# Social Problem-Solving Ability as a Predictor of Distress in Caregiving Partners to Men with HIV and AIDS

A Thesis

Submitted to the Faculty

of

**Drexel University** 

by

William David Good, Jr.

in partial fulfillment of the

requirements for the degree

of

Doctor of Philosophy

July 2003

# **TABLE OF CONTENTS**

LIS	T OF	TABLES .		V			
ΑB	STRA	CT		vi			
1.	INTR	INTRODUCTION					
	1.1	The Acquired Immunodeficiency Syndrome					
		1.1.1	Modes of Transmission	2			
		1.1.2	Fear of Contagion	2			
		1.1.3	Overrepresentation in Socially and Economically Marginalized Groups	3			
		1.1.4	Uncertainties Regarding Disease Progression	4			
		1.1.5	1.5 Economic Impact of HIV and AIDS				
	1.2	Caregivii	ng and HIV/AIDS	5			
		1.2.1	Informal Caregivers to Individuals with HIV/AIDS	7			
		1.2.2	The Caregiving Experience	8			
		1.2.3	HIV and AIDS-Related Caregiving Tasks	11			
		1.2.4	HIV and AIDS-Related Caregiving and Stress	12			
	1.3	Caregivi	ng and Coping	17			
		1.3.1	The Transactional Model of Stress	17			
		1.3.2	The Social Problem-Solving Model	20			
	1.4	Introduct	ion to Predictor Variables	25			
		1.4.1	Care Recipient Characteristics	26			
			1.4.1.1 Functional Impairment of the Care Recipient	26			
		1.4.2	Caregiver/Care Recipient Dyad Characteristics	27			
			1.4.2.1 Quality of the Caregiver/Care Recipient Relationship	27			
		1.4.3	Caregiver Characteristics	28			
			1.4.3.1 Negative Life Events	28			

			1.4.3.2	Physical Health Functioning	28
			1.4.3.3	Availability of and Satisfaction with Social Support	29
			1.4.3.4	Social Problem-Solving Ability	31
	1.5	Summar	y and Hypothe	eses Under Investigation	31
		1.5.1	Primary Hyp	otheses	32
		1.5.2	Summary of	Primary Hypotheses	33
2.	MET	HOD			35
	2.1	Participa	nts		35
		2.1.1	Inclusion Cri	iteria	35
		2.1.2	Exclusion C	riteria	35
	2.2	Descripti	ion of the Sam	nple	35
	2.3	Design a	and Procedure	·	36
	2.4	Ethical C	Considerations		38
	2.5	Materials	S		38
		2.5.1	Care Recipio	ent Characteristics	39
			2.5.1.1	The Index of Independence in Activities of Daily Living	39
			2.5.1.2	Instrumental Activities of Daily Living	39
		2.5.2	Caregiver/C	are Recipient Dyad Relationship Characteristics	39
			2.5.2.1	Dyadic Adjustment Scale	39
		2.5.3	Caregiver C	haracteristics	40
			2.5.3.1	Life Experiences Survey	40
			2.5.3.2	MOS Short Form-36 Health Survey	41
			2.5.3.3	Social Support Questionnaire	41
			2.5.3.4	Social Problem-Solving Inventory – Revised	41
		2.5.4	Measures of	Caregiver Distress	43
			2.5.4.1	Beck Depression Inventory – Second Edition	42
			2512	Reck Anxiety Inventory	/13

			2.5.4.3	Beck Hopelessness Scale	43
3.	RES	ULTS	2.5.4.4	Caregiver Burden Interview	
	3.1	Descripti	ve Results		45
		3.1.1	Descriptive S	Summary of Independent and Dependent Variables	45
			3.1.1.1	Care Recipient Characteristics	45
			3.1.1.2	Caregiver/Care Recipient Dyad Characteristics	46
			3.1.1.3	Caregiver Characteristics	46
			3.1.1.4	Caregiver Distress	47
	3.2	Caregive	r/Care Recipie	: The Relationships among Care Recipient Variables, ent Dyad Variables, Caregiver Variables, and	48
		3.2.1	Care Recipie	ent Variables	48
		3.2.2	Caregiver/Ca	are Recipient Dyad Variables	49
		3.2.3	Caregiver Va	ariables	49
		3.2.4	Caregiver Di	stress	50
	3.3	Primary i	Analyses of Ca	aregiver Distress: Multiple Regression Analyses	51
		3.3.1	Assumptions	3	52
		3.3.2	Results		53
			3.3.2.1	Prediction of Depression in Caregivers	53
			3.3.2.2	Prediction of Anxiety in Caregivers	54
			3.3.2.3	Prediction of Hopelessness in Caregivers	55
			3.3.2.4	Prediction of Burden in Caregivers	56
			3.3.2.5	Summary of Results	57
4.	DISC	CUSSION.			58
	4.1	Overviev	v		58
	4.2	Summar	y of Results		59
		4.2.1	Correlational	I Analyses	59
		4.2.2	Primary Hyp	otheses Under Investigation	61

		4.2.2.1	Baseline Distress as a Predictor of Caregiver Distress	. 61
		4.2.2.2	Negative Life Events, Physical Health Functioning, and Care Recipient Functional Impairment as Predictors of Caregiver Distress	. 61
		4.2.2.3	Dyadic Adjustment and Social Support as Predictors of Caregiver Distress	. 61
		4.2.2.4	Social Problem-Solving Ability as a Predictor of Caregiver Distress	. 62
	4.3	Review of Current Findi	ings and Support of Previous Research	. 63
	4.4	Clinical Implications of t	he Present Study	. 66
	4.5	Limitations of the Prese	nt Study and Suggestions for Future Research	. 68
5.	SUM	MARY AND CONCLUSION	ONS	. 72
LIS	T OF	REFERENCES		. 74
ΑP	PEND	IX 1: TABLES		. 82
ΑP	PEND	IX 2: CONSENT FORM	AND MEASURES	. 92
VIT	-A			125

# LIST OF TABLES

1.	Descriptive Summary of Caregiver Demographic Information	82
2.	Descriptive Statistics of Independent and Dependent Variables Under Investigation	84
3.	Intercorrelations Among Care Recipient Variables, Caregiver/Care Recipient Dyad Variables, Caregiver Variables, and Caregiver Distress	86
4.	Intercorrelations Among Care Recipient Variables, Caregiver/Care Recipient Dyad Variables, Caregiver Variables, and Caregiver Distress (Includes Untransformed Variable Values and Social Problem-Solving Components)	87
5.	Care Recipient Variables, Caregiver/Care Recipient Dyad Variables, and Caregiver Variables as Predictors of Caregiver Depressive Symptoms; Dependent Variable – Beck Depression Inventory – 2 <sup>nd</sup> Edition	88
6.	Care Recipient Variables, Caregiver/Care Recipient Dyad Variables, and Caregiver Variables as Predictors of Caregiver Anxiety Symptoms; Dependent Variable – Beck Anxiety Inventory	89
7.	Care Recipient Variables, Caregiver/Care Recipient Dyad Variables, and Caregiver Variables as Predictors of Caregiver Hopelessness Symptoms; Dependent Variable – Beck Hopelessness Scale	90
8.	Care Recipient Variables, Caregiver/Care Recipient Dyad Variables, and Caregiver Variables as Predictors of Caregiver Burden Symptoms; Dependent Variable – Caregiver Burden Interview	91

#### **ABSTRACT**

Social Problem-Solving Ability as a Predictor of Distress in Caregiving Partners to Men with HIV and AIDS William David Good, Jr.
Christine Maguth Nezu, Ph.D.

HIV and AIDS pose myriad challenges to the individuals who live with it, their families, and the medical and mental health communities who serve them. Frequently, men who are in primary relationships with men living with HIV and AIDS function as their partners' primary caregivers. The purpose of this investigation was to investigate variables that significantly contribute to the distress experienced by this group of caregivers. In this study, variables related to the caregiver (negative life events during the past year, physical health functioning, availability of and satisfaction with social support), care recipient (functional impairment), and caregiver/care recipient dyad (dyadic adjustment) were evaluated. Four hierarchical multiple regression analyses were conducted on data collected from the 44 participating caregivers. Results indicated that caregivers' satisfaction with social support resources and social problem-solving ability significantly contributed to the prediction of their level of depressive symptomatology. However, none of the aforementioned variables reliably improved the prediction of caregiver anxiety, hopelessness, or burden. The limitations of this study, its clinical implications, and suggestions for future research are discussed.

#### 1. INTRODUCTION

The Centers for Disease Control and Prevention (CDC) have reported that as of the end of 2001, approximately 362,000 individuals in the United States were living with the Acquired Immunodeficiency Syndrome (AIDS) (CDC, 2003). Through the end of December 2001, a cumulative total of 816,149 cases of AIDS have been reported in this country (CDC, 2001). While these figures are significant, they do not represent the full impact of AIDS in the United States. Many people who have been infected with the Human Immunodeficiency Virus (HIV), the virus that is believed to cause AIDS (Powell, 1996), have not yet received an HIV test. HIV infection was the fifth leading cause of death for men and women between the ages of 25 and 44 in the United States in the year 2000. It is also estimated that 850,000 to 950,000 people in this country are living with HIV, one quarter of whom are unaware of their infection (CDC, 2001), and that approximately 42 million people worldwide are living with HIV/AIDS (Joint United Nations Programme on HIV/AIDS and World Health Organization, 2002).

The importance of caregivers and the experiences that they encounter in providing care to persons with HIV (PWHIVs) and AIDS (PWAs) is reflected in the numerous and varied roles in which caregivers function. Individuals with AIDS experience significant medical problems, including pneumonia, pulmonary and renal disease, chronic and severe diarrhea, and blindness, as well as various opportunistic infections throughout the course of the illness (Folkman, Chesney, & Christopher-Richards, 1994). These medical problems place significant limitations on the extent to which these individuals can execute daily tasks and other responsibilities. As a result, caregivers often function on their care recipients' behalf, engaging in such tasks as providing and/or arranging nursing care, negotiating legal and financial matters, medical decision making, and running the household (Land, 1992). In addition to these demands, caregivers also have their personal responsibilities outside of the caregiver/care recipient relationship. The obligations associated with providing care to individuals with HIV/AIDS place caregivers at risk for experiencing significant levels of distress (LeBlanc, Aneshensel, & Wight, 1995). This distress, in turn, may impact the quality of care provided by caregivers. It is possible for the poor quality of care to negatively impact the

progression of disease. For these reasons, an understanding of caregivers to individuals with HIV/AIDS and their experiences in providing care is essential.

#### 1.1 The Acquired Immunodeficiency Syndrome (AIDS)

AIDS is "...a specific group of diseases or conditions which are indicative of severe immunosuppression related to infection with the human immunodeficiency virus (HIV)" (CDC, 2001, p. 1). AIDS initially received formal recognition as a disease in 1981. At that time, the CDC reported cases of *Pneumocystis Carinii* pneumonia, a rare respiratory disorder, in five young and previously healthy homosexually active men in Los Angeles (Kalichman, 1995). It has been reported that since 1981, AIDS has reached pandemic proportions and is considered to be a global health threat. Additionally, the impact of AIDS is felt on all continents and nearly every country in the world (Mann, Tarantola, & Netter, 1992).

AIDS has been referred to as the "most controversial disease in modern history" (Powell-Cope & Brown, 1992, p. 571) as well as "one of the most stigmatizing medical conditions in modern history" (Kalichman, 1995, p. 192) and a "public health emergency" (Batchelor, 1984, p. 1279). There are numerous reasons for this, including the following: issues surrounding its modes of transmission, fear of contagion, its overrepresentation in socially and economically marginalized groups, uncertainties about disease progression, as well as its economic impact.

# 1.1.1 Modes of Transmission

In terms of the modes of HIV transmission among men in the United States, homosexual contact accounts for the majority of cases of HIV/AIDS, while injection drug use (IDU) accounts for the second largest number of cases (CDC, 2001). Consequently, HIV and AIDS are primarily associated with behaviors that receive significant negative societal evaluation.

#### 1.1.2 Fear of Contagion

Fear of contagion is another source of HIV- and AIDS-related stigma and controversy (Kalichman, 1995). Research has indicated that much of this fear and stigma results from misinformation and inaccurate perceptions about HIV and AIDS (Bartlett, 1993) and that these types of inaccuracies are commonplace in this country. Mondragon, Kirkman-Liff, and Schneller (1991) demonstrated that hostility towards people with AIDS was associated with

misperceptions about HIV transmission. Additionally, Herek and Capitano (1993) found racial and gender differences in terms of AIDS-related stigma. African Americans expressed more support for public policies that would enforce separating PWAs and were more likely to avoid them while Caucasians were more likely to blame PWAs for their illness and express negative feelings towards PWAs. Overall, males were more likely to endorse that they would avoid PWAs and support public policies such as quarantine than were females. Concerns have also been expressed about potential large-scale ramifications of HIV- and AIDS-related misperceptions, fear of contagion, and stigma. Leonard (1985) demonstrated that employment discrimination could result from fear of contagion that is based on inaccurate information. Moreover, Kegeles, Coates, Christopher, and Lazarus (1989) have cautioned that inaccuracies regarding the transmission of HIV may result in prejudicial health policies. Thus, misperceptions and inaccuracies regarding HIV transmission yield fears of contagion that may, in turn, result in stigma and discriminatory practices against PWAs.

#### 1.1.3 Overrepresentation in Socially and Economically Marginalized Groups

Another contributing factor to the controversy and stigma surrounding HIV and AIDS is the overrepresentation of this disease in socially and economically marginalized groups. For example, groups of people who are at increased risk for contracting HIV include gay and bisexual men, individuals who engage in prostitution, and injection drug users. People with HIV and AIDS who are a member of one or more of these groups are often blamed for contracting the disease because HIV transmission is so frequently associated with behaviors in which one may choose to engage (McDonell, 1993). Ethnic minorities and individuals living in poverty are also at greater risk for contracting the virus. Among men in the United States, African Americans represent 47% of reported AIDS cases, while white (non-Hispanic) and Latino men represent 32% and 19% of reported cases, respectively. Asian/Pacific Islander and American Indian/Alaska Native men each represent 1% of AIDS cases (CDC, 2001).

Individuals are subjected to significant prejudicial beliefs and discrimination on the basis of belonging to one or more of these marginalized groups. Herek and Glunt (1988) reported that the discrimination and stigma that is associated with HIV and AIDS is "layered upon

preexisting stigma" (p.887). Des Jarlais, Friedman, and Hopkins (1985) have referred to this as a dual stigma, in terms of the stigma associated with identifying AIDS as a serious illness and the stigma associated with identifying AIDS with groups who encountered significant prejudice and discrimination prior to the AIDS pandemic. Thus, most people respond to AIDS not as a fatal and communicable disease but rather as a fatal and communicable disease of homosexual men and various other minorities (Herek & Glunt, 1988).

#### 1.1.4 Uncertainties Regarding Disease Progression

AIDS is a disease that is marked by uncertainty and variability regarding its progression and clinical course (Dilley, Ochitill, Perl, & Volberding, 1985). It has been reported that significant periods of time may elapse in which an individual with HIV or AIDS may be symptom free and feel healthy. This is frequently followed by periods of time in which the individual experiences a number of new infections or recurrences of previous diseases with a limited amount of time to recuperate in between (Folkman et al., 1994). In addition to this pervasive uncertainty, individuals with HIV and AIDS also experience a loss of control in terms of determining their futures (Kalichman, 1995). People with AIDS have referred to the experience of uncertainty about disease progression as being on a "roller coaster" (Folkman et al., 1994, p. 37).

# 1.1.5 Economic Impact of HIV and AIDS

The economic impact of AIDS also contributes to the controversy surrounding the disease. This impact is felt on the individual, community, and national levels. It has been estimated that the lifetime treatment and care costs for an individual living with HIV is approximately \$195,000 (Holtgrave & Pinkerton, 1997). Annual expenditures for HIV and AIDS care have been reported to range between \$14,000 and \$34,000 per patient per year, with individuals at advanced stages of illness having higher costs of care than those who are living with HIV and remain healthy consequent to anti-retroviral medication regimens (Feig, 2002).

The economic impact of AIDS is felt on the community level in terms of decreases in the work force as the result of illness as well as increased demands on social service resources (Kalichman, 1995). Furthermore, as more private insurance companies are requiring HIV

tests prior to granting coverage and more privately insured people with AIDS are losing insurance coverage as the disease progresses (Ozawa, Auslander, and Slonim-Nevo, 1993, the need for public funding and assistance increases. Green and Arno (1991) have referred to the increased utilization of Medicaid by individuals with AIDS as "Medicaidization". While the use of Medicaid offers people with AIDS access to necessary treatment that they may not receive otherwise, its long-term feasibility has been questioned. It has been stated that increased reliance on Medicaid places significant financial burdens on public hospitals and inadequate Medicaid reimbursements result in decreased access to quality medical care (Ozawa et al., 1993). The economic impact of AIDS treatment has resulted in a call for increased community- and home-based care for people with AIDS (Mello-Udine, 1992; Taylor, 1994).

# 1.2 Caregiving and HIV/AIDS

Individuals with HIV and AIDS require a significant amount of support as a function of the numerous physical and psychosocial impairments associated with this syndrome. In addition to the effects of the disease on the person with AIDS, his or her social and community networks are also affected (Turner, Catania, & Gagnon, 1994), including families, friends, partners and spouses, and formal institutions; they frequently function in caregiving roles. Land (1992) has reported that caregivers to individuals with AIDS become involved in nearly all facets of the disease. However, given the notable contributions that caregivers make to disease treatment and management as well as the quality of life of individuals with AIDS, there is limited research regarding the impact of providing care to this population (Pakenham, Dadds, & Terry, 1995; Powell-Cope & Brown, 1992). Hoffman (1996) has stated that caregivers are "often forgotten when the psychosocial impact of HIV disease is considered" (p. 216). Coates, Temoshok, and Mandel (1984) have identified the importance of psychosocial research in both understanding and treating AIDS. This includes the systematic investigation of the experiences of individuals with AIDS as well as the experiences of their caregivers. The importance of conceptualizing AIDS within a biopsychosocial framework has been addressed in the literature (Cohen, 1990).

The need for a comprehensive understanding of the experiences of these caregivers is underscored by the current status of available AIDS treatments. Advances in treatment (e.g., antiviral therapies) have resulted in AIDS being conceptualized as a long-term illness (Chesney et al., 1996). Because persons with HIV and AIDS are living for longer periods of time, quality of life issues for persons with HIV and AIDS and their caregivers become more salient. Caregivers offer varying levels (e.g., preventive, palliative) and types of support to their care recipients. Thus, the chronic aspects of the disease reflect the importance of caregivers and their role in the lives of individuals with AIDS. The limited research that has examined the experiences of caregivers to people with AIDS has demonstrated that caregiving involves significant amounts of stress (Pearlin, Semple, & Turner, 1988), involves tasks that are often emotionally and physically exhausting (Moskowitz, Folkman, Collette, & Vittinghoff, 1996), and may have a negative impact on the psychological functioning of caregivers (Irving, Bor, & Catalan, 1995). Martin (1988) has referred to the psychosocial distress that is experienced by these caregivers as the "secondary epidemic" (p. 856).

Distinctions have been made between formal and informal caregivers. Formal caregivers include mental health professionals, nurses, and physicians who "approach the recipient as trained workers contractually engaged to do a job" (Pearlin et al., 1988, p. 502). In contrast, informal caregivers are parents, partners, spouses, siblings, other family members, and friends of the care recipient (Hoffman, 1996). While informal caregivers learn home health care skills, they usually do not receive professional training (Wight, LeBlanc, & Aneshensel, 1995) or compensation for caregiving. Additionally, they are often required to reorganize their lives to facilitate the responsibilities of caregiving. Informal caregivers have been referred to as a "nonprofessional, nonpaid national health resource" (LeBlanc, et al., 1995, p. 127).

The rising costs of health care in the United States and resultant strains on health care institutions have highlighted the need for alternative treatment options. The importance of informal caregiving systems will become more salient as a result of a general shift from hospital-based to community-based and home-based care in this country (McCann & Wadsworth, 1992; Raveis & Siegel, 1991). Pearlin et al. (1988) have reported that relative to

formal caregivers, informal caregivers are at the most risk for exposure to stress and its consequences because these individuals have the greatest emotional investment in their care recipients.

#### 1.2.1 Informal Caregivers to Individuals with HIV and AIDS

Informal caregiving systems make integral contributions to disease management and care provision in this country. These systems will become more essential due to the changing structure of American health care. As a result, there has been interest in discovering the characteristics of informal caregivers to people with AIDS in the United States, the types of caregiving tasks in which caregivers engage, as well as factors that may place these individuals at risk for experiencing negative caregiving-related consequences.

