____ Don't know _____ Yes _____ No

Social Interaction Scale (circle response)

24. About how often do you see or talk to the following persons:

A. Your Primary Caregiver:

Nearly every day	More than once a week	2-3 times a month	One time a month	Several times a year	Hardly ever
------------------	-----------------------	-------------------	------------------	----------------------	-------------

B. Your Mother or Father:

Nearly every day	More than once a week	2-3 times a month	One time a month	Several times a year	Hardly ever
------------------	-----------------------	-------------------	------------------	----------------------	-------------

C. Your Closest Friend or Friends:

Nearly every day	More than once a week	2-3 times a month	One time a month	Several times a year	Hardly ever
------------------	-----------------------	-------------------	------------------	----------------------	-------------

D. Other Relatives(brothers, sisters, children):

Nearly every day	More than once a week	2-3 times a month	One time a month	Several times a year	Hardly ever
------------------	-----------------------	-------------------	------------------	----------------------	-------------

E. Other Friends:

Nearly every day	More than once a week	2-3 times a month	One time a month	Several times a year	Hardly ever
------------------	-----------------------	-------------------	------------------	----------------------	-------------

F. Neighbors:

Nearly every day More than once a week 2-3 times a month One time a month Several times a year Hardly ever

G. Your Case Manager:

Nearly every day More than once a week 2-3 times a month One time a month Several times a year Hardly ever

Satisfaction with Social Interaction and Quality of Relationship (circle response or fill in blanks)

25. How satisfied are you with your family life, that is, the time you spend and the things you do with your family? Would you say that you are:

Very Dissatisfied Somewhat Dissatisfied Somewhat Satisfied Very Satisfied

26. How satisfied are you with your friendships, that is, the time you spend and the things you do with your friends? Would you say that you are:

Very Dissatisfied Somewhat Dissatisfied Somewhat Satisfied Very Satisfied

27. How would you rate your overall relationship with your Primary Caregiver at this time?

Very Poor Poor Average Good Very Good

28. When did you become infected with HIV? 19 _____

29. In what year did you receive your first positive HIV/AIDS test/diagnosis? 19 _____

30. How do you describe your stage of HIV infection?

_____ HIV positive with no symptoms _____ HIV positive with symptoms _____ AIDS

31. Ambulatory Status:

_____ No assistance needed, independent ambulation _____ Non-ambulatory

_____ Ambulatory with assistance

_____ requires physical assistance to transfer

_____ with physical assistance

_____ bed-bound

_____ with walker

_____ with cane

32. What has been your most recent T-cell (CD4) count?(check one)

Less than 200 _____ 200-400 _____

More than 400 _____ Don't Know _____

When was the test: _____ Month _____ Year

33. How do you think you acquired HIV infection?

____ Sexual activity

____ Injecting drug use

____ Blood or blood products

____ Accidental exposure through broken skin (for example, needle stick, etc.)

____ Don't Know

____ Other (Please specify _____)

34. What best describes your sexual identity?

____ Heterosexual (Straight) ____ Homosexual (Gay)

____ Bisexual ____ Other (Please specify _____)

35. In the past month how would you say you have been feeling?

Very Poor Poor Average Good Very Good

NEEDS ASSESSMENT

I would like to ask you about services that you may have needed in the past 6 months. Please tell me if you needed the service, and if you needed the service did you receive it, and if you received the service how satisfied you were with the service.

Services	Did you need the service? (If no, go to next service)	Did you get the service? (If yes, continue across)	How satisfied were you with the service?		
1. Medical care at a clinic or doctor's office.	Yes No	Yes No	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied Very Satisfied
2. Dental care at a clinic or dentist's office.	Yes No	Yes No	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied Very Satisfied
3. Case management (help getting services or benefits)	Yes No	Yes No	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied Very Satisfied
4. Mental health counseling or therapy.	Yes No	Yes No	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied Very Satisfied
5. Housing assistance, i.e. finding a place to live.	Yes No	Yes No	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied Very Satisfied

Services	Did you need the service? (If no, go to next service)		Did you get the service? (If yes, continue across)		How satisfied were you with the service?		
	Yes	No	Yes	No	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied
6. Financial assistance to pay rent/mortgage.							Very Satisfied
7. Financial assistance to pay for medication.	Yes	No	Yes	No	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied
8. Financial assistance to pay for food.	Yes	No	Yes	No	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied
9. Transportation to get HIV/AIDS care or services.	Yes	No	Yes	No	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied

MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT(MSPSS)

We are interested in how you feel about the following statements. I will read each statement carefully. Indicate how you feel about each statement by choosing the appropriate number using the following scale:

Very strongly disagree	1	Strongly disagree	2	Mildly disagree	3	Neutral	4	Mildly agree	5	Strongly agree	6	Very strongly agree	7
---------------------------	---	----------------------	---	--------------------	---	---------	---	-----------------	---	-------------------	---	------------------------	---

1. There is a special person who is around when I am in need. _____
2. There is a special person with whom I can share joys and sorrows. _____
3. My family really tries to help me. _____
4. I get the emotional help and support I need from my family. _____
5. I have a special person who is a real source of comfort to me. _____
6. My friends really try to help me. _____
7. I can count on my friends when things go wrong. _____
8. I can talk about my problems with my family. _____
9. I have friends with whom I can share my joys and sorrows. _____
10. There is a special person in my life who cares about my feelings. _____
11. My family is willing to help me make decisions. _____
12. I can talk about my problems with my friends. _____

NETWORK ORIENTATION SCALE (NOS)

Below is a list of statements concerning relationships with other people. Please indicate the extent to which you agree or disagree with each statement.

	Strongly agree 1	Agree 2	Disagree 3	Strongly Disagree 4
1. Sometimes it is necessary to talk to someone about your problems.				
2. Friends often have good advice to give.				
3. You have to be careful who you tell personal things to.				
4. You often get useful information from other people.				
5. People should keep their problems to themselves.				
6. It's easy for you to talk about personal and private matters.				
7. In the past, friends have really helped you out when you've had a problem.				
8. You can never trust people to keep a secret.				
9. When a person gets upset they should talk it over with a friend.				
10. Other people never understand your problems.				
11. Almost everyone knows someone they can trust with a personal secret.				
12. If you can't figure out your problems, nobody can.				

13. In the past, you have rarely found other people's opinions helpful when you have a problem. _____
14. It really helps when you are angry to tell a friend what happened. _____
15. Some things are too personal to talk to anyone about. _____
16. It's fairly easy to tell who you can trust, and who you can't. _____
17. In the past, you have been hurt by people you confided in. _____
18. If you confide in other people, they will take advantage of you. _____
19. It's okay to ask favors of people. _____
20. Even if you need something, you would hesitate to borrow it from someone. _____

CAREGIVER INFORMATION FORM

For purposes of this study we would like to know who you define as the person most involved in assisting you with daily activities or physical and emotional needs, that is, who is your primary caregiver? None of the information you have provided about yourself will be given to this person. We will be contacting him/her and asking for participation in completing a similar survey.

Name _____ Relationship to you: _____

Telephone Number _____ Address _____

Do we have your permission to contact this person for purposes of the study? _____ Yes _____ No _____ No identified caregiver.

May we tell this person that you gave us their name? _____ Yes _____ No

Is this person aware of your HIV status? _____ Yes _____ No

Appendix 6

DEMOGRAPHIC DATA FORM-CAREGIVER GROUP

1. Date of Birth? ____/____/____
MO DA YR
2. Gender: ____ Male ____ Female ____ Other(explain) ____
3. Race/ethnicity: Please circle: Asian, Black/African American, American Indian, Hispanic, White/Caucasian, Other[Specify ____]
4. Education (in years) (Please circle the appropriate year).

Elementary School	1	2	3	4	5	6	7	8
High School		9	10	11	12			
GED					13 (taken and passed)			
Vocational Training								
College								
5. Religious Preference:
____ Protestant(Please specify ____) ____ Roman Catholic
____ Jewish ____ None ____ Other (Please specify ____)
6. What is your monthly income? A= Under \$500.00 D= \$1,500.00 - \$1,999.99
(circle letter) B= \$500 - \$999.99 E= \$2,000.00 - \$2,499.99
C= \$1,000.00- \$1,499.99 F= Over \$2,500.00

7. Employment Status:

____ Employed, please circle: Part-time Full-time : How many hours per week? ____
____ Unemployed Retired Disabled Other (Please specify ____)

8. Relationship Status:

____ Unmarried, not living with a partner ____ Married, but not living with spouse
____ Unmarried, but living with a partner ____ Married and living with spouse
____ Divorced, not living with a partner ____ Widowed
____ Other (Please specify ____)

9. I am the ____ of the care recipient. (Please check one)

____ Spouse ____ Parent
____ Partner ____ Friend
____ Sibling ____ Other (Please specify ____)

10. How long have you been the caregiver for this person?

____ Less than one year, ____ month(s) ____ 1-5 years
____ 6-10 years ____ more than 10 years

11. Average number of hours per week spent on caregiving for this person. _____

12. Average number of days per week spent on caregiving for this person. _____

13. Do you live with the care recipient?

_____ Yes, (If yes, how long have you been living with the care recipient _____ months _____ years)

_____ No, (If no, # of miles between caregiver and care recipient residence _____)

14. Number of persons living in caregiver residence (including the caregiver _____)

Number of adults _____, number of children under 18 years old _____

15. County of residence _____ City of residence _____

202

Instrumental Support (check all that apply)