Turner, Catania, and Gagnon (1994) have investigated the prevalence of informal caregiving to people with AIDS in the United States. Informal caregivers, in this study, were respondents who answered "yes" to the following question: "Have you ever helped out or taken care of a friend, relative, or lover with AIDS?" (p. 1546). They examined informal caregiving in the United States population as a whole as well as within central cities in this country (e.g., New York, San Francisco, and Philadelphia). The found that 15% of all participants (i.e., caregivers and non-caregivers) reported knowing or having known someone with AIDS. Of these individuals, 20% of the national sample and 24% of the central cities sample reported having served as a caregiver. They found the overall cumulative prevalence of informal caregiving within the entire country and within the central cities to be 3.2% and 5.9%, respectively. It was discovered that the majority of caregivers were Caucasian and younger than 40 years of age. Additionally, they reported that within the central cities, males (particularly gay and bisexual males) were over-represented among caregivers; 53.8% of all gay and bisexual men and 33.3% of lesbian and bisexual women in the central cities have served as informal caregivers while 3.4% of heterosexual males and 5.2% of heterosexual females in these cities have served in this capacity. In terms of male participants who reported knowing someone with AIDS, 64% of gay and bisexual men and 19% of heterosexual men endorsed having served in a caregiving role. They reported that informal caregivers,

relative to non-caregivers, were more likely to have received an HIV test and have tested HIV positive. Additionally, it was found that nearly one-third to one-half of gay men with AIDS is cared for by their partners and/or friends. Folkman, Chesney, Cooke, Boccellari, and Collette (1994) have asserted that "the primary caregivers of many men with AIDS are likely to be their partners" (p. 746).

#### 1.2.2 The Caregiving Experience

Caregiving, irrespective of type of illness, has been associated with chronic distress and negative psychological and immunological changes in caregivers (Kennedy, Kiecolt-Glaser, & Glaser, 1988). However, it has also been reported that caregivers may appraise their caregiving experiences positively (Clipp, Adinolfi, Forrest, & Bennett, 1995). The fact that individuals experience caregiving in different ways has led researchers to question what aspects of caregiving contribute to the experience of positive or negative consequences. Specifically, the foci of research have included the following: caregiver factors, care-recipient factors, and caregiving relationship factors.

The caregiving literature that addresses informal caregivers of chronically ill adults has traditionally focused on the experiences of providing care to people with Alzheimer's Disease, Parkinson's Disease, and cancer (Clipp et al., 1995). These informal caregivers typically include adult daughters, spouses, and parents (Hoffman, 1996; Folkman et al., 1994). They are predominantly female and most often middle-aged or older (Wardlaw, 1994). While this research has made significant contributions to understanding the caregiving experience, it has been suggested that it may not fully capture the unique aspects involved with providing care to someone with AIDS. Four dimensions have been identified that may discriminate caregivers to men with AIDS from traditional family caregivers. They include the following: (a) AIDS caregivers are likely to be young or middle-aged because the disease is prevalent in young and middle-aged individuals; (b) while traditional family caregivers frequently rely on other family members for support, AIDS caregivers and their care recipients are often faced with physical and/or emotional distance from their relatives; (c) males comprise a substantial portion of AIDS caregivers; yet, caregiving is characteristically viewed as part of the female

role in the United States and there are few models of male caregiving; and (d) a notable number of AIDS caregivers are HIV positive themselves (Folkman et al., 1994).

The fact that AIDS caregivers are mostly young and middle-aged has led to the idea that caregiving is an "off-time" event and occurs prematurely in the lives of these individuals (Neugarten, 1979). This, in turn, may create stress above and beyond that directly associated with providing care. Caregivers to people with such diseases as Alzheimer's or Parkinson's Disease, while experiencing caregiving related stressors and distress, are most often in the caregiving role at a time in their lives that society has sanctioned it as predictable. They are more likely to have same-aged peers who are providing care. Thus, they are more likely to have access to individuals or groups with whom they can share their experiences and both provide and receive support. In contrast, AIDS caregivers most often do not have large numbers of same-aged peers who are functioning as caregivers. Additionally, it has been shown that AIDS caregiving decreases the amount of time for employment, earning an income, and career development (Folkman et al., 1994).

Traditional family caregivers often rely on other family members for various types of support. AIDS caregivers and care recipients (especially gay men with AIDS and their caregiving partners), in contrast, often experience strained family relations or no relations at all. Furthermore, it has been demonstrated that fear of contagion and the stigma surrounding AIDS are additional barriers to support from families (Herek, 1990). These caregivers often rely on their partners and friends who share their experiences for support (Hays, Turner, & Coates, 1990).

Caregiving is most often associated with the female role in this country. This provides limited resources for male caregivers in general and male AIDS caregivers in particular for conceptualizing their experiences as caregivers and addressing questions or concerns they may have. Folkman et al. (1994) have asserted that this lack of public support and acknowledgement of the male caregiving role reflects the "non-normative aspects of being a caregiving partner for a person with AIDS" (p. 39).

Another factor that has been discussed as differentiating the AIDS caregiver from traditional caregivers includes the health status of the caregiver; specifically, the caregiver's HIV status. Folkman et al. (1994) have stated that providing care requires HIV positive caregiving partners of men with AIDS to deal with the imminent loss of their partner as well as their own health and concerns about who will serve as their caregivers when that is necessary. Additionally, HIV negative caregivers are faced with the risk of becoming HIV positive. These types of concerns do not seem as salient for caregivers to individuals with other conditions.

It has been advised that caution be used when applying the available literature from other informal caregiving populations to informal caregivers of people with AIDS. This caution has addressed the idea that those literatures may not capture the unique experiences of AIDS caregivers. However, this recommendation neither precludes a comparison of these various populations entirely nor the opportunity to learn from the literature. In fact, comparisons have been made between AIDS and other chronic conditions, such as cancer. For example, it has been demonstrated that AIDS and other chronic diseases share the following similarities: physical decline, loss of physical functioning, unpredictability of disease, uncontrollability of symptoms, and financial burden (Hoffman, 1996; Kalichman, 1995; Folkman et al., 1994). Given the relatively small literature on informal caregivers to persons with AIDS and the similarities between AIDS and other chronic conditions, it appears that a comparison of these various caregiving populations is worthwhile, as long as the unique aspects of AIDS caregivers are also considered. It has also been stated that much of the available literature has been restricted to caregivers of men with AIDS, instead of investigating the experiences of caregivers across the HIV/AIDS continuum as well (Pakenham et al., 1995). The introduction of highly active antiretroviral therapy (HAART) in 1996 has resulted in a notable decrease in the number of AIDS-related deaths in the United States (Karon et al., 2001) and a subsequent increase in the number of individuals living with AIDS (CDC, 2002). Consequently, understanding the experiences of caregivers to people at various stages of HIV and AIDS is essential.

#### 1.2.3 HIV and AIDS-Related Caregiving Tasks

Folkman et al. (1994) has reported that the characteristics of AIDS govern the activities of the informal caregiver. It has also been reported that the requirements placed on the caregiver by the acute and chronic aspects of HIV and AIDS are "profound" (Folkman et al., 1994, p. 37). Caregivers provide various types and levels of practical and emotional support.

The practical support that caregivers offer has been reported to parallel practical support that caregivers offer to individuals with other diseases. For example, caregivers to people with AIDS offer considerable support with activities of daily living (Folkman et al., 1994). This includes assistance with housekeeping, grocery shopping, and transportation to medical appointments. It also includes assistance with personal care tasks such as bathing, dressing, feeding, and toileting. Caregivers offer support with medically related tasks, including medication monitoring, administration of injections, as well as insertion of catheters.

Additionally, caregivers are involved with protecting the safety of their care recipients, especially as the result of various behavioral and cognitive problems associated with AIDS - Related Dementia (Wardlaw, 1994). As the disease progresses, caregivers are often called upon to interact with the medical and legal systems (Folkman et al., 1994; Wardlaw, 1994). It has been found that informal caregivers to people with AIDS can be effective proxies regarding their care recipients' health care needs and provide accurate information regarding care recipients' health management and financial and psychosocial support (Berk, 1995).

The provision of emotional support to people with AIDS is also an integral part of the caregiving experience. It has been stated that emotional support is a salient need throughout the course of the disease, from the time of being diagnosed as HIV positive through the various stages of disease progression (Folkman et al., 1994). Caregivers frequently provide a source of hope to people with AIDS as well as a place in which people with AIDS can express their uncertainties, fear and anger. Furthermore, caregivers provide support to their care recipients during the advanced stages of the disease, including the dying process. Powell (1996) has found that caregivers are oftentimes the target of their care recipients' anger and rage, most often because the caregivers are most accessible to them. In their study of

informal caregivers providing care to men with AIDS, McCann and Wadsworth (1992) found that 70% of their sample were providing both practical and emotional support.

#### 1.2.4 HIV and AIDS-Related Caregiving and Stress

The provision of care to individuals with AIDS has been demonstrated to involve significant demands on the caregivers; caregivers experience chronic levels of stress as a result of providing care. Folkman et al. (1994) have stated that providing care to people with AIDS is "especially taxing for informal caregivers, such as partners" (p. 2). Specifically, they have stated that these caregivers, unlike professional caregivers, experience intense emotional involvement and "do not have the protection of a limited work day or professional distance" (pp. 37, 38). Furthermore, informal caregivers often do not have the level of training and expertise in AIDS-related treatment and management that professional caregivers possess. In consequence, informal caregivers may experience more anxiety than professional caregivers about the course of the disease and what is expected in terms of care provision. Additionally, informal caregivers are often required to acquire various new care-related skills (e.g., administering injections) as they are providing care.

Various sources of stress associated with AIDS caregiving have been identified. They include the following: the caregiver role (i.e., role strain and role conflict), unexpected health improvement, the uncontrollable aspects of AIDS, and the stigmatization associated with AIDS caregiving. Additionally, because AIDS has a significant presence within the gay community, aspects of caregiving that are more salient for the gay community have also been identified.

Pearlin et al. (1988) have described the AIDS caregiving role as "relentless" and "emotionally depleting" (p. 505). Caregiving partners are called to serve in numerous capacities. Because many caregiving tasks are urgent and require being carried out at the same time, caregivers frequently experience difficulty with maintaining order over the caregiving role. Land (1992) has reported that conflicts and strains associated with caregiving occur on a daily basis. In addition to the conflict associated with the various duties within the caregiving role, caregivers also experience role conflict between caregiving and other roles, such as employment (Folkman et al, 1994). This is particularly salient for AIDS caregivers

because most of them are young. A caregiver may be required to leave work to take his care recipient to medical appointments or he may have to leave work as the result of an emergency with the care recipient. These types of situations may result in problems with employers and decreases in income. This is particularly problematic for caregiving partners, especially if they are the only source of income within the relationship. Informal caregivers have reported multiple losses, including their previous lifestyles, personal freedom, and interpersonal relationships (Brown and Powell-Cope, 1993). Pearlin et al. (1988) have also discussed the effects of the multiple responsibilities of caregiving on the caregivers' friendships. They have reported that caregivers may cease relationships with friends after assessing that the amount of support that they derive from these relationships does not equate with the amount of time and energy that they invest in the relationships. Additionally, whereas some relationships may become stronger and individuals may offer increased support to the caregiver, other individuals may decide to end their relationships with the caregiver because the caregiver is unable to offer the same level of investment that he/she did prior to caregiving. Thus, there is the possibility that others may offer decreased resources and support to the caregiver at a time when he or she may most need it.

The potential stress of shifting responsibilities within the caregiving relationship has also been discussed. Particular attention has been paid to this within caregiving relationships in which a male partner is providing care to his partner with AIDS. Folkman et al. (1994) have stated that responsibility for household tasks, employment, and decisions regarding treatment often shift from the person with AIDS to the caregiver as the disease progresses and the person with AIDS has less resources to deal with these decisions. They have asserted that shifts in responsibility may cause distress for the caregiving partner for the following three reasons: (a) these shifts demonstrate a deterioration in the health of the care recipient, (b) the shifts may represent an invasion of the privacy of the care recipient, and (c) the tasks that are involved with these shifting responsibilities may surpass the caregiver's actual or perceived competency.

Unexpected health improvements and dealing with an essentially uncontrollable disease have also been identified as two sources of stress associated with AIDS caregiving.

Kalichman (1995) has discussed the fact that AIDS is characterized by periods where the individual is not experiencing any symptomatology. These periods, however, often end abruptly when the person develops an AIDS-related illness(es). There is considerable variation in the amount of time that elapses between illnesses. It has been pointed out that periods of unexpected improvement in the health of the person with AIDS may increase the distress experienced by the caregiver, especially for caregivers who have been using the time that the person has been ill to prepare for the death of the individual. These unexpected health improvements are one example of the fact that caregivers and their recipients deal with a disease that is uncontrollable in nearly all ways. Folkman et al. (1994) have reported that caregiving partners of men with AIDS often feel completely helpless and experience lack of control in providing care to their partners who are ill. In addition, these caregivers frequently feel frustrated and display anger towards the disease, the health care system, and also towards their partners.

Caregivers, in addition to dealing with the responsibilities of providing care, are also faced with negative societal reactions regarding their caregiving roles. Hoffman (1996) has reported that informal caregivers are stigmatized by society for being a caregiver to a person with AIDS. The stigma associated with the caregiving role is derived from misinformation regarding the disease and the fact that many people have acquired the disease via routes that are stigmatized in society. Powell-Cope and Brown (1992) have demonstrated that family caregivers often experience this stigma in terms of loss of friendships, harassment, and rejection. Caregivers who fear being stigmatized if it is discovered that they provide care to individuals with AIDS have been referred to as "hidden grievers" (Murphy & Perry, 1988). Additionally, it has been shown that it is common for caregivers who feel stigmatized or who are secretive about the illness to wish that their care recipients would die (Lippman, James, & Frierson, 1993).

In addition to the aforementioned aspects of caregiving, aspects of caregiving that are more salient for the gay community have also been identified. They are particularly noteworthy given the epidemiological characteristics of informal caregivers; gay men comprise the majority of partners providing care to individuals with AIDS (Brown & Powell-Cope, 1993). Hoffman (1996) has noted that gay men who are caregivers to their partners with AIDS are faced with significant changes in their primary relationships. Most heterosexual couples do not address these changes until they have been together for a greater number of years. These caregivers may also worry that they will be required to go through this process again with a new partner. Furthermore, for caregivers who are themselves HIV positive, providing care may result in thoughts concerning their own mortality and who will provide care for them when it is needed (Brown & Powell-Cope, 1993).

The death of a partner represents a significant loss for gay men who have provided care. Hoffman (1996) has reported that society frequently discounts these relationships and does not offer the same quality or quantity of support to these men that is afforded to individuals in heterosexual relationships. An additional consideration is that gay males providing care may have already experienced the deaths of friends or previous partners to AIDS. These losses result in a decrease in the size of social networks, leaving caregivers with the potential for less support at a time when it may be particularly needed.

The fact that informal caregivers to people with AIDS experience the general stressors of caregiving as well as factors more specific to AIDS caregiving has led researchers to investigate the consequences of this role on caregiver well-being. Previous research with other caregiving populations has demonstrated that caregiving is associated with negative consequences to caregivers' emotional and physical health (LeBlanc et al., 1995). For example, studies have indicated that informal caregivers have significantly higher rates of depressive symptoms than the general population (Wright, Clipp, & George, 1993).

Available research on the consequences of AIDS-related caregiving on caregiver well being has demonstrated similar results. In an investigation of gay men in New York City, Lennon, Martin, and Dean (1990) have reported that caregivers to individuals with AIDS

experience significant emotional distress. Caregivers have also demonstrated high levels of anxiety and increased negative ruminations as the result of providing care (Lego, 1994).

Irving et al. (1995) investigated psychological distress in gay men who support lovers or partners with AIDS. Results indicated that these individuals experienced significant levels of global and AIDS-specific psychological distress. The levels of distress were high enough to suggest the majority of these individuals may have been experiencing significant psychiatric morbidity. LeBlanc et al. (1995) investigated depression and utilization of psychotherapy among caregivers to people with AIDS. It was found that stressors associated with caregiving resulted in elevated depressive symptoms and that the depressive symptoms were positively associated with psychotherapy use in this group of caregivers. Caregivers in this study also demonstrated higher rates of psychotherapy use than is found in the general population (31% versus approximately 6-7%, respectively) (Shapiro et al., 1984). It also appears that caregivers may be at risk for psychological distress after the death of their care recipients. For example, Trice (1988) found that mothers who provided full time care to their sons with AIDS demonstrated patterns of symptoms that resembled Post-Traumatic Stress Disorder.

Numerous studies have demonstrated that caregivers in general, and caregivers to people with AIDS in particular, are at risk for experiencing psychological distress. However, other studies have reported only small to moderate amounts of burden and distress in AIDS caregivers. It has also been demonstrated that AIDS caregivers appraise their caregiving experiences as positive more so than as threatening or stressful (Clipp et al., 1995). Folkman et al. (1994) found that while caregivers experienced dysphoria, they also reported levels of well being comparable to that of community samples. Additionally, Wardlaw (1994) reported that while some caregivers reported only negative consequences of caregiving, others reported positive consequences from their caregiving experiences (e.g., improved relationships with care recipients, increased self esteem and self confidence). Overall, most caregivers believed that they had coped well with their caregiving experiences. These differences have led researchers to question what factors are implicated in coping with the demands of providing care to individuals with AIDS.

# 1.3 Caregiving and Coping

#### 1.3.1 The Transactional Model of Stress

It has been suggested that Lazarus and Folkman's (1984) Transactional Model of stress and coping is a useful model by which to conceptualize the caregiving experience. This is a cognitive-based model that emphasizes the dynamic, bi-directional, and mutually reciprocal relationship between the person and his or her environment. Stress, according to this model, is defined as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p. 19).

Two processes, cognitive appraisal and coping, have been identified as "critical mediators of stressful person-environment relationships and their immediate and long-term outcomes" (Folkman, Lazarus, Gruen, & DeLongis, 1986, p. 572). Cognitive appraisal is a process of evaluation by which the person determines whether an interaction with the environment is relevant to his or her well being. Cognitive appraisal consists of two parts, primary appraisal and secondary appraisal. Primary appraisal refers to the process of determining the personal significance of a particular person-environment transaction to his or her well being. A transaction may be irrelevant, in which there is no personal significance; benign, in which there is personal significance but no threat or harm; or stressful, in which there is threat, harm/loss, or challenge. Secondary appraisal refers to the process by which the person assesses resources and options for changing the relationship (Folkman & Chesney, 1995; Folkman et al., 1986).

Coping, within this model, is defined as a person's behavioral and cognitive activities to control the external and internal demands of person-environment transactions that are appraised as taxing or exceeding a person's resources (i.e., stressful). The means by which a person copes, according to the Transactional Model, is influenced by the appraisal of a particular person-environment transaction. Thus, coping is viewed as contextual. In order to understand why an individual is coping in a specific way, his or her appraisal of the particular

person-environment transaction in which he or she is coping must first be understood (Lazarus & Folkman, 1984).

These authors describe coping in terms of two general forms of coping, problem-focused and emotion-focused coping. Problem-focused coping refers to strategies in which the goal is to change problematic aspects of stressful situations. Emotion-focused coping refers to strategies in which the goal is to change a situation's meaning without changing the environment and to manage one's emotional responses to stressful situations (Chesney et al., 1996). Examples of problem-focused and emotion-focused coping strategies include cognitive problem-solving and positive reappraisal of a situation, respectively. Folkman and Lazarus (1985) have demonstrated that individuals in almost every type of stressful situation use both forms of coping.

The decision to utilize problem-focused or emotion-focused coping in a particular stressful situation is determined by an individual's appraisal of the situation as either controllable/changeable or uncontrollable/unchangeable (Chesney et al., 1996). Adaptive coping, in this model, refers to those situations in which a person chooses a coping strategy (i.e., problem-focused or emotion-focused) and the chosen strategy "fits" with the changeability of the stressful situation. Maladaptive coping refers to situations in which a person chooses emotion-focused strategies to manage changeable stressors or problem-focused strategies to manage stressors that are unchangeable. It has been reported that maladaptive coping results in significant increases in psychological distress (Chesney et al., 1996).

It has been demonstrated that coping strategies used in response to situations that are appraised as stressful mediate the impact of stressors as well as adaptational outcomes, such as psychosocial functioning (McCain & Smith, 1994; Lazarus and Folkman, 1984).

Additionally, the Transactional Model asserts that the individual engages in the process of reappraisal. Reappraisal refers to ongoing reinterpretation of a situation based on new information that is acquired by the person (McCain & Smith, 1994).

The components of the Transactional Model will be illustrated with an example of problem situations that arise for caregiving partners to men with AIDS. For example, a physician may tell a caregiving partner that his partner has lost his vision as the result of Cytomegalovirus Retinitis infection. According to the Transactional Model, the caregiving partner evaluates whether or not this person-environment transaction is relevant to his well being (cognitive appraisal). He determines the personal significance of this transaction to his well being and whether or not it is irrelevant, benign, or stressful (primary appraisal). In this example, the caregiver determines that this transaction is significant (because it involves his partner), threatening (it is a reminder that his partner has a very serious illness and is becoming more impaired), and unchangeable (the physician informs him that the damage is irreparable). Furthermore, he assesses his available resources and options for managing the situation and determines that there is a number of resources available (secondary appraisal). The caregiver may engage in a variety of strategies to manage his reactions to this situation, such as joining a support group, exercise, meditation, or humor (coping). In turn, he may effectively manage the stress, gain more courage, and view the situation as a challenge rather than a threat (reappraisal). If he engages in such emotion-focused coping strategies, the Transactional Model suggests that there will be a "fit" between the unchangeable situation and the use of such strategies. This, in turn, will result in decreased psychological distress and increased psychological well being. If, however, he were to engage in problem-focused coping strategies to deal with this unchangeable situation, the outcome, according to Lazarus and Folkman's model, would be increased psychological distress and decreased psychological well being. There would not be a "fit" between the appraisal of changeability of the situation and type of coping strategy employed (Chesney et al., 1996). For example, if the caregiver were to take his partner to various physicians to see if his vision could be restored (i.e., use problem-focused coping strategies to try to change a situation that is unchangeable) he would repeatedly be faced with the fact that nothing could be done. This would likely result in increased psychological distress (e.g., frustration, anger, depression).

#### 1.3.2 The Social Problem-Solving Model

Social Problem Solving has been defined generally as "the process by which people both understand, and react to, problems in living" (Nezu, Nezu, & Perri, 1989). More specific definitions have also been offered. For example, Nezu (1987) has defined problem solving as the "...metacognitive process by which individuals understand the nature of problems in living and direct their attempts at altering either the problematic nature of the situation itself or their reactions to them" (p. 122). It has been noted that social problem solving may be viewed from a number of different perspectives, including behavioral, social-learning, and mental health (Nezu et al., 1989).

Problems, according to the Social Problem-Solving Model, are present or anticipated life situations that involve a discrepancy between an individual's actual situation and what he or she desires (D'Zurilla, 1986). D'Zurilla and Goldfried (1971) have asserted that problem situations demand responses for adaptive functioning, but that these demands are not met as the result of obstacles that keep individuals from engaging in such effective coping responses. These obstacles may include the following: lack of resources, novelty, ambiguity, and conflicting demands (Nezu et al., 1989). It has also been asserted that these obstacles yield maladaptive coping by individuals, which increases the probability of experiencing distress and psychological symptomatology.

An important aspect of this model is that of individual differences. That is, the Social Problem-Solving model highlights the fact that different people may perceive and respond to similar situations in different ways. As such, the demands of problem situations are most aptly described as perceived demands. A problem situation is the product of a relationship between an individual and the environment in which the demands perceived by the individual exceed his or her coping resources (Nezu et al., 1989). These definitions represent the transactional nature of the Social Problem-Solving Model.

It has been noted that the Social Problem-Solving Model and Lazarus and Folkman's Transactional Model both incorporate transactional views of stress (Nezu et al., 1989). The former model, like the latter, emphasizes the person-environment relationship, whereby the

person engages in activities to either alter the problematic nature of a situation (i.e., problem-focused coping), his or her emotional reactions (i.e., emotion-focused coping), or both (Nezu & D'Zurilla, 1989; D'Zurilla, 1986). The Social Problem-Solving Model differs, however, in terms of its conceptualization of the relationship between problem- and emotion-focused coping and problem solving. D'Zurilla (1986) has illustrated the difference between these models by describing the Problem-Solving Model's emphasis on problem solving as a **general** coping process. Problem solving, within Lazarus and Folkman's model, is one example of coping (Lazarus & Folkman, 1984) whereas in the Social Problem-Solving Model, it is broader in scope (Nezu et al., 1989).

The requirements of problem solving, as a general coping process, include a flexible, creative, and versatile approach in the development of an adaptive solution to a problematic situation (D'Zurilla, 1986). As such, the problem solving process utilizes both problem- and emotion-focused coping strategies. Problem solving also requires flexibility as a coping process in order for a person to manage his or her problems and so that the person's emotional distress and perceived control over situations are minimized and maximized, respectively (Nezu & D'Zurilla, 1989).

There are five major components in the Social Problem-Solving Model. They include Problem Orientation, Problem Definition and Formulation, Generation of Alternatives, Decision Making and Solution Implementation and Verification. These five components each have specific goals. While each of them has a particular purpose, it is important to note that they are interrelated components (Nezu & D'Zurilla, 1989; Nezu et al., 1989).

Problem orientation differs from the other four components because it is a general response set while the other components reflect specific skills that are utilized to deal with problems adaptively and effectively (Nezu et al., 1989). It has been defined as "a set of orienting responses representing the immediate cognitive-affective-behavioral reactions of a person when first confronted with a problematic situation" (Nezu, Nezu, Rothenberg, & D'Zurilla, 1996, p. 189). The orienting responses may include a person's attentional set as well as a general set of underlying assumptions, appraisals, beliefs, and expectations

concerning his or her problem-solving ability. An individual's problem perception, problem attribution, problem appraisal, personal control beliefs, and approach/avoidance style contribute to his or her problem orientation. Positive problem orientation and negative problem orientation are discussed in this model; a person may possess a positive orientation, a negative orientation, or possess aspects of both a positive and negative orientation. The degree of avoidance and impulsivity that an individual possesses and utilizes in solving problems is also addressed in the model. The motivational process of problem orientation can either facilitate or inhibit the other problem-solving components (Nezu et al., 1989).

Problem definition and formulation involves the obtainment of a thorough understanding of a problem as well as the identification of a realistic goal for problem solving (Nezu et al., 1989). In order to reach these goals, an individual gathers all available information about the problem, separates facts from assumptions, describes the facts in clear and unambiguous language, identifies specific elements that make the particular situation a problem for him or her, and then sets realistic goals. The importance of problem definition and formulation to the remaining problem-solving components has been identified (Nezu et al., 1989).

The aim of generation of alternatives, the third problem-solving component, is for an individual to develop an extensive list of possible alternative solutions for a particular problem situation such that the likelihood that the most effective solution will be among those in the list is maximized. The foci of this component include brainstorming and creativity. Generating as extensive a list as possible, deferring one's judgment of the solutions on the list, and deriving both general strategies and specific tactics for solving the problem are key aspects of this third component (Nezu et al., 1989).

The fourth component of the problem-solving process is decision making. It involves the systematic evaluation of the alternatives that have been generated and, based on the evaluation, the choice of the most effective solution for that particular problem. This systematic evaluation system includes a comparison of the solutions based on judgments of their potential effectiveness for solving the problem, the likelihood that the individual can implement the solution, as well as the personal, social, short term and long term

consequences of each solution. The solution(s) that is chosen for implementation should be judged to be the most effective for solving the problem and should maximize positive consequences and minimize negative consequences (Nezu et al., 1989).

The fifth component is solution implementation and verification. At this point, an individual develops and implements a solution plan that is based on the solution(s) that has been chosen. The individual predicts the consequences of implementing the solution(s) and monitors the situation as it occurs. He or she then evaluates the effectiveness of the implemented solution through a comparison of the actual consequences with the predicted consequences (Nezu et al., 1989).

Research on problem-solving ability has demonstrated that it is significantly associated with measures of psychological distress, including depression (Nezu, 1987) and anxiety (Nezu & Carnevale, 1987). Gotlib and Asarnow (1979) have demonstrated that college students who were depressed, as assessed by the Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), did not perform as well as nondepressed students on the Means End Problem Solving Procedure (MEPS; Platt & Spivack, 1975), a measure of interpersonal problem-solving skill. Zemore and Dell (1983) also utilized the MEPS in an investigation with college students. They have reported that students with poor interpersonal problem-solving skills were more prone to depression than students who displayed good problem-solving skills.

Additional research has investigated the role of problem solving in the stress-distress relationship. Specifically, the attenuating properties of problem solving on the deleterious effects of stressful events have been investigated (Nezu et al., 1989). Nezu, Nezu, Saraydarian, Kalmar, and Ronan (1986) examined the moderating effects of social problem solving relative to negative stressful life events and depressive symptoms in university students. They found that people who were classified as effective problem solvers reported significantly lower levels of depressive symptoms under high levels of stress than did those classified as ineffective problem solvers under similar levels of high stress. While this study

provided preliminary support for problem solving as a moderator of stress-related depression, its cross-sectional nature limited the conclusions that could be drawn.

Nezu and Ronan (1988) addressed these methodological issues by examining the moderating effects of problem solving in university students within a prospective design.

Results similar to those of the Nezu et al. (1986) study were found. Specifically, under similarly high levels of stress, effective problem solvers reported significantly lower depression scores than ineffective problem solvers. These results further supported the moderating effects of social problem solving relative to negative stressful life events and depressive symptoms.

The role of social problem solving has also been investigated in other disorders, such as anxiety, obesity, alcoholism, and schizophrenia, and with other populations, including individuals with mental retardation and individuals with cancer (Nezu, Nezu, & Houts, 1993).

Nezu et al. (1999) explored the role of social problem solving in the distress experienced by individuals diagnosed with cancer. It was found that higher levels of anxiety, depressive symptoms, and higher numbers of cancer-related problems were reported by those individuals who demonstrated less effective problem solving skills. Additionally, it was demonstrated that problem solving was a significant predictor of psychological distress in females who had successfully undergone breast cancer-related surgical procedures, controlling for recent negative life events.

The role of problem solving has initially been explored with several caregiving populations. Research specific to caregivers of individuals with Dementia of the Alzheimer's Type (DAT) has demonstrated that a significant relationship exists between a caregiver's confidence in his or her problem-solving skills and caregiver distress (Pratt, Schmall, Wright, & Cleland, 1985). Parsons and Cox (1989) explored the role of problem solving as a coping strategy for family members providing care to individuals with DAT. They found "problem-solving talk" (i.e., enhancement of decision making skills) to facilitate coping for these individuals. While these studies lend support to the beneficial role of problem solving, they fail to address the multiple components of the Social Problem-Solving Model.

Houts et al. (1998) have referred to caregivers as problem solvers. Nezu, Nezu, and Houts (1993) have asserted that the Social Problem-Solving Model can aid in resolving the problems faced by caregivers. They have suggested that while social problem solving is a significant element of treatment in working with caregivers, caregivers may not have deficits in problem solving. Instead, they have referred to a diathesis-stress perspective and note that as the level of stress increases, the probability for experiencing distress also increases, regardless of an individual's coping ability. Additionally, they have noted that individuals who have coping difficulties may be particularly at risk for experiencing distress. Thus, social problem solving can be an effective strategy for caregivers in terms of resolving problems associated with caregiving as well as problems associated with difficulties in coping with the caregiving experience.

The majority of research that has explored the role of problem solving in caregiver distress has included caregivers of people with neurodegenerative disorders (e.g., DAT). Additionally, this research has called for investigation of problem solving as an intervention strategy. However, little research is available regarding the predictive role of problem solving in the distress experienced by caregivers (Gonyea, 1989). The predictive role of problem solving, as conceptualized within the Social Problem Solving Model, in the distress experienced by caregivers to individuals with AIDS has not been examined. The present study contributes to the caregiving literature by investigating factors that predict distress in caregiving partners to men with AIDS. The unique role of social problem-solving ability as a predictive variable is explored.

#### 1.4 Introduction to Predictor Variables

The present study investigated the relationships among several variables and caregiver distress in caregiving partners to men with HIV and AIDS. Variables included characteristics of the care recipient, the caregiver, and caregiver/care recipient dyad.

The care recipient's level of functional impairment has been demonstrated as an important variable to consider in the experience of caregiver distress (Miller, McFall, & Montgomery, 1991). Consequently, it was included in this study.

The quality of the relationship between caregivers and their care recipients was also studied. Previous research has reported an association between relationship quality and caregiver distress in various caregiving populations, including caregivers to persons with HIV/AIDS (Folkman et al., 1994).

A number of caregiver-related variables were also included. In particular, caregivers' negative life events, health functioning, as well as two coping strategies (social support and social problem-solving ability) were investigated. While caregivers' negative life events and health functioning have been shown to relate to their experience of distress, the research into these relationships is limited. Social support research, in general, has demonstrated supported its role as both a predictor and moderator of distress in caregiving populations; however, attention to its role in the experience of HIV/AIDS caregiver distress has been limited. Given this, it was included in the present study.

This study also evaluated the unique contribution of social problem-solving ability to caregiver distress. While HIV/AIDS caregiver research is limited in general, investigation of social problem-solving ability with these caregivers is even more limited. This study considered the relationship between caregivers' degree of skill and attitudes toward problem solving and their experience of distress.

# 1.4.1 Care Recipient Characteristics

#### 1.4.1.1 Functional Impairment of the Care Recipient

Individuals with HIV and AIDS experience significant levels of impairment from the various conditions with which they are afflicted (Folkman et al., 1994). The level of impairment increases as the illness progresses. Research with caregivers to people with DAT has demonstrated that functional limitations contribute significantly to caregiver burden and distress (Poulshock & Deimling, 1984).

Research with caregivers to people with AIDS has found similar results. Folkman et al. (1994) have investigated caregiver burden in caregiving partners to men with AIDS. They found a significant positive relationship between the instrumental needs of the care recipient and caregiver burden. Clipp et al. (1995) have also demonstrated that caregivers to people

with AIDS experienced burden as the result of providing instrumental care. Additionally, Pakenham et al. (1995) have found that care recipients' HIV-related emotional and existential concerns were associated with caregivers' level of adjustment and, to a lesser degree, burden.

# 1.4.2 Caregiver/Care Recipient Dyad Characteristics

#### 1.4.2.1 Quality of the Caregiver/Care Recipient Relationship

Previous caregiver research has investigated the association between the quality of the caregiver/care recipient relationship (dyadic adjustment) and caregiver distress and burden. Williamson and Schulz (1990), in investigating caregivers to individuals with DAT, found that a close relationship between the dyad was associated with decreased levels of caregiver distress and burden. Other studies of caregivers to the elderly have found similar beneficial effects of close relationships between caregiver and care recipient (Horowitz & Shindleman, 1983; Horowitz, 1979). Cantor (1983), however, in another study of caregivers to the elderly found that a close relationship between caregiver and care recipient contributed to caregiver burden.

The predictive merit of the quality of the caregiver/care recipient relationship to caregiver burden has also been investigated in caregiving partners of men with AIDS (Folkman et al., 1994). The quality of the relationship has been conceptualized as a social resource available to caregivers in coping with the stresses of providing care. No significant differences were found between the level of dyadic adjustment in the HIV positive caregiver/care recipient and the HIV negative caregiver/care recipient relationships. Significant negative associations were found between dyadic adjustment and caregiver burden. Additionally, dyadic adjustment was found to significantly contribute to the prediction of caregiver burden in this sample of caregivers. Given the support for this variable in previous caregiver research, the present study assesses the predictive merit of dyadic adjustment to caregiver distress and burden.

# 1.4.3 Caregiver Characteristics

#### 1.4.3.1 Negative Life Events

It has been stated that stressors such as negative life events have not been widely incorporated in studies of caregiver experiences. Folkman et al. (1994), in their investigation of caregiving partners of men with AIDS, considered the negative life events of the caregivers. Their rationale for doing so was that "...such events can tax the psychological, social, and material resources that otherwise could be available for caregiving" (p. 747) and may contribute to the distress experienced by those providing care. They found a significant positive association between negative life events and burden in HIV positive caregivers.

# 1.4.3.2 Physical Health Functioning

Research on caregivers to the elderly has demonstrated that the physical health of the caregiver is associated with increased caregiver burden (Pratt et al., 1985). It has been suggested that caregivers in poor physical health may have decreased resources to utilize in caregiving. The possible association between the physical health of caregivers to people with HIV and AIDS and caregiver distress and burden has also been discussed. Folkman et al. (1994) proposed that caregivers whose health is impaired by HIV infection might have fewer resources to utilize in the demands of caregiving. In their study of caregiver burden in caregiving partners of men with AIDS, there was a small but significant negative relationship between the severity of caregiver health symptoms and caregiver burden in HIV-negative caregivers, but not in caregivers who were HIV positive. However, caregiver health did not significantly contribute to the prediction of caregiver burden in their investigation. They also examined the effect of HIV status on caregiver burden. While HIV positive and HIV negative caregivers significantly differed on a number of variables (e.g., physical health and income), religiosity/spirituality was the only variable that contributed independently to burden in HIV positive caregivers. The authors have suggested that there is a relatively weak association between HIV status and caregiver burden.

Given the attention that has been paid to caregiver health in this population, empirical investigation of this variable has remained very limited. The present study addresses the

limited empirical investigation of this variable by including it as a potential predictive variable of caregiver distress.

# 1.4.3.3 Availability of and Satisfaction with Social Support

It has been suggested that social support may be a significant component in the reduction and prevention of psychological problems (Wortman & Dunkel-Schetter, 1987). Empirical studies of social support have investigated it as a main effect factor as well as a buffering interaction effect factor (Cohen & McKay, 1984). As a main effect factor, it is hypothesized that social support is related to individuals' mental and physical health, regardless of the severity of stressors. As an interaction effect factor, it is hypothesized that social support is related to psychopathology only under high stressor conditions. Specifically, a high level of social support is hypothesized to be a significant factor in reducing and/or preventing psychological symptomatology for individuals under high levels of stress. Under low or normal demand conditions, social support is viewed as unrelated to psychological disorder (Cohen & McKay, 1984). Peterson (1991) has reported that support exists for both of these hypotheses and that this support appears to depend on measurement and population factors.

Lieberman (1986) has suggested that a fundamental problem with social support is the lack of available consensus regarding its definition and measurement. In light of these methodological and conceptual problems, social support has continued to receive support as a moderating variable in causal models of psychopathology (Cohen & McKay, 1984) and is believed to help individuals cope with stress and prevent psychopathology (Cohen & Wills, 1985).

It has been reported that a relatively small literature exists on the role of social support in the management of HIV and AIDS. In general, the available literature has provided support for a relationship between social support and the psychological health of individuals with HIV (Green, 1993). It has also been discussed that a positive relationship exists between an individual's psychological state (e.g., level of depression) and the perceived availability of and satisfaction with social support in persons with HIV (Ostrow et al., 1989). Namir, Alumbaugh, Fawzy, and Wolcott (1989) investigated the social support networks of a sample of

homosexual men diagnosed with AIDS. They demonstrated that satisfaction with total available social support, as well as emotional and instrumental support, were positively associated with physical and psychological well being.

Social support research particular to caregivers has demonstrated that social support can act as a buffer against the stress associated with the caregiving experience (Jankowski, Videka-Sherman, & Laquidara-Dickinson, 1996). The availability of social support has been investigated in caregivers to people with DAT. For example, a positive association has been demonstrated between the availability of social support and effective coping in caregivers (Pearson-Scott, Roberto, & Hutton, 1986). Schulz and Williamson (1991), in their study of caregivers to people with DAT, found that caregivers' depression scores increased over time as the availability of social support declined. They also demonstrated that the quality of and satisfaction with social support are significant contributors to the prediction of depression.

Jankowski, Videka-Sherman, and Laquidara-Dickinson (1996) have stated that little information is available concerning the role of social support in the experiences of family members and friends of people with AIDS. They conducted a qualitative investigation of social support's role in the experiences of confidants to people with AIDS. A confidant has been defined as "the person to whom one can turn for any and every problem under any circumstances" (p. 206). They have found that the confidants reported loss of contact with friends and acquaintances. It was also reported that confidants frequently maintained secrecy about their care recipients' diagnosis, often by misrepresenting the diagnosis as something else, such as myocardial infarction or a blood disease. Available social support for confidants was limited as the result of this misrepresentation and secrecy, as well as by factors such as stigma and fear of rejection. The authors further reported that confidants who had limited social support during the illness process might have been placed at additional risk for physical and psychological distress. While this study has addressed the role of social support in the experiences of confidants to people with AIDS, its small sample size (i.e., 11 confidants) warrants caution regarding the generalizability of the results.

Folkman et al. (1994) have investigated the contributions of perceived emotional support, material support, and social integration to the prediction of burden in caregiving partners to men with AIDS. They have found a significant negative relationship between perceived social support and caregiver burden. However, these variables did not significantly contribute to the prediction of caregiver burden. While social support has been implicated as a significant predictor of distress in caregivers, investigation of its role in the experiences of caregivers to people with HIV and AIDS has remained limited. The few studies that have investigated its role in this population have yielded inconsistent results. The present study addresses these concerns by investigating the predictive value of availability and satisfaction with social support in the distress of caregiving partners of men with HIV and AIDS.

# 1.4.3.4 Social Problem-Solving Ability

As previously stated, the predictive role of social problem-solving ability in caregiver distress has received limited attention. No previous research on the role of this variable (as conceptualized by the Social Problem-Solving Model) specific to the distress of caregivers to people with HIV and AIDS has been found. The present study addresses the unavailability of such research by examining the unique role of social problem-solving ability in this population.

# 1.5 Summary and Hypotheses Under Investigation

HIV and AIDS continue to pose myriad challenges for the health care system, nearly a quarter century into the epidemic. Professionals from various disciplines are called to address the many biomedical, psychological, social, and economic concerns posed in this crisis. Primary caregiving systems have come to the forefront as the result of a general shift towards community- and home-based HIV/AIDS care in the United States. While primary caregivers are at risk for experiencing significant caregiving-related distress, there is a relatively small amount of research that considers the experiences of these individuals.

Historically, caregiver research has been conducted primarily with caregivers to elderly individuals with neurodegenerative disorders, such as Dementia of the Alzheimer's Type and Parkinson's Disease. While this has contributed to the understanding and conceptualization

of the caregiving experience, concerns have been expressed that such research may not capture the unique aspects of HIV/AIDS caregiving.