16. Which of the following things do you help with?

_____ emotional support _____ housecleaning _____ other (_____)

_____ transportation _____ shopping

_____ cooking _____ physical care (bathing, dressing)

17. Is there anyone else who can fill in for you if you are away?

_____ Don't know _____ Yes _____ No _____

Social Interaction Scale (circle response)

18. About how often do you see or talk to the following persons?

A. Your Care Recipient:

Nearly every day	More than once a week	2-3 times a month	One time a month	Several times a year	Hardly ever
---------------------	--------------------------	----------------------	---------------------	-------------------------	-------------

B. Your Closest Relative:

Nearly every day	More than once a week	2-3 times a month	One time a month	Several times a year	Hardly ever
---------------------	--------------------------	----------------------	---------------------	-------------------------	-------------

C. Your Closest Friend or Friends:

Nearly every day	More than once a week	2-3 times a month	One time a month	Several times a year	Hardly ever
---------------------	--------------------------	----------------------	---------------------	-------------------------	-------------

D. Other Relatives(brothers, sisters, children):

Nearly every day	More than once a week	2-3 times a month	One time a month	Several times a year	Hardly ever
---------------------	--------------------------	----------------------	---------------------	-------------------------	-------------

E. Other Friends:

Nearly every day	More than once a week	2-3 times a month	One time a month	Several times a year	Hardly ever
------------------	-----------------------	-------------------	------------------	----------------------	-------------

F. Neighbors:

Nearly every day	More than once a week	2-3 times a month	One time a month	Several times a year	Hardly ever
------------------	-----------------------	-------------------	------------------	----------------------	-------------

Satisfaction with Social Interaction and Quality of Relationship (circle response)

19. How satisfied are you with your family life, that is, the time you spend and the things you do with your family? Would you say that you are:

Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
-------------------	-----------------------	--------------------	----------------

20. How satisfied are you with your friendships, that is, the time you spend and the things you do with your friends? Would you say that you are:

Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
-------------------	-----------------------	--------------------	----------------

21. How would you rate your overall relationship with the care recipient at this time?

Very Poor	Poor	Average	Good	Very Good
-----------	------	---------	------	-----------

22. In the past month how would you say you have been feeling?

Very Poor	Poor	Average	Good	Very Good
-----------	------	---------	------	-----------

BURDEN INTERVIEW (BI)

INSTRUCTIONS: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way, never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

Please answer the following questions corresponding to the person you are caring for: relative, refers to biological or marital relation and friend, refers to all other relationships.

1. Do you feel that your relative/friend asks for more help than he/she needs?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always
----------	-----------	--------------	---------------------	------------------

2. Do you feel that because of the time you spend with your relative/friend that you don't have enough time for yourself?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always
----------	-----------	--------------	---------------------	------------------

3. Do you feel stressed between caring for your relative/friend and trying to meet other responsibilities for your family or work?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always
----------	-----------	--------------	---------------------	------------------

4. Do you feel embarrassed over your relative's/friend's behavior?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always
----------	-----------	--------------	---------------------	------------------

5. Do you feel angry when you are around your relative/friend?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always
----------	-----------	--------------	---------------------	------------------

6. Do you feel that your relative/friend currently affects your relationship with other family members or friends in a negative way?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
7. Are you afraid what the future holds for your relative/friend?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
8. Do you feel your relative/friend is dependent upon you?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
9. Do you feel strained when you are around your relative/friend?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
10. Do you feel your health has suffered because of your involvement with your relative/friend?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
11. Do you feel that you don't have as much privacy as you would like because of your relative/friend?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
12. Do you feel that your social life has suffered because you are caring for your relative/friend?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

13. Do you feel uncomfortable about having friends over, because of your relative/friend?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
14. Do you feel that your relative/friend seems to expect you to take care of him/her, as if you were the only one he/she could depend on?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
15. Do you feel that you don't have enough money to care for your relative/friend, in addition to the rest of your expenses?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
16. Do you feel that you will be unable to take care of your relative/friend much longer?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
17. Do you feel you have lost control of your life since your relative's/friend's illness?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
18. Do you wish you could just leave the care of your relative/friend to someone else?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
19. Do you feel uncertain about what to do about your relative/friend?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

20. Do you feel you should be doing more for your relative/friend?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

21. Do you feel you could do a better job in caring for your relative/friend?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

22. Overall, how burdened do you feel in caring for your relative/friend?

0. Not at all 1. A little 2. Moderately 3. Quite a bit 4. Extremely

MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT(MSPSS)