Caregiver-related variables have been investigated in research on caregiver distress and burden. A positive relationship between the negative life events of the caregiver and distress has been previously demonstrated in caregiving partners of men with AIDS. A relationship between the health functioning of the caregiver and caregiver burden and distress has been demonstrated in various caregiving populations. While caregiver health functioning has been addressed as a potential contributor to distress in caregivers to individuals with HIV and AIDS, empirical investigation of this relationship is lacking. Social support has also received a significant amount of attention in caregiver research. It has been demonstrated that the availability of and satisfaction with social support is negatively associated with caregiver burden and distress in various caregiving populations. Relative to HIV/AIDS caregivers, the limited amount of existing research on social support has yielded inconsistent results. The moderating effect of social problem-solving ability in the stress-distress relationship has been documented in a variety of populations; however, its effects have not been investigated among HIV/AIDS caregivers.

Care recipient-related variables have also been investigated in caregiver research. Specifically, the functional impairment of the care recipient has been demonstrated to predict caregiver burden and distress. The quality of the caregiver/care recipient relationship has also been investigated in caregiver research. While some studies have reported a negative relationship between dyadic adjustment and caregiver burden and distress as well as the predictive merit of dyadic adjustment to caregiver symptomatology, a close relationship has also been shown to contribute to increased caregiver burden.

# 1.5.1 Primary Hypotheses

A number of hypotheses were evaluated, based upon the available literature on caregiving.

Caregivers' negative life events during the past year and their physical health functioning, as well as the care recipients' level of functional impairment were initially assessed and hypothesized to significantly contribute to predicting caregiver distress. Specifically, the

following hypotheses were made: (1) level of caregiver distress would increase as the number of negative life events during the past year increased, (2) level of caregiver distress would increase as caregivers' level of physical functioning decreased, and (3) level of caregiver distress would increase as the degree of functional impairment of care recipients decreased.

Hypotheses related to quality of caregiver/care-recipient relationship and caregiver distress, as well as social support and caregiver distress were also evaluated. Specifically, it was hypothesized that caregivers who reported higher levels of relationship satisfaction with their partners/care recipients would experience less symptoms of distress. It was further hypothesized that caregivers who reported larger social support networks and greater satisfaction with their available social support would experience less distress symptoms.

Finally, as the available research on social problem-solving ability and caregiver distress is limited, its relationship to caregiver distress was independently evaluated, beyond the contributions of the aforementioned variables. It was hypothesized that caregivers with a positive problem orientation and higher levels of problem-solving skills would experience fewer symptoms of distress than those caregivers possessing a negative problem orientation, deficient problem-solving skills, and an avoidant and/or impulsive style of problem solving.

1.5.2 Summary of Primary Hypotheses

This study evaluated the predictive value of each of the aforementioned variables to the distress experienced by caregiving partners to men diagnosed with HIV and AIDS.

Specifically, the hypotheses include the following:

- Based upon previous research, baseline measures of distress (depression, anxiety, hopelessness, and burden) will significantly contribute to the prediction of caregiver distress (at Time 2);
- (2) Based upon previous research, the negative life events of the caregiver, the caregiver's physical health functioning, and the functional impairment of the care recipient will significantly contribute to the prediction of caregiver distress, while controlling for baseline levels of caregiver distress;

- (3) Based upon previous research, the level of dyadic adjustment in the caregiver/care recipient relationship and the caregiver's availability of and satisfaction with social support will significantly contribute to the prediction of caregiver distress, while controlling for the aforementioned variables;
- (4) The caregiver's social problem-solving ability will significantly contribute to the prediction of caregiver distress, above and beyond the contributions of the aforementioned variables.

# 2. METHOD

# 2.1 Participants

Participants in this study included 44 men providing care to their partners living with HIV or AIDS. Eligibility for participation was based on the following inclusion and exclusion criteria:

To be eligible to participate in this study, an individual must have identified himself as (a) a male who is in a relationship with a man who has been reliably diagnosed as HIV positive or with AIDS, (b) the primary caregiver to the male with HIV or AIDS, (c) providing care within the home for no less than six months prior to participation in this study, and (d) 18 years of age or older. In this study, "primary caregiver" was defined as "a person at home who has primary responsibility for the care of a significant other who is ill" (Folkman et al., 1994, p. 746). A diagnosis of AIDS implied that care recipients met the criteria of the 1993 revision of the CDC AIDS case definition (CDC, 1992).

#### 2.1.2 Exclusion Criteria

2.1.1 Inclusion Criteria

Caregivers excluded from this study included those who (a) volunteered or were formally employed as an HIV/ AIDS care provider (e.g., buddy volunteer, nurse, physician) and (b) did not understand the English language.

# 2.2 Description of the Sample

Based upon the inclusion and exclusion criteria, 44 participants completed this study. The sample included males with a mean age of 39.9 years, with a range of 24 to 60 years of age. (The mean age of this sample's care recipients was 40.4 years, with a range of 27 to 56 years.) Further, 61.4% of this sample were Caucasian, 18.2% were African American, 6.8% were Asian, and 13.6% identified themselves as Hispanic. Caregivers in this sample had been in a relationship with their care recipients a mean of 63.5 months, with a range of 12.0 to 251.0 months.

With regard to education, 40.9% received a college degree, while 36.4% received some graduate/professional training or a graduate/professional degree. 18.2% received some college/vocational training, while 4.5% received a high school diploma.

Caregivers who were employed comprised 88.6% of the sample, while 70.5% of their care recipients were employed. The mean household income for this sample was \$61,651, with a range of \$21,648 to \$110,000. 93.2% of the sample had health insurance for themselves, while 90.9% of care recipients currently had health insurance.

With regard to HIV status, 63.6% of caregivers were HIV-, 25.0% were HIV+, and 11.4% had AIDS. Also, 65.9% of this sample's care recipients were HIV+, and 34.1% had AIDS. Of the 16 participants who were HIV+, 100% reported currently following an HIV medication regimen. 95.5% of their care recipients were reported currently following an HIV medication regimen.

In terms of providing care, 43.2% of caregivers in this sample reported receiving some type of external support (e.g., attending a support group, visiting nurse service, etc.) Whether or not they received external support, over half (52.5%) of the caregivers in this sample spent between 0 – 5 hours providing care to their care recipients. 42.3% of the sample provided care between 6 – 10 hours per week. Further, 2.2% of this sample provided care between 11 – 20 hours per week, 2.0% provided care between 21 – 30 hours per week, and 1.0% provided care between 31 – 40 hours per week. Lastly, 50.0% of the caregivers in this sample reported that providing care to their partner made them "occasionally" think about who would provide care to them if they would need it. 25.0% reported that they think about this "sometimes", 15.9% reported that they "never" think about this, and 9.1% reported that they think about this "frequently". Caregiver demographic information is summarized in Table 1 (see Chapter 6).

# 2.3 Design and Procedure

Participants were recruited through a variety of Philadelphia and New York City area resources as well as via the Internet (e.g., HIV/AIDS-, and gay/bisexual-oriented websites). Specifically, these resources included the following: The Partnership Comprehensive Care Practice (within the Section of HIV/AIDS Medicine in the Division of Infectious Diseases, in the Department of Medicine) of MCP Hahnemann University Hospitals, Action AIDS (a non profit community based organization providing care to individuals affected by AIDS), Philadelphia

Community Health Alternatives (an AIDS service organization providing HIV and AIDS-related information and services), the William J. Craig Foundation (a non profit community service organization for impoverished individuals and individuals of color living with HIV and AIDS), the AIDS Information Network, and Southwest Philadelphia Community Fact Center (a community based association designed to provide care to people at risk for or having HIV disease in Southwest and West Philadelphia). Participants were also recruited through fliers distributed at gay-oriented businesses in Philadelphia and New York.

Fliers inviting primary caregivers of men with HIV or AIDS with whom they are in a relationship to participate in a research study on caregiving experiences were distributed at these facilities and made available in support groups. Internet-based recruitment included posting the aforementioned fliers on websites, electronic bulletin boards, and listservs and providing potential participants the options of contacting the investigator either via telephone or e-mail. Some agencies and organizations contacted by the investigator regarding potential recruitment of participants were not receptive to the investigator meeting with their case managers to discuss the study or describing the study during support groups. In general, their concern was that case managers and group facilitators were burdened with heavy caseloads and that the caseloads would take priority. In such cases, the agencies offered the investigator the option of leaving fliers in the reception areas of their offices. Of the 44 participants, 27 were recruited via the Internet and 17 were recruited through fliers placed at the aforementioned businesses and agencies.

All interested persons who contacted the investigator were provided with information regarding this protocol. In addition to the 44 participants who completed this study, there were 12 individuals who declined participation in the study after initially contacting the investigator. Three of these individuals did not respond to the investigator's attempts to contact them to discuss participation. The other nine individuals elected to not participate based upon the amount of time required to complete questionnaires.

Individuals who met the study's inclusion and exclusion criteria were invited to complete two sets of self-report inventories, taking approximately 45 – 60 minutes to complete.

(Participants were informed that they would be asked to complete the second set of inventories three months after completing the first set.) Each participant was provided the option of completing the two sets of inventories either through the mail or by speaking to the investigator over the telephone. Participants subsequently completed the inventories via the method that they found more suitable. In this sample, all 44 caregivers chose to complete the inventories through the mail.

Upon completion of the Time 2 measures, each participant was entered into drawings for a \$100.00 prize. There were three drawings for \$100.00, one at six months following the beginning of data collection, the second at one year following the beginning of data collection, and the third at the end of data collection.

All participation in this study was voluntary, and informed consent for participation in this study was obtained. Each participant was provided with two copies of the Informed Consent form; one to sign and return to the investigator and one for them to keep.

#### 2.4 Ethical Considerations

Procedures were established in this study to address any potential concerns expressed by participants, given the available research on caregivers that identifies them as a population at risk for high levels of burden and distress. These procedures included providing follow-up to any participants who endorsed items on distress and burden measures that reflected moderate to severe levels of distress. These participants were encouraged to participate in caregiver support services, if not already participating in such services.

#### 2.5 Materials

Given the prospective nature of this present study, participants were asked to complete inventories at two different time periods. Specifically, at Time 1, participants were asked to complete a demographics form, the Life Experiences Survey (LES), the MOS Short Form-36 Health Survey (SF-36), the Activities of Daily Living Scale (ADLS), the Dyadic Adjustment Scale (DAS), the Social Support Questionnaire (SSQ), the Social Problem-Solving Inventory-Revised (SPSI-R), the Beck Depression Inventory-Second Edition (BDI-II), the Beck Anxiety Inventory (BAI), the Beck Hopelessness Scale (BHS), and the Caregiver Burden Interview

(CBI). Time 2 data collection occurred three months after Time 1 measures were completed. At that time, participants were recontacted and asked to complete a second BDI-II, BAI, BHS, and CBI. Additionally, those items that may be viewed as potential confounds with depressive symptoms were removed as scorable items on the LES. These included "major change in sleeping habits (much more or less sleep)", "major change in eating habits", and "sexual difficulties".

# 2.5.1 Care Recipient Characteristics

## 2.5.1.1 The Index of Independence in Activities of Daily Living

(Index of ADL; Katz, Ford, & Moskowitz, 1963) is a 6-item instrument that assesses an individual's functional limitation in executing the following six daily activities: ambulation, bathing, dressing, feeding, grooming, and toileting. In this study, caregivers completed the measure with reference to their care recipients. Reported estimates of test-retest reliability have ranged from .74 to .88.

#### 2.5.1.2 Instrumental Activities of Daily Living

(IADL; Lawton & Brody, 1969) is a device that assesses an individual's loss of ability to perform the following eight instrumental skills: ability to handle finances, food preparation, housekeeping, laundry, responsibility for medication, shopping, traveling, use of telephone. In this study, caregivers completed the measure with reference to their care recipients.

The Index of ADL and the IADL were combined into one measure in this study to provide an overall evaluation of care recipients' level of functional impairment. Higher scores on the ADLS reflect lower levels of functional impairment.

# 2.5.2 Caregiver/Care Recipient Dyad Relationship Characteristics

#### 2.5.2.1 Dyadic Adjustment Scale

(DAS; Spanier, 1976) is a 32-item self-report instrument that assesses the quality of marital and similar relationships. Either one or both partners in the relationship complete the DAS. Respondents are asked to rate the degree of agreement or disagreement between he/she and the partner for a variety of items (e.g., handling family finances, religious matters, and sex relations) on Likert-type scales. Five, six, and seven point Likert scales are used in this

instrument, and the anchors vary depending on the particular item (e.g., "always agree" to "always disagree"; "all the time" to "never"; "every day" to "never"; "all of them" to "none of them"; "never" to "more often"; "extremely unhappy" to "perfect"). Respondents are also asked to indicate a "yes" or "no" response for two items and to pick one of six possible responses to the last item on the scale.

The DAS yields a total scale score called the Dyadic Adjustment score. Additionally, there are four subscales on the DAS. These include the following: Dyadic Consensus (assesses the extent of agreement between partners on such relationship matters as finances, religion, and household tasks), Dyadic Satisfaction (assesses the amount of tension in the relationship and the extent to which the respondent has considered terminating the relationship), Affectional Expression (assesses the individual's satisfaction with sex and expression of affect in the relationship), Dyadic Cohesion (assesses the couple's common activities and interests). Adequate test-retest and inter-rater reliability has also been reported for the DAS. A total scale internal consistency reliability estimate of .96 has been reported for the DAS. Content, criterion-related, concurrent, predictive, and convergent validity have also been demonstrated (Spanier, 1976).

# 2.5.3 Caregiver Characteristics

# 2.5.3.1 Life Experiences Survey

(LES; Sarason, Johnson, & Siegel, 1978) is a 47-item self-report measure that assesses the positive or negative impact of various life change events that an individual may have experienced during the past year. Additionally, the person responding has the option to list other events not included on the LES. Respondents are asked to identify how long ago the event(s) occurred and to indicate the perceived stressful impact rating of the event(s) on a 7-point Likert scale, ranging from –3 ("very negative") to +3 ("very positive"). Positive, negative, and total life stress impact scores can be calculated for this measure. A negative impact score was used in this study, operationally defined as the absolute value of the negative impact score. Sarason et al. (1978) have reported reliability estimates for the LES ranging from .63 to .88.

# 2.5.3.2 MOS Short Form-36 Health Survey

(SF-36; MOS Trust, Inc., 1992) is a 36-item assessment of overall health status. The following eight dimensions are assessed by the SF-36: (1) physical functioning; (2) role limitations from physical health problems; (3) bodily pain; (4) social functioning; (5) general mental health, including psychological distress and well being; (6) role limitations from emotional problems; (7) vitality, energy, or fatigue; and (8) general health perceptions. Estimates of test-retest reliability have ranged from .60 to .90. McHorney, Ware, and Raczek (1993) employed principal components analysis to demonstrate the validity of the scale dimensions. It has been found that the scales that primarily assess mental health distinguish best among those groups differing in the presence and severity of psychiatric disorders while those scales that primarily assess physical health distinguish best among those groups differing in severity of a chronic medical condition. In this study, the SF-36 Physical Functioning scale was used to provide an overall assessment of caregivers' level of physical health functioning.

# 2.5.3.3 Social Support Questionnaire

(SSQ; Sarason, Levine, Basham, & Sarason, 1983; Sarason, Sarason, Shearin, & Pierce, 1987) is a 12-item instrument that assesses the availability of (SSQA) and satisfaction with (SSQS) an individual's social support systems. Each of the 12 items prompt the respondent for the following two things: how many people he/she can count on to support them in the situation described and a rating of how satisfied he/she is with the overall support received, on a 6-point Likert scale ranging from 1 ("not satisfied at all") to 6 ("extremely satisfied"). Reported estimates of test-retest reliability for the SSQ's SSQA and SSQS have been .90 and .83, respectively. Criterion validity has also been demonstrated (i.e., correlations between the SSQ and a depression scale ranged from -.22 to -.43).

#### 2.5.3.4 Social Problem-Solving Inventory-Revised

(SPSI-R; D'Zurilla, Nezu, & Maydeu-Olivares, 1996) is a 52-item self-report instrument that assesses an individual's social problem-solving ability. Respondents are asked to rate their affective, behavioral, or cognitive response to problem situations that occur in life based on a

5-point Likert scale ranging from 0 ("not at all true of me") to 4 ("extremely true of me"). The SPSI-R is a revised version of the original SPSI developed by D'Zurilla and Nezu (1990). Maydeu-Olivares and D'Zurilla (1996) have conducted a factor analysis of the SPSI, which yielded five problem-solving dimensions. Specifically, the five orthogonal scales of the SPSI-R include the following:

<u>Negative Problem Orientation (NPO)</u> — This is a general set that inhibits successful problem solving. NPO includes viewing problems as threats, believing that problems are unsolvable, experiencing frustration and having little tolerance when experiencing problems, and doubting one's ability to successfully solve problems.

<u>Positive Problem Orientation (PPO)</u> — This is a general set that facilitates successful problem solving. PPO includes appraising problems as challenges, believing that problems are solvable, addressing problems rather than avoiding them, believing that successfully solving problems requires time and effort, and believing in one's own ability to solve problems successfully.

<u>Rational Problem Solving (RPS)</u> — This involves an approach to problems that is systematic and rational and effectively applying the problem-solving methods. These methods are measured with the following RPS subscales: Problem Definition and Formulation (PDF), Generation of Alternative Solutions (GAS), Decision Making (DM), and Solution Implementation and Verification (SIV).

<u>Impulsivity/Carelessness Style (ICS)</u>— This involves the use of problem-solving strategies in an impulsive and careless manner.

<u>Avoidance Style (AS)</u>— This refers to a style of problem solving that includes avoidance of problems, dependency on others to solve one's problems, and procrastination.

A total Social Problem-Solving score (SPS) may also be obtained with this inventory; the greater the SPS score, the more effective a person's social problem-solving skills (D'Zurilla et al., 1996). Reported estimates of the internal consistency of the 5 scales have ranged between .69 and .95. Reported estimates of test-retest reliability have ranged between .72

and .91. D'Zurilla et al. (1996) have reported data that strongly support the content, concurrent, and predictive validity of the SPSI-R.

# 2.5.4 Measures of Caregiver Distress

# 2.5.4.1 Beck Depression Inventory—Second Edition

(BDI-II; Beck, 1996; Beck, Steer, & Brown, 1996) is a 21-item self-report measure of the presence and degree of depressive symptoms in adults and adolescents who are 13 years of age or older. Respondents are asked to pick one statement from each of the 21 groups of statements that best describes the way he or she has been feeling during the last two weeks, including the day on which the measure is completed. Each of the items is rated on a 4-point scale that ranges from 0 to 3. A total BDI-II score is obtained by summing the ratings for the 21 items. An internal consistency reliability estimate of .93 has been reported for the BDI-II. A test-retest reliability estimate of .93 has also been reported. Beck, Steer, and Brown (1996) have provided evidence for the BDI-II's content, construct, and factorial validity.

#### 2.5.4.2 Beck Anxiety Inventory

(BAI; Beck, Epstein, Brown, & Steer, 1988) is a 21-item self-report measure of the severity of anxiety in adolescents and adults. Respondents are asked to rate each of 21 statements of anxiety symptoms in terms of the severity with which they have experienced each symptom during the past week, including the day on which the measure is completed. Each item is rated on a 4-point scale that ranges from 0 ("Not at all") to 3 ("Severely; I could barely stand it"). A total BAI score is obtained by summing the ratings for the 21 items. An internal consistency reliability estimate of .92 has been reported for the BAI. A test-retest reliability estimate of .75 has also been demonstrated for this measure. Further, content, concurrent, construct, discriminant, and factorial validity have been reported for the BAI (Beck et al., 1988).

#### 2.5.4.3 Beck Hopelessness Scale

(BHS; Beck, Weissman, Lester, & Trexler, 1974) is a scale that assesses the presence of negative attitudes towards the immediate and long-term future. Respondents are asked to endorse, in a True/False format, whether each of 20 statements describes his or her attitude

during the past week. A total BHS score is obtained by summing the keyed hopelessness responses. Higher total scores indicate a greater level of hopelessness. Internal consistency reliability estimates for individuals with Dysthymic Disorder, single-episode Major Depressive Disorder and recurrent-episode Major Depressive Disorder have been reported as .87, .92, and .92, respectively. A test-retest reliability of .66 has also been demonstrated for this measure. Additionally, content, concurrent, discriminant, construct, factorial and predictive validity have been demonstrated with the BHS Beck & Steer, 1988).

## 2.5.4.4 Caregiver Burden Interview

(CBI; Zarit, Reever, & Bach-Peterson, 1980) is a 22-item assessment of the degree of burden that is experienced by caregivers to cognitively impaired adults. This tool assesses the following areas: physical and psychological well being, interpersonal relations, and social and financial concerns. High test-retest reliability (r=.79) has been demonstrated for the CBI. Additionally, estimates of the correlation between the CBI and a brief symptom inventory have ranged from .50 to .60; this suggests adequate concurrent and construct validity.

# 3. RESULTS

A number of statistical tests were conducted in order to examine this study's hypotheses.

More specifically, analyses were performed to investigate the relationships among caregiver, care recipient, and caregiver/care recipient dyad variables and the contribution of these variables to caregiver distress.

Prior to the analyses, variables were inspected to detect missing data, ensure the accuracy of data entry, and assess the assumptions of multivariate analysis. In this sample, no cases had missing data. Additionally, all values were within range and had plausible means and standard deviations. Each variable's coefficient of variation was within acceptable limits, demonstrating that each variable has sufficient variability to approach honest correlations with the other variables.

# 3.1 Descriptive Results

#### 3.1.1 Descriptive Summary of Independent and Dependent Variables

The means and standard deviations for all variables under investigation are reported in Table 2. These findings are also summarized below. It is important to note that a number of variables in this study were transformed in order to adjust for variable skewness. While not used in statistical analyses in this study, mean and standard deviation values for untransformed variables are included in Table 2 (see Chapter 6) for those variables that underwent transformation. These values are included to facilitate the descriptive summary of the variables.

#### 3.1.1.1 Care Recipient Characteristics

Caregivers in this sample reported small amounts of functional impairment in their care recipients ( $\underline{M} = 13.64$ ,  $\underline{SD} = .685$ ). Three-quarters of caregivers in this sample reported no functional impairment in their care recipients. A survey of responses indicated that when impairment in care recipients was reported, it involved difficulty with ambulation and executing medication regimens.

# 3.1.1.2 Caregiver/Care Recipient Dyad Characteristics

With regard to dyadic adjustment scores, caregivers in this sample, in general, reported experiencing average levels of satisfaction in their relationships with their partners  $(\underline{M_{untransformed}} = 107.66, \underline{SD} = 18.63; \underline{M_{transformed}} = 4.32, \underline{SD} = 1.93)$ . However, a wide range of dyadic adjustment scores were reported in this sample, with some participants reporting very low levels of dyadic adjustment and others reporting very high levels.

# 3.1.1.3 Caregiver Characteristics

As previously mentioned, baseline measures of caregiver distress were collected on all 44 participants, given the prospective nature of this study. With regard to baseline levels of depression, it appears that, on average, participants in this sample were experiencing minimal levels of depressive symptoms (Muntransformed = 8.84, SD = 7.20; Mtransformed = 2.74, SD = 1.17). Level of depressive symptomatology is determined by the following established criteria for the BDI-II: 0-13 suggests "minimal" depression, 14-19 suggests "mild" depression, 20-28 suggests "moderate" depression, and 29-63 suggests "severe" depression. Based on these criteria, 75.0% of participants endorsed items suggesting minimal depressive symptoms, 9.1% endorsed items suggesting mild depressive symptomatology, and 15.9% endorsed items suggesting moderate depressive symptomatology. With regard to baseline levels of anxiety, caregivers in this sample appeared to experience marginal levels of anxiety ( $\underline{M}_{untransformed}$  = 7.25,  $\underline{SD} = 6.66$ ;  $\underline{M}_{transformed} = 2.40$ ,  $\underline{SD} = 1.23$ ). Level of anxiety is determined by the following established criteria for the BAI: 0-7 suggests "minimal" anxiety, 8-15 suggests "mild" anxiety, 16-25 suggests "moderate" anxiety, and 26-63 suggests severe anxiety. In light of these criteria, 68.2% of caregivers in this study endorsed items reflecting minimal anxiety, 22.6% endorsed items suggesting mild levels of anxiety, 4.6% endorsed items reflecting moderate levels of anxiety, and 4.6% endorsed items reflecting severe levels of anxiety.

With regard to baseline levels of hopelessness and negative attitudes toward the future, it appears that caregivers, on average, were experiencing levels within the normal range of functioning ( $\underline{M_{untransformed}} = 3.09$ ,  $\underline{SD} = 3.25$ ;  $\underline{M_{transformed}} = 1.50$ ,  $\underline{SD} = .93$ ). Level of hopelessness symptomatology is determined by the following established criteria for the BHS:

0-3 suggests within the normal range, 4-8 suggests "mild" hopelessness, 9-14 suggests "moderate" hopelessness, and scores of 14 or more suggest "severe" hopelessness. Using these criteria, 70.5% of caregivers in this sample endorsed items within the normal range, 20.5% endorsed items suggesting mild levels of hopelessness, and 9.0% endorsed items suggesting moderate levels of hopelessness. With regard to baseline levels of caregiver burden, participants, on average, reported "rarely" feeling burdened by their caregiving responsibilities (Muntransformed = 47.57, SD = 14.95; Mtransformed = 6.82, SD = .59). A review of frequency data on CBI scores suggests that 54.5% of caregivers in this sample "rarely" felt burdened by caregiving, 29.6% of caregivers "sometimes" felt burdened by providing care, and 15.9% of caregivers endorsed items suggesting that they "quite frequently" felt burdened by providing care to their partners.

Regarding negative life events during the past year, caregivers in this sample reported a mean negative impact rating of 6.55 ( $\underline{SD} = 4.19$ ). They also reported generally good levels of physical health functioning ( $\underline{M}_{untransformed} = 91.48$ ,  $\underline{SD} = 12.65$ ;  $\underline{M}_{transformed} = .61$ ,  $\underline{SD} = .59$ ). In terms of coping skills, participants reported having an average of 24 individuals in their social support systems ( $\underline{M} = 23.64$ ,  $\underline{SD} = 7.76$ ) and, generally, were moderately to very satisfied with their available social support ( $\underline{M} = 27.00$ ,  $\underline{SD} = 6.19$ ). Caregivers' social problem-solving scores reflect a range that was within normal limits and, on average, indicated effective problem-solving skills ( $\underline{M}_{\underline{SPS}} = 13.86$ ,  $\underline{SD}_{\underline{SPS}} = 2.63$ ;  $\underline{M}_{\underline{PPO}} = 11.84$ ,  $\underline{SD}_{\underline{PPO}} = 3.24$ ;  $\underline{M}_{\underline{NPO}} = 10.09$ ,  $\underline{SD}_{\underline{NPO}} = 6.84$ ;  $\underline{M}_{\underline{RPS}} = 45.48$ ,  $\underline{SD}_{\underline{RPS}} = 11.64$ ;  $\underline{M}_{\underline{ICS}} = 7.45$ ,  $\underline{SD}_{\underline{ICS}} = 5.46$ ;  $\underline{M}_{\underline{AS}} = 7.23$ ,  $\underline{SD}_{\underline{AS}} = 4.51$ ).

# 3.1.1.4 Caregiver Distress

With regard to levels of depression at Time 2, caregivers in this sample, on average, were experiencing minimal levels of depressive symptomatology ( $\underline{M}_{untransformed} = 7.18$ ,  $\underline{SD} = 5.27$ ;  $\underline{M}_{transformed} = .2.49$ ,  $\underline{SD} = 1.01$ ). Based on the aforementioned criteria that have been established for BDI-II scores, 84.1% of this sample endorsed items reflecting minimal depressive symptoms and 15.9% endorsed items reflecting mild depressive symptoms.

With regard to Time 2 levels of anxiety, participants in this sample, on average, were experiencing minimal anxiety ( $\underline{M}_{untransformed} = 5.39$ ,  $\underline{SD} = 5.95$ ;  $\underline{M}_{transformed} = 1.92$ ,  $\underline{SD} = 1.31$ ). 68.2% of participants endorsed items suggesting minimal anxiety, 25% endorsed items suggesting mild anxiety, 4.5% endorsed items suggesting moderate anxiety, and 2.3% endorsed items suggesting severe anxiety.

With regard to Time 2 levels of hopelessness, 75.0% of participants' scores were within the normal range, 22.7% endorsed items suggesting mild levels of hopelessness, and 2.3% endorsed items suggesting moderate levels of hopelessness ( $\underline{M}_{untransformed} = 2.23$ ,  $\underline{SD} = 2.38$ ;  $\underline{M}_{transformed} = 1.23$ ,  $\underline{SD} = .83$ ).

Lastly, with regard to levels of caregiver burden at Time 2, 54.5% of caregivers in this sample "rarely" felt burdened by caregiving, 34.1% of caregivers "sometimes" felt burdened by providing care, and 11.4% of caregivers endorsed feeling burdened by caregiving "quite frequently" ( $\underline{M}_{untransformed} = 47.25$ ,  $\underline{SD} = 14.71$ ;  $\underline{M}_{transformed} = 6.79$ ;  $\underline{SD} = 1.07$ ).

It is interesting to note that the means for each of the four measures of distress at Time 2 were lower than the means at Time 1.

# 3.2 Correlational Analyses: The Relationships among Care Recipient Variables, Caregiver/Care Recipient Dyad Variables, Caregiver Variables, and Caregiver Distress

Correlational analyses were performed, via SPSS 11.0, on measures for all 44 caregivers in this study. Zero-order Pearson correlation coefficients were utilized to examine the relationships among care recipient, caregiver/care recipient dyad, and caregiver variables and measures of caregiver distress. These analyses are summarized in a correlation matrix that includes transformed variable values in Table 3 (see Chapter 6). An additional correlation matrix that includes the untransformed variable values and social problem-solving components is found in Table 4 (See Chapter 6).

#### 3.2.1 Care Recipient Variables

Care recipients' level of functional impairment (ADLS) significantly correlated with a number of variables in this study. More specifically, it was significantly negatively correlated with all measures of baseline caregiver distress (BDI-II,  $\underline{r} = -.46$ ,  $\underline{p} < .01$ ; BAI,  $\underline{r} = -.42$ ,  $\underline{p} < .01$ ;

BHS,  $\underline{r}=-.34$ ,  $\underline{p}<.05$ ; CBI,  $\underline{r}=-.48$ ,  $\underline{p}=.001$ ), as well as measures of depression, anxiety, and burden at Time 2 (BDI-II,  $\underline{r}=-.40$ ,  $\underline{p}<.01$ ; BAI,  $\underline{r}=-.41$ ,  $\underline{p}<.01$ ; CBI,  $\underline{r}=-.41$ ,  $\underline{p}<.01$ ). However, care recipients' functional impairment was not significantly correlated to caregiver hopelessness at Time 2 ( $\underline{r}=-.27$ ,  $\underline{p}=.07$ ). Interestingly, the correlations between functional impairment and hopelessness were the weakest of correlations between functional impairment and caregiver distress at baseline and Time 2 measurement.

# 3.2.2 Caregiver/Care Recipient Dyad Variables

Caregivers' dyadic adjustment, or overall satisfaction in their relationship with their partners, was significantly correlated with a number of other variables. More specifically, caregivers' dyadic adjustment was significantly positively correlated with all baseline measures of caregiver distress (BDI-II,  $\underline{r}=.66$ ,  $\underline{p}<.001$ ; BAI,  $\underline{r}=.54$ ,  $\underline{p}<.001$ ; BHS,  $\underline{r}=.50$ ,  $\underline{p}<.01$ ; CBI,  $\underline{r}=.81$ ,  $\underline{p}<.001$ ), as well as measures of caregiver distress at Time 2 (BDI-II,  $\underline{r}=.65$ ,  $\underline{p}<.001$ ; BAI,  $\underline{r}=.61$ ,  $\underline{p}<.001$ ; BHS,  $\underline{r}=.48$ ,  $\underline{p}<.01$ ; CBI,  $\underline{r}=.74$ ,  $\underline{p}<.001$ ). It was also significantly positively correlated with caregivers' negative life events during the past year (LES,  $\underline{r}=.38$ ,  $\underline{p}<.05$ ). Lastly, dyadic adjustment was significantly negatively correlated with caregivers' availability of social support (SSQA,  $\underline{r}=-.61$ ,  $\underline{p}<.001$ ), satisfaction with social support (SSQS,  $\underline{r}=-.49$ ,  $\underline{p}<.01$ ), and social problem-solving ability (SPSI-R,  $\underline{r}=-.47$ ,  $\underline{p}<.01$ ). It is important to note that prior to the square root transformation of the dyadic adjustment variable, it was first reflected due to its negative skewness. As a result of reflection, the interpretation of this variable, including the direction of its correlations with other variables, is the opposite of what it would be prior to reflection.

# 3.2.3 Caregiver Variables

With regard to baseline measures of caregiver distress, all measures were highly correlated with each other (p < .001). Caregivers' negative life events during the past year scores (LES) was also significantly positively associated with the baseline distress measures (BDI-II, r = .53, p < .001; BAI, r = .47, p < .01; BHS, r = .40, p < .01; CBI, r = .48, p < .01).

There were significant positive correlations between caregivers' physical health functioning (SF-36PF) and other caregiver variables, including baseline measures of distress (p < .05),

satisfaction with social support (p < .05), and social problem-solving ability (p < .01). The physical health functioning variable, like dyadic adjustment discussed above, was reflected prior to its  $log_{10}$  transformation due to its negative skewness. Therefore, the interpretation of the direction of its correlations with other variables is also the opposite of what it would be prior to reflection.

The availability of social support was significantly negatively correlated with baseline levels of depression ( $\underline{r} = -.36$ ,  $\underline{p} < .05$ ), and burden ( $\underline{r} = -.42$ ,  $\underline{p} < .01$ ), but not with anxiety or hopelessness. It was also significantly positively associated with satisfaction with social support ( $\underline{r} = .69$ ,  $\underline{p} < .001$ ).

Lastly, there were significant negative correlations between baseline measures of distress and caregivers' social problem-solving ability (SPSI-R,  $p \le .001$ ). With regard to specific problem-solving components, there were high positive correlations between negative problem orientation (NPO) and baseline depression ( $\underline{r} = .83$ ,  $\underline{p} < .001$ ), anxiety ( $\underline{r} = .73$ ,  $\underline{p} < .001$ ) and hopelessness ( $\underline{r} = .84$ ,  $\underline{p} < .001$ ), and a lower positive correlation between negative problem orientation and burden ( $\underline{r} = .57$ ,  $\underline{p} < .001$ ). Further, there was a moderate correlation between impulsivity/carelessness style (ICS) and baseline hopelessness ( $\underline{r} = .66$ ,  $\underline{p} < .001$ ) and moderate correlations between avoidance style (AS) and baseline depression ( $\underline{r} = .70$ ,  $\underline{p} < .001$ ) and avoidance style and baseline hopelessness ( $\underline{r} = .66$ ,  $\underline{p} < .001$ ). Additionally, there was a significant positive correlation between social problem-solving ability and satisfaction with social support ( $\underline{r} = .46$ ,  $\underline{p} < .01$ ).

# 3.2.4 Caregiver Distress

All measures of caregiver distress at Time 2 were significantly positively correlated with each other ( $\underline{p} < .001$ ). They were also significantly positively correlated with baseline measures of distress ( $\underline{p} < .001$ ).

Other variables found to be significantly correlated with Time 2 measures of caregiver depression, anxiety, hopelessness, and burden included negative life events during the past year, caregiver physical health functioning, dyadic adjustment, availability and satisfaction with social support, and social problem-solving ability. In terms of specific problem-solving

components, there was a high positive correlation between negative problem orientation and depression ( $\underline{r}=.83$ ,  $\underline{p}<.001$ ), as well as moderate positive correlations between negative problem orientation and anxiety ( $\underline{r}=.67$ ,  $\underline{p}<.001$ ) and hopelessness ( $\underline{r}=.72$ ,  $\underline{p}<.001$ ). Moderate positive correlations were demonstrated between impulsivity/carelessness style and depression ( $\underline{r}=.69$ ,  $\underline{p}<.001$ ), and hopelessness ( $\underline{r}=.67$ ,  $\underline{p}<.001$ ). A moderate positive correlation was also found between avoidance style and depression ( $\underline{r}=.73$ ,  $\underline{p}<.001$ ). However, care recipients' functional impairment did not significantly correlate with Time 2 caregiver hopelessness.

# 3.3 Primary Analyses of Caregiver Distress: Multiple Regression Analyses

The primary hypotheses in this study consider the merit of care recipient-, caregiver/care recipient dyad-, and caregiver variables in predicting distress in caregiving partners to men with HIV and AIDS. More specifically, these hypotheses consider (a) how baseline measures of distress contribute to predicting caregiver distress (at Time 2), (b) how caregivers' negative life events, physical health functioning, and functional impairment of the care recipient contribute to predicting caregiver distress, (c) how level of dyadic adjustment in the caregiver/care recipient relationship and caregiver's availability of and satisfaction with social support contribute to predicting caregiver distress, and (d) how caregivers' social problem-solving ability uniquely contribute to predicting caregiver distress, above and beyond the contributions of the aforementioned variables.

It is suggested that with statistical power of .80, an alpha level of .01, and eight independent variables, 147 participants are needed to achieve a medium effect size when conducting multiple regression analyses (Cohen, 1992). There are 11 independent variables in this study. With a total sample size of 44 participants, results in this study will be interpreted with considerable caution.

This study included a total of four blockwise hierarchical multiple regression analyses, one for each of the four respective dependent variables. Baseline measure of distress (depression, anxiety, hopelessness, or burden) was the first independent variable entered into each analysis. The choice of baseline measure entered was based on the particular

dependent variable being analyzed (e.g., baseline depression was the first independent variable entered for the regression analysis that used Time 2 depression as the dependent variable). Caregivers' negative life events, physical health functioning, and care recipients' level of functional impairment was the second block of independent variables entered into the regression model. Dyadic adjustment as well as the availability of and satisfaction with social support were entered as the third block of independent variables. The decision regarding the order of entry of variables was based upon previous empirical and theoretical support that identified these variables as potentially contributing to distress in caregivers. Social problemsolving ability was the final variable to be entered in the regression model. The decision to enter social problem-solving ability as the final independent variable, and to therefore assess its unique contribution to caregiver distress above and beyond the other variables, was based upon the paucity of research investigating social problem solving and caregiver distress in general, and in caregiving partners to men with HIV/AIDS in particular.

The unstandardized regression coefficients ( $\underline{B}$ ), semipartial correlations ( $\underline{sr}^2$ ),  $\underline{R}^2$ ,  $\underline{R}^2$ <sub>cumulative</sub> adjusted  $\underline{R}^2$ , and incremental and cumulative  $\underline{F}$  values for each of the four regression analyses are summarized in Tables 4 through 7, respectively.

### 3.3.1 Assumptions

Prior to performing the statistical analyses, the four assumptions behind multivariate analysis were assessed. They include the following: (1) multivariate normality, (2) linearity, (3) homoscedasticity, and (4) multicollinearity. Because violations of univariate normality may influence multivariate normality, the distributions of individual variables were also evaluated. Additionally, analyses were performed to detect the presence of univariate and multivariate outliers and influential data points. This was examined by calculating and assessing  $\underline{z}$  scores at a  $\underline{p}$  level of .001.

Results of these analyses revealed that a number of variables were non-normally distributed. As a result, transformation of these variables was considered. Square root transformation was applied to all distress measures (baseline and Time 2), to adjust for their moderate positive skewness. With regard to the independent variables, the caregiver physical

health functioning variable was reflected and then logarithmically transformed to adjust for its substantial negative skewness, and the dyadic adjustment variable was reflected and then a square root transformation was applied to adjust for its substantial negative skewness.  $\underline{z}$  scores and Mahalanobis Distance values identified no univariate or multivariate outliers.

Scatterplots of residuals were also used to assess the assumption of multivariate normality, in addition to evaluating linearity and homoscedasticity. Inspection of scatterplots revealed that each of these assumptions was met. Further, there was no evidence of multicollinearity or singularity, as there were no correlations between the independent variables that were greater than or equal to .90.

# 3.3.2 Results

Results of each of the four primary analyses are described below. These analyses include the prediction of caregiver distress as measured by the following four dependent variables:

(1) depression, as measured by the BDI-II, (2) anxiety, as measured by the BAI, (3) hopelessness, as measured by the BHS, and (4) burden, as measured by the CBI.

# 3.3.2.1 Prediction of Depression in Caregivers

A blockwise hierarchical multiple regression analysis was used to examine the contributions of caregiver and care recipient variables to predicting depression, as measured by the BDI-II, in this sample of 44 caregivers.

Given the prospective nature of this study, caregivers' baseline depression scores (specifically, the square root transformation of Time 1 BDI-II) were prioritized as the first variable block to be entered into the analysis. This variable accounted for 62% of the total variance in step 1, ( $\underline{R}^2 = .62$ ,  $\underline{F}$  (1,42) = 68.597,  $\underline{p}$  < .001). The  $\underline{B}$  weight coefficient indicates that as the number of depressive symptoms at baseline (Time 1) increases, so do the number of depressive symptoms measured at Time 2 ( $\underline{B} = .68$ ,  $\underline{p}$  < .001).

Caregivers' negative life events during the past year, their level of physical functioning (specifically, the  $log_{10}$  of physical functioning), and care recipients' functional impairment were entered in step 2. Entering these variables did not result in a significant contribution to predicting depression in this sample ( $\underline{R}^2 = .003$ ,  $\underline{F}_{change}$  (3,39) = .100,  $\underline{p}$  = .959).

Entering dyadic adjustment (specifically, the square root of the dyadic adjustment total score), as well as social support variables in step 3 yielded a significant increment in predicting caregiver depression ( $\mathbb{R}^2$  = .120,  $\underline{F}_{change}$  (3,36) = 5.639,  $\underline{p}$  < .01). Specifically, SSQS uniquely accounted for 8% of the total variance, given the entry of other independent measures through this step ( $\underline{sr}^2$  = .08,  $\underline{p}$  < .01). The  $\underline{B}$  weight coefficient indicates that as satisfaction with social support increases, depression scores decrease ( $\underline{B}$  = -.07,  $\underline{p}$  < .01).