We are interested in how you feel about the following statements. I will read each statement carefully. Indicate how you feel about each statement by choosing the appropriate number using the following scale:

Very strongly disagree	1	Strongly disagree	2	Mildly disagree	3	Neutral	4	Mildly agree	5	Strongly agree	6	Very strongly agree	7
---------------------------	---	----------------------	---	--------------------	---	---------	---	-----------------	---	-------------------	---	------------------------	---

1. There is a special person who is around when I am in need. _____
2. There is a special person with whom I can share joys and sorrows. _____
3. My family really tries to help me. _____
4. I get the emotional help and support I need from my family. _____
5. I have a special person who is a real source of comfort to me. _____

6. My friends really try to help me. _____
7. I can count on my friends when things go wrong. _____
8. I can talk about my problems with my family. _____
9. I have friends with whom I can share my joys and sorrows. _____
10. There is a special person in my life who cares about my feelings. _____
11. My family is willing to help me make decisions. _____
12. I can talk about my problems with my friends. _____

NETWORK ORIENTATION SCALE (NOS)

Below is a list of statements concerning relationships with other people. Please indicate the extent to which you agree or disagree with each statement.

- | | Strongly
agree
1 | Agree
2 | Disagree
3 | Strongly
Disagree
4 |
|--|------------------------|------------|---------------|---------------------------|
| 1. Sometimes it is necessary to talk to someone about your problems. | | | | |
| 2. Friends often have good advice to give. | | | | |
| 3. You have to be careful who you tell personal things to. | | | | |
| 4. You often get useful information from other people. | | | | |
| 5. People should keep their problems to themselves. | | | | |

6. It's easy for you to talk about personal and private matters. _____
7. In the past, friends have really helped you out when you've had a problem. _____
8. You can never trust people to keep a secret. _____
9. When a person gets upset they should talk it over with a friend. _____
10. Other people never understand your problems. _____
11. Almost everyone knows someone they can trust with a personal secret. _____
12. If you can't figure out your problems, nobody can. _____
13. In the past, you have rarely found other people's opinions helpful when you have a problem. _____
14. It really helps when you are angry to tell a friend what happened. _____
15. Some things are too personal to talk to anyone about. _____
16. It's fairly easy to tell who you can trust, and who you can't. _____
17. In the past, you have been hurt by people you confided in. _____
18. If you confide in other people, they will take advantage of you. _____
19. It's okay to ask favors of people. _____
20. Even if you need something, you would hesitate to borrow it from someone. _____

Appendix 7

CONFIDENTIALITY PLEDGE

**RURAL AND URBAN DIFFERENCES IN PERSONS LIVING WITH AIDS AND
THEIR CAREGIVERS**

Principal Investigator: Mary Maureen Newton, M.S.W., L.C.S.W.

I, _____, understand that any and all information that I obtain about clients in connection with this research project is to remain completely confidential.

Confidentiality is to be specifically ensured in four ways:

- Client information specific to AIDS Response Knoxville will not be taken from the agency at any time.
- All persons involved in the project will follow the AIDS Response Knoxville employee confidentiality guidelines.
- Participants in the project will not discuss any client information with anyone other than the Principal Investigator or other members of the research team, nor discuss such information in public or in the presence of anyone outside the project.
- Data will be analyzed by the Principal Investigator, using only a specially constructed data set that contains no client names.

I have received a copy of the confidentiality pledge and agree to all terms.

(Signature)

(Date)

(Principal Investigator)

(Date)

VITA

Mary Maureen Newton is the last of six children for Kenneth and Mary Newton and was born on May 9, 1964 in Knoxville, Tennessee. In June, 1982 she graduated from Doyle High School in her hometown and was female basketball player of the year for the county and all-state basketball player in Tennessee. In September, 1982 she entered the University of Alabama at Birmingham (UAB) with a full, four-year scholarship to play Division I basketball. She completed her Bachelor of Science in Social Work at UAB in June, 1986 with an accompanying Certificate in Gerontology. She was the academic player of the year her senior year at UAB. She immediately entered Florida State University (FSU) in June, 1986 and graduated with her Masters Degree in Social Work in May, 1987. Following graduation from FSU, she returned to her hometown of Knoxville, TN and worked in alcohol and drug treatment, home health, and hospice until August, 1989.

In the fall of 1989, she entered the University of Tennessee doctoral program in social work in Knoxville, Tennessee. During her education she had a research assistantship and worked on several research projects, including a study funded by the National Institute of Mental Health to assess children in the custody of the state of Tennessee. She completed her required course work and comprehensive examinations by the spring of 1992. She re-entered the work force and obtained significant professional experience in the field of HIV/AIDS, hospice care, and grief counseling. In 1997 she began an independent practice which includes: counseling, group facilitation, teaching, and consulting.