A significant increment in predicting caregiver depression resulted from the addition of caregiver social problem solving (total score) at step 4 ( $\underline{R}^2$  = .055,  $\underline{F}_{change}$  (1,35) = 9.517,  $\underline{p}$  < .01). It uniquely accounted for 5% of the total variance, given the entry of all other independent measures through this step ( $\underline{sr}^2$  = .05,  $\underline{p}$  < .01). The  $\underline{B}$  weight coefficient indicates that as social problem-solving ability increases, depression scores decrease ( $\underline{B}$  = -.144,  $\underline{p}$  < .01).

In summary, entry of all of the independent variables accounted for 80% of the variance in the prediction of depression in caregivers ( $\underline{R}^2_{\text{cumulative}} = .80$ ,  $\underline{F}_{\text{cumulative}}$  (8,35) = 17.33,  $\underline{p}$  < .001). These results are summarized in Table 5 (see Appendix 1).

# 3.3.2.2 Prediction of Anxiety in Caregivers

A blockwise hierarchical multiple regression analysis was also used to examine the contributions of caregiver and care recipient variables to predicting anxiety, as measured by the BAI, in this sample of 44 caregivers.

Given the prospective nature of this study, caregivers' baseline anxiety scores (specifically, the square root transformation of Time 1 BAI) were prioritized as the first variable block to be entered into the analysis. This variable accounted for 69% of the total variance in step 1, ( $\mathbb{R}^2$  = .69,  $\mathbb{F}$  (1,42) = 92.968,  $\mathbb{p}$  < .001). The  $\mathbb{B}$  weight coefficient indicates that as the number of anxiety symptoms at baseline (Time 1) increases, so do the number of anxiety symptoms measured at Time 2 ( $\mathbb{B}$  = .88,  $\mathbb{p}$  < .001).

Caregivers' negative life events during the past year, their level of physical functioning (specifically, the log<sub>10</sub> of physical functioning), and care recipients' functional impairment were again entered in step 2. Similar to the prediction of caregiver depression, entering these

variables did not result in a significant contribution to predicting anxiety in this sample ( $\underline{R}^2 = .01$ ,  $\underline{F}_{change}$  (3,39) = .291,  $\underline{p}$  = .83).

Entering dyadic adjustment (specifically, the square root of the dyadic adjustment total score), as well as social support variables in step 3 did not yield a significant increment in predicting caregiver anxiety ( $\underline{\mathbb{R}}^2 = .04$ ,  $\underline{F}_{change}$  (3,36) = 1.856,  $\underline{p}$  = .15).

Further, the addition of caregiver social problem solving (total score) at step 4 did not significantly improve the prediction of anxiety above and beyond the contributions of the independent variables already entered ( $\underline{R}^2 = .00$ ,  $\underline{F}_{change}$  (1,35) = .005,  $\underline{p}$  = .94).

In summary, entry of all of the independent variables accounted for 74% of the variance in the prediction of anxiety in caregivers ( $\underline{R}^2_{\text{cumulative}} = .74$ ,  $\underline{F}_{\text{cumulative}}$  (8,35) = 12.22,  $\underline{p}$  < .001). These results are summarized in Table 6 (see Appendix 1).

# 3.3.2.3 Prediction of Hopelessness in Caregivers

A blockwise hierarchical multiple regression analysis was also used to examine the contributions of caregiver and care recipient variables to predicting hopelessness, as measured by the BHS, in this sample of 44 caregivers.

Given the prospective nature of this study, caregivers' baseline hopelessness scores (specifically, the square root transformation of Time 1 BHS) were prioritized as the first variable block to be entered into the analysis. This variable accounted for 78% of the total variance in step 1,  $(R^2 = .78, F(1,42) = 92.968, p < .001)$ .

The  $\underline{B}$  weight coefficient indicates that as the number of hopelessness symptoms at baseline (Time 1) increases, so do the number of hopelessness symptoms measured at Time 2 ( $\underline{B}$  = .81,  $\underline{p}$  < .001).

Caregivers' negative life events during the past year, their level of physical functioning (specifically, the  $log_{10}$  of physical functioning), and care recipients' functional impairment were again entered in step 2. Similar to the prediction of caregiver depression and anxiety, entering these variables did not result in a significant contribution to predicting hopelessness in this sample ( $\underline{\mathbb{R}}^2 = .01$ ,  $\underline{F}_{change}$  (3,39) = .794,  $\underline{p} = .50$ ).

Entering dyadic adjustment (specifically, the square root of the dyadic adjustment total score), as well as social support variables in step 3 did not yield a significant increment in predicting caregiver hopelessness ( $\underline{R}^2 = .02$ ,  $\underline{F}_{change}$  (3,36) = .980,  $\underline{p}$  = .41).

Adding caregiver social problem solving (total score) at step 4 did not significantly improve the prediction of hopelessness above and beyond the contributions of the independent variables already entered ( $\underline{R}^2 = .00$ ,  $\underline{F}_{change}$  (1,35) = .912,  $\underline{p}$  = .35).

In summary, entry of all of the independent variables accounted for 81% of the variance in the prediction of hopelessness in caregivers ( $\underline{R}^2_{\text{cumulative}} = .81$ ,  $\underline{F}_{\text{cumulative}}$  (8,35) = 18.89,  $\underline{p}$  < .001). These results are summarized in Table 7 (see Appendix 1).

# 3.3.2.4 Prediction of Burden in Caregivers

A blockwise hierarchical multiple regression analysis was also used to examine the contributions of caregiver and care recipient variables to predicting burden, as measured by the CBI, in this sample of 44 caregivers.

Given the prospective nature of this study, caregivers' baseline burden scores (specifically, the square root transformation of Time 1 CBI) were prioritized as the first variable block to be entered into the analysis. This variable accounted for 89% of the total variance in step 1, ( $\mathbb{R}^2$  = .89,  $\mathbb{F}$  (1,42) = 351.24,  $\mathbb{p}$  < .001). The  $\mathbb{B}$  weight coefficient indicates that as the number of burden symptoms at baseline (Time 1) increases, so do the number of burden symptoms measured at Time 2 ( $\mathbb{B}$  = .95,  $\mathbb{p}$  < .001).

Caregivers' negative life events during the past year, their level of physical functioning (specifically, the  $\log_{10}$  of physical functioning), and care recipients' functional impairment were again entered in step 2. Similar to the prediction of caregiver depression, anxiety, and hopelessness, entering these variables did not result in a significant contribution to predicting burden in this sample ( $\underline{R}^2 = .01$ ,  $\underline{F}_{change}$  (3,39) = .782,  $\underline{p} = .51$ ).

Entering dyadic adjustment (specifically, the square root of the dyadic adjustment total score), as well as social support variables in step 3 did not yield a significant increment in predicting caregiver burden ( $\underline{R}^2 = .02$ ,  $\underline{F}_{change}$  (3,36) = 2.346,  $\underline{p} = .09$ ). While this increment is not significant at the .05 level, its  $\underline{p}$  value of .09 approached significance. While not

interpretable, due to its lack of statistical significance, results indicated that dyadic adjustment accounted for 1% of the total variance, given the entry of other independent measures through this step ( $\underline{sr}^2 = .01$ ,  $\underline{p} = .06$ ). The  $\underline{B}$  weight coefficient indicates that as dyadic adjustment increases, burden scores decrease ( $\underline{B} = -.11$ ,  $\underline{p} = .06$ ).

Adding caregiver social problem solving (total score) at step 4 did not significantly improve the prediction of burden above and beyond the contributions of the independent variables already entered ( $R^2 = .00$ ,  $F_{change}$  (1,35) = 1.075, p = .31).

In summary, entry of all of the independent variables accounted for 92% of the variance in the prediction of burden in caregivers ( $\underline{R}^2_{\text{cumulative}}$  = .92,  $\underline{F}_{\text{cumulative}}$  (8,35) = 49.138,  $\underline{p}$  < .001). These results are summarized in Table 8 (see Appendix 1).

# 3.3.2.5 Summary of Results

A number of findings were yielded from the four multiple regression analyses in this study. A consistent pattern was found across each of the four analyses with regard to baseline measures of distress. More specifically, baseline measures of caregiver depression, anxiety, hopelessness, and burden each significantly contributed to the prediction of their respective distress measures at Time 2. However, caregivers' negative life events during the past year, physical health functioning, and care recipients' functional impairment did not significantly contribute to caregiver distress in any of the four analyses. While dyadic adjustment did not significantly contribute to the prediction of caregiver distress across any of the four distress measures, it did approach significance with regard to caregiver burden.

It appears that caregiver depression was the only dependent measure in this study in which independent variables offered reliable improvement in prediction of distress above and beyond the baseline measures of distress. With regard to social support, caregivers' satisfaction with their social support did significantly contribute to the prediction of depression. Similarly, caregivers' social problem-solving ability uniquely contributed to the prediction of depression in this sample of caregivers.

# 4. DISCUSSION

#### 4.1 Overview

HIV and AIDS remain a formidable public health concern, nearly 25 years after receiving formal recognition as a disease. Despite considerable improvements in its understanding and treatment, HIV/AIDS continues to pose myriad challenges to the individuals who live with it, their families and social networks, as well as the medical and mental health communities, on many different levels. The purpose of this study was to identify variables that contribute to the distress experienced by caregiving partners to men with HIV/AIDS, including care recipient variables, caregiver/care recipient dyad variables, and caregiver variables.

Level of functional impairment was the care recipient variable included in this study. With regard to the caregiver/care recipient dyad, dyadic adjustment, or overall level of satisfaction in the relationship, was assessed. Caregiver variables included baseline measures of distress (depression, anxiety, hopelessness, and burden), negative life events experienced during the past year, physical health functioning and availability of and satisfaction with social support systems. Previous research has supported their roles in understanding caregiver distress. Social problem-solving ability was the final caregiver variable included in this study. Despite the vast amount of research on the relationship between social problem-solving ability and psychological distress, research on problem solving and caregiver distress in general, and distress experienced by caregivers to men with HIV/AIDS in particular, is quite limited.

Dependent variables in this study included (a) depression, as measured by the BDI-II, (b) anxiety, as measured by the BAI, (c) hopelessness, as measured by the BHS, and (d) caregiver burden, as measured by the CBI. Depression, anxiety, and hopelessness are constructs often investigated in general psychological and mental health research, and their respective Beck measures are widely used in their assessment, offering sound and well-established psychometric properties. Burden, as a construct, is more specific to caregiver research. In this study, burden was assessed with the CBI. The CBI is most frequently used to assess the degree of burden experienced by caregivers to cognitively impaired adults. Given the paucity of HIV/AIDS caregiver research and assessment measures for this specific

population of caregivers, as well as its frequent use in caregiver research and established psychometric properties, the CBI was included as an assessment tool in this study. The inclusion of these four dependent measures reflected an interest in understanding the unique distress that results from the caregiving experience (i.e., burden), as well as how this distress may compare to that experienced in other distressed populations (e.g., individuals experiencing depression, anxiety, and hopelessness).

The purpose of the current study was to investigate the caregiving experience in men who are primary caregivers to their male partners living with HIV/AIDS. This study explored the relationships between care recipient-, caregiver/care recipient dyad-, caregiver variables and caregiver distress. More specifically, the study explored the unique role of social problem-solving ability in predicting depression, anxiety, hopelessness and burden, while controlling for the contribution of a number of other variables.

#### 4.2 Summary of Results

#### 4.2.1 Correlational Analyses

Relationships among the care recipient variables, caregiver/care recipient dyad variables, caregiver variables, and caregiver distress were investigated through the use of Pearson correlations. These results were summarized in Table 3.

Firstly, it was hypothesized that greater levels of care recipient functional impairment would be associated with increased caregiver distress. As previously discussed, the ADLS was used as the measure of functional impairment. Significant low to moderate negative correlations existed between ADLS scores and caregiver depression, anxiety, and burden, both at baseline and Time 2 measurement. With regard to caregiver hopelessness, the negative correlation between ADLS scores and baseline measurement of hopelessness was significant; however, it approached significance at Time 2 measurement (p = .07). While the majority of caregivers in this sample reported little to no functional impairment in their care recipients, it appears that the challenges caregivers face with the loss of daily living scales in their partners are associated with the experience of distress.

With regard to dyadic adjustment in the caregiver/care recipient relationship, it was hypothesized that greater levels of relationship satisfaction would be associated with lower levels of caregiver distress. This hypothesis was supported, as caregivers who reported greater satisfaction in their relationships also endorsed lower levels of distress.

As expected, baseline measures of caregiver distress were highly positively correlated with measures of distress at Time 2. With regard to caregivers' negative life events during the past year, it was hypothesized that this would be associated to caregiver distress. Examination of these correlations supported this. As the number of negative events caregivers experienced increased, they were found to be more depressed, anxious, hopeless and burdened by caregiving.

In considering caregivers' physical health functioning, it was hypothesized that health functioning would be related to caregiver distress. Low to moderate correlations between these variables were found and indicated that as the level of health functioning decreased, caregivers were found to be more distressed. Further, it was found that caregivers in poorer health endorsed lower levels of satisfaction with their social support systems.

Caregivers' social support and social problem-solving ability were also hypothesized to be correlated with caregiver distress. In general, caregivers who had larger social support networks and experienced greater satisfaction with these networks experienced less distress across the majority of outcome measures. With regard to social problem-solving ability, caregivers with more effective problem solving skills were found to be less depressed, anxious, hopeless, and burdened. More specifically, it was demonstrated that caregivers who reported higher levels of depression also reported higher levels of negative problem orientation, and greater impulsivity/carelessness and avoidance styles in problem solving. Higher levels of hopelessness were associated with higher levels of negative problem orientation and impulsivity/carelessness style, and higher levels of anxiety were also associated with higher levels of negative problem orientation. Further, it was found that as caregivers' problem solving skills increase, satisfaction with their social support networks also increases.

# 4.2.2 Primary Hypotheses Under Investigation

The primary hypotheses in this study considered the predictive merit of a number of care recipient-, caregiver/care recipient dyad-, and caregiver variables to caregiver distress with a sample of caregiving partners to men living with HIV/AIDS. Four blockwise hierarchical multiple regression analyses were performed, one for each of the caregiver distress outcome measures.

# 4.2.2.1 Baseline Distress as a Predictor of Caregiver Distress

As hypothesized, caregivers' baseline depression, anxiety, hopelessness, and burden scores significantly contributed to the prediction of their respective scores measured at Time 2. Possible explanations for this include the high level of intercorrelations among baseline and Time 2 distress measures in this sample, as well as the utility of assessing a past behavior in predicting that same behavior in the future.

4.2.2.2 Negative Life Events, Physical Health Functioning, and Care Recipient Functional Impairment as Predictors of Caregiver Distress

In each of the four regression analyses, caregivers' negative life events during the past year (LES), physical health functioning (SF36-PF), and care recipients' level of functional impairment (ADLS) were subsequently added to better understand their relationship to caregiver distress above and beyond the contribution of baseline caregiver distress. None of these variables significantly strengthened the prediction of depression, anxiety, hopelessness or burden in this sample of caregivers. One possible explanation for the lack of significance is the small sample size in this study, particularly in relation to the number of variables and analyses that were conducted. Another possible explanation is that the range and variability of scores for these three independent variables in this sample was small. In general, caregivers in this sample reported low negative impact ratings for the past year's life events, good health functioning, and very little loss of daily living skills in their care recipients.

4.2.2.3 Dyadic Adjustment and Social Support as Predictors of Caregiver Distress

Dyadic adjustment (DAS) and social support (specifically, the availability of [SSQA] and satisfaction with [SSQS] social support) were subsequently added to each of the four

regression analyses to better understand their role in predicting caregiver distress above and

beyond the contributions of the aforementioned variables. Caregivers' satisfaction with social support uniquely contributed to the prediction of depression, as measured by the BDI-II. One possible explanation for this finding is that outcome measures such as the BDI-II possess high sensitivity to cognitive formulations of depression (e.g., cognitive appraisal and distortions, realistic versus unrealistic expectations), and satisfaction with social support is a cognitive related variable, as it relies on an individual's perception of resources.

Although dyadic adjustment did not significantly strengthen the prediction of caregiver distress across any of the four outcome measures, it did approach significance in the prediction of caregiver burden. While not interpretable due to lack of statistical significance, one possible explanation for this trend towards significance is that both of these variables assess aspects of the relationship between caregiver and care recipient.

# 4.2.2.4 Social Problem-Solving Ability as a Predictor of Caregiver Distress

Social problem-solving ability was the final variable added to each of the four analyses in order to understand its unique role in contributing to caregiver distress above and beyond the contributions of baseline caregiver distress, caregivers' negative life events and physical health functioning, care recipient functional impairment, dyadic adjustment in the caregiver/care recipient relationship, and caregivers' availability of and satisfaction with their social support networks. As discussed, the predictive merit of social problem-solving ability to caregiver distress has not been previously investigated in a population of caregiving partners to men living with HIV/AIDS.

While social problem-solving ability includes a number of different components, this study included the *overall* construct in its analyses. Across the four outcome measures, social problem-solving ability significantly contributed to the prediction of caregiver depression. Despite the limitations in this study, it is quite interesting to note the significant predictive relationship of social problem solving to depression in this sample of caregivers to men with HIV/AIDS. HIV/AIDS presents numerous challenges and problems to the caregiver across the course of the disease. Given this, it appears that caregiving partners to men with HIV/AIDS

who utilize less effective social problem-skills may be at greater risk for depressive symptomatology.

# 4.3 Review of Current Findings and Support of Previous Research

Firstly, it is important to note that some caregivers in this sample endorsed items reflecting elevated levels of distress, both at baseline and Time 2 measurement. While caregivers' scores, on average, reflected minimal levels of depression, minimal to mild levels of anxiety, minimal levels of hopelessness, and rarely feeling burdened by caregiving, there were caregivers whose scores reflected moderate to severe levels of distress. For example, baseline distress measures indicated that one-quarter of caregivers reported mild to moderate levels of depression, nearly one-third reported mild to severe levels of anxiety and mild to moderate levels of hopelessness, and nearly one-half of caregivers reported feeling burdened sometimes to quite frequently. These findings are consistent with research that suggests that the demands associated with caregiving to people with HIV/AIDS are associated with elevated levels of distress (LeBlanc et al., 1995; Pakenham et al., 1995, Folkman et al., 1994; Trice, 1988). Interestingly, given that the majority of caregivers in this sample endorsed items suggesting minimal levels of distress, such findings are also consistent with research that has demonstrated minimal levels of distress, such as depressive symptoms, in this population of caregivers (Folkman et al., 1994). Overall, these results appear to reflect the importance of individual differences in stress and coping with the caregiving experience.

With regard to care recipient functional impairment, caregivers in this sample reported quite small levels of such impairment in their care recipients. It appears that the majority of caregivers in this sample were providing care to men who were able to independently manage their own daily instrumental needs (e.g., feeding, toileting). However, results of the current study offer support to previous research demonstrating positive associations between functional impairment in instrumental activities and caregiver distress and burden (Clipp et al., 1995). Across the four distress measures in this study, care recipient functional impairment was significantly negatively correlated with depression, anxiety and burden measured at Time 2.

The fact that this sample of caregivers reported small amounts of functional impairment in their care recipients may contribute to explaining why these caregivers also reported relatively small amounts of time per week in which they provided care to their partners. Over 50% of this particular sample of caregivers reported providing care for 5 or less hours per week, and the sample, in general, reported low levels of distress. While the average number of caregiving hours per week for caregiving partners to men with HIV and AIDS is not known, it is important to consider that the general population of these caregivers may be providing care to their partners for a greater number of hours per week and, consequently, may experience higher levels of distress.

Consistent with previous research (Folkman et al., 1994), this study supports the finding of a significant positive relationship between caregiver negative life events and caregiver burden. In addition to this relationship, significant positive relationships were found between caregiver negative life events and depression, anxiety and hopelessness.

With regard to caregiver health functioning, the results of this study support previous findings that demonstrate a significant negative relationship between level of health functioning and burden (Folkman et al., 1994). Folkman et al. found such a relationship in HIV- caregivers, but not in caregivers who were HIV+. The current study did not consider caregivers' HIV status while investigating this relationship. Rather, across baseline and Time 2 distress measures, small significant positive associations were found between caregivers' level of health functioning (regardless of HIV status) and depression, anxiety, hopelessness, and burden. (The *positive* direction of these correlations is due to the fact that caregiver physical health functioning, as measured by the SF36 Physical Functioning scale, was reflected prior to its log<sub>10</sub> transformation.)

Consistent with past research, results of the current study support the negative association that has been found between dyadic adjustment in the caregiver/care recipient relations hip and caregiver burden in HIV/AIDS caregivers as well as in other caregiving populations (Folkman et al., 1994; Williamson and Schulz, 1990). Results from the current study also indicated significant associations between higher levels of dyadic adjustment and lower levels

of depression, anxiety and hopelessness. (While these correlations are in the *positive* direction in this study, this is due to the fact that dyadic adjustment, as measured by the Dyadic Adjustment Scale, was reflected prior to its square root transformation.)

With regard to social support, the correlational analyses in this study offer some support to the small amount of previous research that has demonstrated negative associations between the availability and satisfaction of social support and caregiver distress (Jankowski et al., 1996; Folkman et al., 1994). In terms of social support availability, a moderate negative correlation, although not statistically significant, was found between the availability of social support in this sample of HIV/AIDS caregivers and Time 2 depression. Significant negative correlations were demonstrated between availability of social support and anxiety, hopelessness, and burden. In term of satisfaction with social support, significant negative correlations were demonstrated between satisfaction and caregiver depression, anxiety, hopelessness, and burden. In terms of prediction, availability of social support did not significantly contribute to caregiver distress across any of the four dependent measures. However, satisfaction with social support did significantly contribute to the prediction of depression in this sample of caregivers. It is interesting to note that satisfaction with social support, a variable that is based upon one's cognitive appraisal, was more highly correlated with the four measures of distress and was the only social support variable that significantly contributed to caregiver distress (i.e., depression).

With regard to social problem-solving ability, correlational analyses in this study offer support to previous research demonstrating a relationship between one's problem-solving skills and distress (Nezu et al., 1999; Nezu & Ronan, 1988; Nezu, 1987; Nezu & Carnevale, 1987). In terms of prediction, the results of the present study have indicated that social problem-solving ability reliably strengthened the prediction of depression in this sample of caregivers. In addition, the magnitude of the correlation between social problem-solving ability and depression was the strongest of the correlations between problem solving and the four distress measures in this study. (While the correlations between social problem solving and anxiety, hopelessness and burden ranged from -.50 to -.59, the correlations between social

problem solving and baseline and Time 2 depression were -.71 and -.73 respectively.) The limited research on the relationship between social problem-solving ability and distress in caregivers in general, and caregiving partners to men with HIV/AIDS in particular, make the present findings particularly interesting, in terms of a preliminary investigation of this relationship. These findings also offer support to previous work by Houts et al. (1993) suggesting the utility of social problem solving as a tool that caregivers can use to resolve caregiving-related problems and cope with the potential psychological demands of caregiving.

### 4.4 Clinical Implications of the Present Study

The results of the present study suggest that men who provide care to their male partners living with HIV and AIDS may experience distress in response to the multiple demands and stressors associated with caregiving. While caregivers in this sample, on average, were experiencing minimal levels of depression, anxiety, hopelessness and burden, there were caregivers who reported moderate to severe levels of distress. This variability in severity of distress highlights the importance of individual differences when conceptualizing the caregiving experience, as well as the importance of identifying and targeting variables that will improve functioning in distressed caregivers or will prevent distress from occurring in those individuals who may be at risk. Interestingly, there was a decrease in scores across each of the four distress measures from baseline to Time 2. While these decreases were small, it is important to note that this sample of caregivers were generally functioning at or below the same level of distress three months after initial inquiry.

Clinical assessment of caregivers' needs, as with assessment of other populations at risk for distress, should include a multifaceted approach. A number of caregiver, care recipient, and caregiver/care recipient dyad variables were investigated in this study as potential contributors to caregiver distress. In addition to standard assessment techniques, such as psychosocial history, the findings of the present study suggest other possible areas of importance to screen and address with these caregivers include current levels of psychological distress, degree of satisfaction with the caregiver/care recipient relationship (i.e., dyadic adjustment), and coping factors, such as social support and social problem

solving. While other variables included in this study, including caregiver negative life events, caregiver health functioning, and care recipient functional impairment, were not demonstrated to reliably contribute to the prediction of distress in this sample of caregivers, they were shown to be correlated to such distress. Given the very limited amount of research with this population of caregivers, as well as the notable limitations present in this study, the potential importance of these variables in caregiver assessment should not be disregarded.

Of the four dependent measures of distress assessed in this study, depression was the variable that yielded the most information with regard to its prediction. Based upon the findings of this study, it appears that caregivers who may be at increased risk for experiencing depressive symptomatology include those with baseline depressive symptomatology, who are dissatisfied with available social support resources, and who utilize ineffective problem-solving skills. Given the preliminary nature of and limitations associated with this study, this is not offered as a clinical profile; however, the predictive merit of these variables to caregiver depression, despite the study's limitations, highlight the potential importance of these variables in relation to depression.

The findings of this study offer preliminary support to the idea that, with respect to caregiver depression, it may be important to target cognitive, behavioral, and affective components within clinical research and psychotherapy. Given the predictive merit of satisfaction with social support resources to depressive symptomatology, it appears that identifying and working with caregivers on the processes that result in dissatisfaction with available support resources (e.g., negative appraisals, cognitive distortions) may be helpful in ameliorating depressive symptoms. In addition, the predictive merit of social problem-solving ability to caregiver depression suggests that evaluating and working with caregivers on their problem-solving abilities may be a useful component to evaluation and treatment. One means of achieving this goal might be implementation of social problem-solving therapy. As previously discussed, social problem-solving therapy has been demonstrated as an effective intervention in the treatment of depression (Nezu et al., 1989).

Caregiving partners to men with HIV and AIDS face innumerable challenges in the daily care of their partners. In these types of difficult medical caregiving situations, where many of the variables cannot be changed (e.g., the diagnosis, financial burden), it is essential to search for and identify those variables that can be changed. The results of the current study suggest that social support and social problem solving are two such variables that may aid mental health professionals in developing interventions to reduce caregiver distress.

### 4.5 Limitations of the Present Study and Suggestions for Future Research

While the present study identified relationships among a number of variables and caregiver distress, these findings must be interpreted with a considerable amount of caution, particularly when attempting to generalize these results to the general population of men who provide care to their male partners living with HIV and AIDS.

The primary limitation of this study relates to sample size. Despite an attempt to be conservative with the number of statistical analyses performed, the statistical power available with this study was quite certainly exceeded given the small number of participants. Future research should be conducted with a larger sample in order to more properly evaluate such research questions and support the generalizability and validity of the results.

A second concern raised in this study concerns the recruitment of participants and the nature of the sample. Given that all participation in this study was voluntary, there is a concern that the nature of the sample is biased. While the voluntary nature of participation is a limitation of many research studies, it nonetheless must be considered as a limitation to the generalizability of results. Further, recruitment efforts were conducted through distribution of fliers at various gay- oriented facilities and businesses and via caregiving-, HIV/AIDS-, and gay-oriented websites on the Internet. Such efforts may have limited the range of potential participants to those who utilize such resources and, consequently, biased the results. Perhaps the experiences and resources available to those individuals who are aware of and utilize such facilities are different than those who either do not have access to such resources or decide to not make use of them. It may be that individuals who utilize such facilities and the Internet have greater access to formal and informal support networks and resources and,

consequently, are coping more effectively (i.e., are less distressed) with the demands of providing care than individuals who do not utilize these resources. Conversely, the results may also have been biased by the fact that those caregivers who participated in this study did so in response to fliers and announcements identifying a study on stress and coping. Perhaps there were individuals who responded to that aspect of the flier who were disproportionately more distressed than other caregivers and were seeking out assistance in whatever form available, including a research study. Observations like these may help to explain the fact that the majority of caregivers in this sample were not clinically distressed, and that those who did endorse symptomatology outside of the normal range of functioning did so at moderate to severe levels.

With further regard to the characteristics of this sample, it is important to note that the 44 participants returned complete data to the researcher. Given the relatively large number of questionnaires to be completed in this study, this is an interesting finding. One possible explanation for this may be that this is a well-educated sample, and perhaps their educational histories have led them to be more sensitive to thoroughness in completing questionnaires of this type. An alternative explanation may be that there was a need on the part of the participants to "present well" to the researcher, in terms of data completion and perhaps in terms of levels of distress as well. (This may offer an additional explanation for the generally low levels of distress that were reported in this sample.) While the particular reason for this finding is unclear, it is important to note that such a finding may reflect characteristics of this sample that limit the generalizability of this study's results.

An additional limitation to consider in this study concerns choice of measurement devices. More specifically, it is interesting that the majority of caregivers in this sample identified such a small amount of functional impairment in their care recipients. These findings may be due to the fact that care recipients of this sample of caregivers were functioning quite well in maintaining their own daily instrumental needs. An alternative explanation for this finding may be that the instrument used to assess care recipient functional impairment in this study did not capture some of the unique aspects of functional impairment associated with HIV and AIDS.

The measures used to assess functional impairment in this study were developed for assessment of the elderly population. The decision to utilize these measures was based on the lack of available measures of functional impairment in individuals with HIV and AIDS. Perhaps a measure of functional impairment more specific to HIV and AIDS would have increased the range of care recipient impairment endorsed by caregivers. Future research to identify domains of biological and psychosocial functioning pertinent to HIV and AIDS and the development of HIV/AIDS-specific assessment measures is essential.

This concern about utilizing measurement devices with a sample from a population that differs from the one on which it was developed also points to a larger consideration regarding clinical and research aspects of caregiving. Indeed, there are aspects of the caregiving process that are shared across different populations of caregivers, and the utility of drawing from different caregiving literatures to inform other caregiving research and clinical work has been demonstrated. Nevertheless, a woman providing care to her child with leukemia, an adult daughter providing care to her elderly father with Alzheimer's Disease, and a gay male providing care to his partner with AIDS will each experience a multitude of differences in terms of the types of caregiving tasks required, the types of burden experienced, as well as the contexts in which they provide care. As such, it is necessary to maintain an awareness of the similarities and differences experienced across populations of caregivers and to adapt caregiver-related clinical and research endeavors accordingly.

There were other variables included in data collection for this study that were not included in statistical analyses in order to underscore the importance of the primary hypotheses and to conserve statistical power. These included demographic variables (e.g., income/financial resources, length of the caregiver/care recipient relationship), caregiver HIV serostatus, length of time since caregiver and care recipient were diagnosed with HIV or AIDS, type of support available to caregivers, and the extent to which providing care to partners results in caregivers thinking about their own need for care should it be required. Some of these variables have been investigated in previous research and have yielded inconsistent results (Pakenham et al., 1995; LeBlanc et al., 1995; Folkman et al., 1994). Given the limited amount of available

research with HIV and AIDS caregivers in general, and caregiving partners to men with HIV and AIDS in particular, efforts should be made to include such variables in future research.

With regard to social problem-solving ability, the present study was the first known investigation of its role in predicting distress in caregiving partners to men with HIV and AIDS. Despite the significant limitations in this study, the predictive merit of social problem solving to caregiver depression, above and beyond a number of other important variables, was demonstrated. Consequently, it appears that this variable may be quite strongly associated with depression in this group of caregivers. As previously discussed, social problem solving, according to the Social Problem-Solving Model (Nezu et al., 1989), includes five major components, and these five components are assessed in the SPSI-R measure. For sake of conserving statistical power, the *overall* SPSI-R score was included in this study's analyses. Based on the significance of its role in predicting depression in this study, as well as correlational analyses of the specific problem-solving components and distress measures, future research should attempt to include the SPSI-R subscales in statistical analyses in an effort to discern the relationships between these problem-solving components and caregiver distress.

### 5. SUMMARY AND CONCLUSIONS

The purpose of the present study was to identify variables that contribute to distress experienced by men who provide care to their male partners living with HIV and AIDS. Variables related to the caregiver (i.e., negative life events, physical health functioning, availability of and satisfaction with social support), care recipient (i.e., functional impairment), and caregiver/care recipient dyad (i.e., dyadic adjustment) were included in this investigation based upon previous research that has identified their relationships to caregiver distress. In addition, caregiver social problem-solving ability was included in this study, and its role in predicting caregiver distress above and beyond the contributions of the aforementioned variables was investigated. This is the first known investigation of the relationship of social problem solving and distress in this population of caregivers.

Four hierarchical multiple regression analyses were conducted on data collected from the 44 caregivers who participated in this study. Across the four regression analyses, caregivers' baseline levels of depression, anxiety, hopelessness, and burden significantly contributed to respective measures of depression, anxiety, hopelessness, and burden assessed at Time 2. Caregivers' negative life events, physical health functioning, and care recipients' functional impairment did not significantly improve prediction across any of the four measure of distress. Dyadic adjustment did not significantly contribute to prediction of depression, anxiety or hopelessness. While its contribution to the prediction of caregiver burden was not significant either, it did approach significance. While not interpretable due to lack of significance, this trend suggested that caregivers who endorsed higher levels of satisfaction in their relationships with their partners endorsed fewer symptoms of burden from providing care.

With regard to predicting depression, caregivers' satisfaction with social support networks and resources reliably improved its prediction. Based on these findings, it appears that caregivers in this sample who reported less satisfaction with their support networks endorsed greater levels of depressive symptomatology. Further, caregivers' social problem-solving ability also significantly contributed to the prediction of depression, above and beyond the other variables included in this study. It appears that caregivers who endorsed greater total

social problem-solving scores reported lower levels of depressive symptoms. While these findings must be considered with a great deal of caution, given the limitations of this study that were previously discussed, these findings do offer preliminary support to the idea that coping variables are an important area to assess, both in terms of research and clinical work, in caregiving partners to men with HIV and AIDS. With specific regard to social problem solving, the results of the current study underscore the importance of further investigation of the role of this variable in caregiver distress, particularly the role of its cognitive and behavioral components.

Men who provide care to their male partners with HIV and AIDS face substantial challenges and difficulties in the caregiving process. Some of these challenges are common to caregivers across different populations, and research that investigates the experiences of different groups of caregivers can be of great utility in conceptualizing research and clinical interventions for these caregivers. Other challenges are more unique to the experience of providing care to a person living with HIV or AIDS. While achievements have been made in understanding and responding to the needs of HIV/AIDS caregivers, the need to understand and support this invaluable group of individuals continues.

### **LIST OF REFERENCES**

- Bartlett, J.G. (1993). Zidovudine now or later? *New England Journal of Medicine, 329,* 351-352.
- Batchelor, W.F. (1984). AIDS: A public health and psychological emergency. *American Psychologist*, *39(11)*, 1279-1284.
- Beck, A.T., Epstein, N., Brown, G., & Steer, R.A. (1988). An inventory for measuring clinical anxiety: Psychometric properties. *Journal of Consulting and Clinical Psychology*, *56*, 893-897.
- Beck, A.T. & Steer, R.A. (1988). *Beck Hopelessness Scale.* Manual. San Antonio, TX. The Psychological Corporation.
- Beck, A.T., Steer, R.A., & Brown, G.K. (1996). *Beck Depression Inventory—Second Edition (BDI-II)*. Manual. San Antonio, TX: The Psychological Corporation.
- Beck, A.T., Ward, C.H., Mendelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry*, *5*, 462-467.
- Beck, A.T., Weissman, A., Lester, D., & Trexler, L. (1974). The measurement of pessimism: The Hopelessness Scale. *Journal of Consulting and Clinical Psychology, 42,* 861-865.
- Berk, R.A. (1995). Use of primary caretakers as proxies to measure the health care needs of patients with AIDS. *Public Health Nursing*, *12(2)*,109-116.
- Brown, M.A., & Powell-Cope, G. (1993). Themes of loss and dying in caring for a family member with AIDS. Research in Nursing and Health, 16, 179-191.
- Cantor, M.H. (1983). Strain among caregivers: A study of experience in the United States. *The Gerontologist*, 23, 597-604.
- Centers for Disease Control and Prevention (1992). 1993 revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults. *Morbidity and Mortality Weekly Report, 41(RR-17),* 1-19.
- Centers for Disease Control and Prevention (1994). 1994 revised classification system for human immunodeficiency virus infection in children less than 13 years of age. *Morbidity and Mortality Weekly Report, 43(RR-12),* 1-10.
- Centers for Disease Control and Prevention (2003). Characteristics of persons living with AIDS and HIV, 2001. HIV/AIDS Surveillance Supplemental Report, 9(2); 1-27
- Centers for Disease Control and Prevention (2001). HIV/AIDS Surveillance Report, 13(2), 1-44.
- Chesney, M.A., & Folkman, S. (1994). Psychological impact of HIV disease and implications for intervention. *Psychiatric Clinics of North America*, *17*, 163-173.
- Chesney, M., Folkman, S., & Chambers, D. (1996). Coping effectiveness training for men living with HIV: Preliminary findings. *International Journal of STD and AIDS*, 7(S2), 75-82.

- Clipp, E.C., Adinolfi, A.J., Forrest, L., & Bennett, C.L. (1995). Informal caregivers of persons with AIDS. *Journal of Palliative Care*, 11(2), 10-18.
- Coates, T.J., Temoshok, L., & Mandel, J. (1984). Psychosocial research is essential to understanding and treating AIDS. *American Psychologist*, *39*, 1309-1314.
- Cohen, J. (1992). A power primer. Psychological Bulletin, 112(1), 155-159.
- Cohen, M.A.A. (1990). Biopsychosocial approach to the human immunodeficiency virus epidemic: A clinician's primer. *General Hospital Psychiatry*, *12*, 98-123.
- Cohen, S., & McKay, G. (1984). Social support, stress, and the buffering hypothesis: A theoretical analysis. In A. Baum, J.E. Singer, & S.E. Taylor (Eds.), *Handbook of Psychology and Health, Vol. 4: Social psychological aspects of health.* Hillsdale, NJ: Lawrence Erlbaum Associates.
- Cohen, S., & Wills, T.A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98,* DesJarlais, D.C., Friedman, S.R., & Hopkins, W. (1985). Risk reduction for the Acquired Immunodeficiency Syndrome among intravenous drug users. *Annals of Internal Medicine, 103,* 755-759.
- Dilley, J.W., Ochitill, H.N., Perl, M., & Volberding, P.A. (1985). Findings in psychiatric consultations with patients with Acquired Immune Deficiency Syndrome. *American Journal of Psychiatry*, *142*, 82-86.
- D'Zurilla, T.J. (1986). *Problem-solving therapy: A social competence approach to clinical intervention*. New York: Springer.
- D'Zurilla, T.J., & Goldfried, M. (1971). Problem solving and behavior modification. *Journal of Abnormal Psychology*, 78, 107-126.
- D'Zurilla, T.J., & Nezu, A.M. (1990). Development and preliminary evaluation of the Social Problem-Solving Inventory (SPSI). *Psychological Assessment: A Journal of Consulting and Clinical Psychology*, 2, 156-163.
- D'Zurilla, T.J., Nezu, A.M., & Maydeu-Olivares, A. (1996). Social Problem-Solving Inventory-Revised (SPSI-R). Test Manual.
- Feig, C. (2002, July 10). *Study explores high cost of HIV care in U.S.* Retrieved July 20, 2003, from http://www.cnn.com/2002/HEALTH/conditions/07/10/aids.costs
- Folkman, S., & Chesney, M. (1995). Coping with HIV infection. In M. Stein & A. Baum (Eds.), Perspectives in Behavioral Medicine: Chronic Diseases. Mahwah, NJ: Lawrence Erlbaum Associates.
- Folkman, S., Chesney, M.A., & Christopher-Richards, A. (1994). Stress and coping in caregiving partners of men with AIDS. *The Psychiatric Clinics of North America*, 17, 35-53.
- Folkman, S., Chesney, M.A., Cooke, M., Boccellari, A., & Collette, L. (1994). Caregiver burden in HIV-positive and HIV-negative partners of men with AIDS. *Journal of Consulting and Clinical Psychology*, *62(4)*, 746-756.
- Folkman, S., & Lazarus, R.S. (1985). If it changes it must be a process: A study of emotion and coping during three stages of a college examination. *Journal of Personality and Social Psychology*, 48, 150-170.

- Folkman, S., Lazarus, R.S., Gruen, R.J., & DeLongis, A. (1986). Appraisal, coping, health status, and psychological symptoms. *Journal of Personality and Social Psychology, 50(3),* 571-579.
- Fondacaro, M.R., & Moos, R.H. (1987). Social support and coping: A longitudinal analysis. *American Journal of Community Psychology*, *15*(5), 653-673.
- Gonyea, J.G. (1989). Alzheimer's disease support groups: An analysis of their structure, format, and perceived benefits. *Social Work in Health Care, 14(1),* 61-72.
- Gotlib, I.H., & Asarnow, R.F. (1979). Interpersonal and impersonal problem-solving skills in mildly and moderately depressed university students. *Journal of Consulting and Clinical Psychology*, 47, 86-95.
- Green, G. (1993). Social support and HIV [editorial review]. AIDS Care, 5, 87-103.
- Green, J., & Arno, P. (1991). The "Medicaidization" of AIDS: Trends in the financing of AIDS-related medical care. *Journal of the American Medical Association*, 264, 1261-1266.
- Haley, W.E., & Pardo, K.M. (1989). Relationship of severity of dementia to caregiving stressors. *Psychology and Aging, 4,* 389-392.
- Hays, R.B., Turner, H., & Coates, T.J. (1990). Help-seeking for AIDS-related concerns: A comparison of gay men with various HIV diagnoses. *American Journal of Community Psychology*, 18, 743-755.
- Herek, G.M. (1990). Illness, stigma, and AIDS. In J.P.T. Costa & G.R. VandenBos (Eds.), Psychological aspects of serious illness: Chronic conditions, fatal diseases, and clinical care. Washington, D.C.: American Psychological Association.
- Herek, G.M., & Capitano, J.P. (1993). Public reactions to AIDS in the United States: A second decade of stigma. *American Journal of Public Health*, 83, 574-577.
- Herek, G.M., & Glunt, E.K. (1988). An epidemic of stigma: Public reactions to AIDS. *American Psychologist*, *43*, 886-891.
- Hoffman, M.A. (1996). Counseling clients with HIV disease: Assessment, intervention, and prevention. New York: Guilford.
- Holtgrave, D.R., & Pinkerton, S.D. (1997). Updates of cost of illness and quality of life extimates for use in economic evaluations of HIV prevention programs. *Journal of Acquired Immune Deficiency Syndromes*, *16*, 54-62.
- Horowitz, A. (1979). Families who care: A study of natural support systems of the elderly. *Aging International, 6,* 19-20.
- Horowitz, A., & Shindleman, L. (1983). Reciprocity and affection: Past influences on current caregiving. *Journal of Gerontological Social Work, 5,* 5-20.
- Houts, P.S. (1998). Home care guide for HIV and AIDS: For family and friends giving care at home. Philadelphia: American College of Physicians.
- Irving, G., Bor, R., & Catalan, J. (1995). Psychological distress among gay men supporting a lover or partner with AIDS: A pilot study. *AIDS Care, 7(5),* 605-617.

- Jankowski, S., Videka-Sherman, L., & Laquidara-Dickinson, K. (1996). Social support networks of confidants to people with AIDS. *Social Work*, *41*(2), 206-213.
- Joint United Nations Programme on HIV/AIDS and World Health Organization (2002, December). *AIDS Epidemic Update 2002*. Retrieved February 13, 2003, from http://www.unaids.org/worldaidsday/2002/press/update/epiupdate\_en.pdf
- Kalichman, S. (1995). *Understanding AIDS: A guide for mental health professionals.*Washington, DC: American Psychological Association.
- Katz, S., Ford, A.B., & Moskowitz, R.W. (1963). Studies of illness in the aged: The Index of ADL, a standardized measure of biological and psychosocial function. *Journal of the American Medical Association*, *185*(12), 914-919.
- Kegeles, S.M., Coates, T.J., Christopher, T.A., & Lazarus, J.L. (1989). Perceptions of AIDS: The continuing saga of AIDS-related stigma. *AIDS*, *3(Suppl.)*, S253-S258.
- Kennedy, S., Kiecolt-Glaser, J.K., & Glaser, R. (1988). Immunological consequences of acute and chronic stressors: Mediating role of interpersonal relationships. *British Journal of Medical Psychology, 61, 77-85*.
- Lakey, B., & Heller, K. (1988). Social support from a friend, perceived support, and social problem solving. *American Journal of Community Psychology, 16(6),* 811-824.
- Land, H. (1992). Stress and coping in AIDS caregivers: Partners, friends, and family members. In H. Land (Ed.), *AIDS: A Complete Guide to Psychosocial Intervention*. Milwaukee, WI: Family Service America, Inc.
- Lawton, M.P., & Brody, E. (1969). Assessment of older people: Self-Maintaining and Instrumental Activities of Daily Living. *The Gerontologist*, *29*, 179-185.
- Lazarus, R.S., & Folkman, S. (1984). Stress, appraisal, and coping. New York: Springer.
- LeBlanc, A.J., Aneshensel, C.S., & Wight, R.G. (1995). Psychotherapy use and depression among AIDS caregivers. *Journal of Community Psychology*, 23, 127-142.
- Lego, S. (1994). AIDS-related anxiety and coping methods in a support group for caregivers. *Archives of Psychiatric Nursing*, *8*(3), 200-207.
- Lennon, M.C., Martin, J.L., & Dean, L. (1990). The influence of social support on AIDS-related grief reaction among gay men. *Social Science and Medicine*, *31*(4), 477-484.
- Leonard, A.S. (1985). Employment discrimination against persons with AIDS. *University of Dayton Law Review, 10,* 681-703.
- Lieberman, M.A. (1986). Social supports—the consequences of psychologizing: A commentary. *Journal of Consulting and Clinical Psychology, 54,* 461-465.
- Lippman, W.A., James, W.A., & Frierson, R.L. (1993). AIDS and the family: Implications for counselling. *AIDS Care*, *5*, 71-78.
- Mann, J., Tarantola, D.J.M., & Netter, T.W. (1992). *AIDS in the world.* Cambridge, MA: Harvard University Press.
- Martin, J. (1988). Psychological consequences of AIDS-related bereavement among gay men. *Journal of Consulting and Clinical Psychology, 56,* 856-862.

- Maydeu-Olivares, A., & D'Zurilla, T.J. (1996). A factor analytic study of the Social Problem-Solving Inventory: An integration of theory and data. *Cognitive Therapy and Research, 20,* 115-133.
- McCain, N.L., & Smith, J.C. (1994). Stress and coping in the context of psychoneuroimmunology: A holistic framework for nursing practice and research. *Archives of Psychiatric Nursing*, *8*(4), 221-227.
- McCann, K., & Wadsworth, E. (1992). The role of informal carers in supporting gay men who have HIV-related illness: What do they do and what are their needs? *AIDS Care, 4,* 25-34.
- McDonnell, J.R. (1993). Judgments of personal responsibility for HIV infection: An attributional analysis. Social Work, 38, 403-410.
- McHorney, C.A., Ware, J.E., & Raczek, A.E. (1993). The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. *Medical Care*, *31*, 247-263.
- Medical Outcomes Trust (1992). *How to score the SF-36 Short-Form Health Survey.* Boston: The Medical Outcomes Trust.
- Mello-Udine, L. (1992). Home care for AIDS patients. New Jersey Medicine, 89(1), 52-54.
- Miller, B., McFall, S., & Montgomery, A. (1991). The impact of elder health, caregiver involvement, and global stress on two dimensions of caregiver burden. *Journal of Gerontology*, 46(1), 9-19.
- Mondragon, D., Kirkman-Liff, B., & Schneller, E.S. (1991). Hostility to people with AIDS: Risk perception and demographic factors. *Society of Science and Medicine*, *32*, 1137-1142.
- Moskowitz, J.T., Folkman, S., Collette, L., & Vittinghoff, E. (1996). Coping and mood during AIDS-related caregiving and bereavement. *Annals of Behavioral Medicine*, 18(1), 49-57.
- Murphy, P., & Perry, K. (1988). Hidden grievers. Death Studies, 12, 451-462.
- Namir, S., Alumbaugh, M.J., Fawzy, F.I., & Wolcott, D.L. (1989). *Psychology and Health, 3,* 77-86.
- Neal, G.W., & Heppner, P.P. (1986). Problem solving self-appraisal, awareness and utilization of campus helping resources. *Journal of Counseling Psychology*, 33, 39-44.
- Neugarten, B. (1979). Time, age, and the life cycle. *American Journal of Psychiatry, 136,* 887-894.
- Nezu, A.M. (1987). A problem-solving formulation of depression: A literature review and proposal of a pluralistic model. *Clinical Psychology Review, 7,* 121-144.
- Nezu, A.M., & Carnevale, G.C. (1987). Interpersonal problem solving and coping reactions of Vietnam veterans with posttraumatic stress disorder. *Journal of Abnormal Psychology, 96,* 155-157.
- Nezu, A.M., & D'Zurilla, T.J. (1989). Social problem solving and negative affective states. In P.C. Kendall & D. Watson (Eds.), *Anxiety and depression: Distinctive and overlapping features* (pp. 285-315). New York: Academic Press.

- Nezu, A.M., Nezu, C.M., & Perri, M.G. (1989). *Problem-solving therapy for depression: Theory, research and clinical guidelines.* New York: Wiley.
- Nezu, A.M., Nezu, C.M., Rothenberg, J.L., & D'Zurilla, T.J. (1996). Problem-solving therapy. In J.S. Kantor (Ed.), *Clinical depression during addiction recovery: Process, diagnosis, and treatment* (pp. 187-219). New York: Marcel Dekker.
- Nezu, A.M., Nezu, C.M., Saraydarian, L., Kalmar, K., & Ronan, G.F. (1986). Social problem solving as a moderating variable between negative life stress and depressive symptoms. *Cognitive Therapy and Research*, *10(5)*, 489-498.
- Nezu, A.M., & Ronan, G.F. (1988). Social problem solving as a moderator of stress-related depressive symptoms: A prospective analysis. *Journal of Counseling Psychology*, 35(2), 134-138.
- Nezu, C.M., Nezu, A.M., Friedman, S.H., Houts, P., DelliCarpini, L.A., Nemeth, C.B., & Faddis, S. (1999). Cancer and psychological distress: The role of social problem solving. *Journal of Psychosocial Oncology, 16, 27-40.*
- Nezu, C.M., Nezu, A.M., & Houts, P.S. (1993). Multiple applications of problem solving principles in clinical practice. In K.T. Kuehlwein & H. Rosen (Eds.), *Cognitive Therapies in Action: Evolving Innovative Practice*. San Francisco: Jossey-Bass.
- Ostrow, D.G., Monjan, A., Joseph, J., Vanraden, M., Fox, R., Kingsley, L., Dudley, J., & Phair, J. (1989). HIV-related symptoms and psychological functioning in a cohort of homosexual men. *American Journal of Psychiatry*, *146*, 737-742.
- Ozawa, M.N., Auslander, W.F., Slonim-Nevo, V. (1993). Problems in financing the care of AIDS patients. *Social Work, 38(4), 369-377*.
- Pakenham, K.I., Dadds, M.R., & Terry, D.J. (1995). Carers' burden and adjustment to HIV. *AIDS Care, 7(2),* 189-203.
- Parsons, R.J., & Cox, E.O. (1989). Family mediation in elder caregiving decisions: An empowerment intervention. *Social Work, 34(2),* 122-126.
- Pearlin, L.I., Semple, S., & Turner, H. (1988). Stress of AIDS caregiving: A preliminary overview of the issues. *Death Studies*, *12*, 501-517.
- Pearson-Scott, J., Roberto, K.A., & Hutton, J.T. (1986). Families of Alzheimer's victims: Family support to the caregivers. *Journal of the American Geriatrics Society*, *34*(5), 348-354.
- Peterson, R.A. (1991). Psychosocial determinants of disorder: Social support, coping, and social skills interactions. In P. Martin (Ed.), *Handbook of behavior therapy and psychological science: An integrative approach.* New York: Pergamon.
- Platt, J.J., & Spivack, G. (1975). *Manual for the Means-End Problem-Solving Procedure* (MEPS): A measure of interpersonal cognitive problem-solving skills. Philadelphia: Hahnemann Community Mental Health/Mental Retardation Center.
- Poulshock, S.W., & Deimling, G.T. (1984). Families caring for elders in residence: Issues in the measurement of burden. *Journal of Gerontology*, *39*, 230-239.
- Powell, J. (1996). AIDS and HIV-related diseases: An educational guide for professionals and the public. New York: Plenum.

- Powell-Cope, G.M., & Brown, M.A. (1992). Going public as an AIDS family caregiver. *Social Science and Medicine*, *34*(5), 571-580.
- Pratt, C., Schmall, V., Wright, S., & Cleland, M. (1985). Burden and coping strategies of caregivers to Alzheimer's patients. *Family Relations*, *34*, 27-33.
- Raveis, V.H., & Siegel, K. (1991, February). The impact of care giving on informal or familial care givers. *AIDS Patient Care*, 39-43.
- Sarason, I.G., Johnson, J.H., & Siegel, J.M. (1978). Assessing the impact of life changes: Development of the Life Experiences Survey. *Journal of Consulting and Clinical Psychology*, *46*(*5*), 932-946.
- Sarason, I.G., Levine, H.M., Basham, R.B., & Sarason, B.R. (1983). Assessing social support: The Social Support Questionnaire. *Journal of Personality and Social Psychology, 44(1),* 127-139.
- Sarason, I.G., Sarason, B.R., Shearin, E.N., & Pierce, G.R. (1987). A brief measure of social support: Practical and theoretical implications. *Journal of Social and Personal Relationships*, *4*, 497-510.
- Schulz, R., & Williamson, G.M. (1991). A 2-year longitudinal study of depression among Alzheimer's caregivers. *Psychology and Aging*, *6*(4), 569-578.
- Shapiro, S., Skinner, E.A., Kessler, L.G., Von Korff, M., German, P.S., Tischler, G.L., Leaf, P.J., Benham, L., Cottler, L., & Regier, D.A. (1984). Utilization of health and mental health services: Three epidemiologic catchment area sites. *Archives of General Psychiatry*, *41*, 971-978.
- Spanier, G.B. (1976, February). Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. *Journal of Marriage and the Family*, 15-28.
- Taylor, K.S. (1994, January 20). Fighting AIDS at home: Hospitals, physicians seek community AIDS strategies. *Hospitals and Health Networks*, 52-53.
- Trice, A.D. (1988). Posttraumatic stress syndrome like symptoms among AIDS caregivers. *Psychological Reports*, *63*, 656-658.
- Turner, H.A., Catania, J.A., & Gagnon, J. (1994). The prevalence of informal caregiving to persons with AIDS in the United States: Caregiver characteristics and their implications. *Social Science and Medicine*, *38*(11), 1543-1552.
- Wardlaw, L.A. (1994, June). Sustaining informal caregivers for persons with AIDS. *Families in Society: The Journal of Contemporary Human Services*, 373-384.
- Wight, R.G., LeBlanc, A.J., & Aneshensel, C.S. (1995). Support service use by persons with AIDS and their caregivers. *AIDS Care*, *7*(4), 509-520.
- Williamson, G.M., & Schulz, R. (1990). Relationship orientation, quality of prior relationship, and distress among caregivers of Alzheimer's patients. *Psychology and Aging, 5,* 502-509.
- Winstead, B.A., Derlega, V.J., Lewis, R.J., & Sanchez-Hucles, J. (1992). Friendship, social interaction, and coping with stress. *Communication Research*, 19(2), 193-221.

- Wortman, C.B., & Dunkel-Schetter, C. (1987). Conceptual and methodological issues in the study of social support. In A. Baum & J.E. Singer (Eds.), *Handbook of psychology and health, volume 5.* Hillsdale, NJ: Lawrence Erlbaum Associates.
- Wright, L.K., Clipp, E.S., & George, L.K. (1993). Health consequences of caregiver stress. *Medicine, Exercise, Nutrition, and Health, 2,* 181-195.
- Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist*, *20*(6), 649-655.
- Zemore, R., & Dell, L.W. (1983). Interpersonal problem-solving skills and depression-proneness. *Personality and Social Psychology Bulletin, 9,* 231-235.

Table 1. Descriptive Summary of Caregiver Demographic Information

Variab (n = 44		Mean	Standard Deviation	Range
1. Age	9	39.98	9.05	24 – 60
	ngth of Relationship (in months)	63.55	56.81	12 – 251
	usehold Income per Year (in dollars)	61, 651	21,769	21,648 – 110,000
4	Pale in initial	Per	centage	
4.	Ethnicity African-American	18.2	00/	
	Asian-American	6.8		
	Caucasian	61.4		
_	Hispanic	13.6	9%	
5.	Education		-0.4	
	High School Diploma	4.5		
	Partial College/Vocational	18.2		
	College Degree	40.9		
	Partial Graduate/Professional	15.9		
	Graduate/Professional Degree	20.5	5%	
6.	Employment			
	Yes	88.6		
	No	11.4	<b>%</b>	
7.	Health Insurance			
	Yes	93.2		
	No	6.89	<b>%</b>	
8.	HIV Status			
	HIV-	63.6		
	HIV+	25.0		
	AIDS	11.4	<b>!</b> %	
9.	Care Recipient HIV Status			
	HIV+	65.9		
	AIDS	34.1	%	

# Table 1 (continued)

# Variable (n = 44)

(11 – -	<del></del> )	Doroontogo
10.	External Support	Percentage
	Yes	43.2%
	No	56.8%
11.	Hours per Week Providing Care	
	0-5	52.5%
	6-10	42.3%
	11-20	2.2%
	21-30	2.0%
	31-40	1.0%

Table 2. Descriptive Statistics of Independent and Dependent Variables Under Investigation

Variable (n = 44)		Mean	Standard Deviation	Range
Care Reci	pient Variables			
1.	Activities of Daily Living Scales	13.64	.685	12-14
Caregiver/	Care Recipient Dyad Variables			
2.	Dyadic Adjustment Scale*	4.32	1.93	1.00-9.22
	Dyadic Adjustment Scale**	107.66	18.63	45-129
Caregiver	Variables			
	Beck Depression Inventory, 2 <sup>nd</sup> Edition*	2.74	1.17	1-5
	Beck Depression Inventory, 2 <sup>nd</sup> Edition**	8.84	7.20	1-25
4.	Beck Anxiety Inventory*	2.40	1.23	.00-5.20
	Beck Anxiety Inventory**	7.25	6.66	0-27
5.	Beck Hopelessness Scale*	1.50	.93	.00-3.32
	Beck Hopelessness Scale**	3.09	3.25	0-11
6.	Caregiver Burden Interview*	6.82	.59	.00-1.71
	Caregiver Burden Interview**	47.57	14.95	26-79
7.	Life Experiences Survey	6.55	4.19	0-16
8.	Short Form-36 Physical Functioning Scale*	.61	.59	.00-1.71
	Short Form-36 Physical Functioning Scale**	91.48	12.65	50-100
9.	Social Support Questionnaire – Availability	23.64	7.76	7-44
10.	Social Support Questionnaire – Satisfaction	27.00	6.19	14-36
11.	Social Problem-Solving Inventory-Revised	13.86	2.63	8.95-18.20

Table 2 (continued)

Variable (n = 44)	Mean	Standard Deviation	Range
Caregiver Distress Variables			
12. Beck Depression Inventory, 2 <sup>nd</sup> Edition*	2.49	1.01	1.00-4.36
Beck Depression Inventory, 2 <sup>nd</sup> Edition**	7.18	5.27	1-19
13. Beck Anxiety Inventory*	1.92	1.31	.00-5.10
Beck Anxiety Inventory**	5.39	5.95	0-26
14. Beck Hopelessness Scale*	1.23	.83	.00-3.00
Beck Hopelessness Scale**	2.23	2.38	0-9
<ol> <li>Caregiver Burden Interview*</li> </ol>	6.79	1.07	4.58-8.66
Caregiver Burden Interview**	47.25	14.71	21-75

<sup>\*</sup> Transformed variable values\*\* Untransformed variable values

Table 3. Intercorrelations Among Care Recipient Variables, Caregiver/Care Recipient Dyad Variables, Caregiver Variables, and Caregiver Distress

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Care Recipient  1. ADLS  Caregiver/	-	29	46 <sup>b</sup>	42 <sup>b</sup>	33 <sup>a</sup>	48 <sup>b</sup>	46 <sup>b</sup>	17	.01	07	.12	39 <sup>b</sup>	42 <sup>b</sup>	27	41 <sup>b</sup>
Caregiver/ Care Recipient Dyad 2. DAS	-	-	.66 <sup>c</sup>	.54 <sup>c</sup>	.50 <sup>b</sup>	.82 <sup>c</sup>	.38 <sup>a</sup>	.27	61 <sup>c</sup>	49 <sup>b</sup>	47 <sup>b</sup>	.65 <sup>c</sup>	.60°	.48 <sup>b</sup>	.74 <sup>c</sup>
Caregiver 3. T1 BDI-II	-	-	-	.85 <sup>c</sup>	.72 <sup>c</sup>	.62 <sup>c</sup>	.53 <sup>c</sup> .47 <sup>b</sup>	.45 <sup>b</sup>	36ª	45 <sup>b</sup>	71 <sup>c</sup>	.79 <sup>c</sup>	.72°	.62 <sup>c</sup>	.61°
4. T1 BAI 5. T1 BHS	-	-	-	-	.63 <sup>c</sup> -	.55° .56°	.47 <sup>b</sup> .48 <sup>b</sup>	.40 <sup>b</sup> .51 <sup>c</sup> .36 <sup>a</sup>	28 29 42 <sup>b</sup>	39 <sup>b</sup> 52 <sup>c</sup> 39 <sup>b</sup>	59 <sup>c</sup> 72 <sup>c</sup> 50 <sup>b</sup>	.74 <sup>c</sup> .73 <sup>c</sup> .65 <sup>c</sup>	.83 <sup>c</sup> .65 <sup>c</sup> .52 <sup>a</sup>	.52 <sup>c</sup> .88 <sup>c</sup> .52 <sup>a</sup>	.58° .59° .95°
6. T1 CBI 7. LES 8. SF-36 PF	-	-	-	-	-	-	.40 - -	.09	42 .12 14	.01 30 <sup>a</sup>	40 <sup>b</sup> 48 <sup>b</sup>	.65 .46 <sup>b</sup> .33 <sup>a</sup>	.42 <sup>b</sup> .36 <sup>a</sup>	.32 <sup>a</sup> .37 <sup>a</sup>	.95 .41 <sup>b</sup> .39 <sup>b</sup>
9. SSQA 10. SSQS	-	-	-	-	-	-	-	-	- -	.69 <sup>c</sup>	.26 .46 <sup>b</sup>	42 60°	35 <sup>a</sup> 34 <sup>a</sup>	33 <sup>a</sup> 56 <sup>c</sup>	44 <sup>b</sup> 46 <sup>b</sup>
11. SPSI-R Caregiver Distress	-	-	-	-	-	-	-	-	-	-	-	73 <sup>c</sup>	50 <sup>c</sup>	59 <sup>c</sup>	54 <sup>c</sup>
12. BDI-II 13. BAI	-	-	-	-	-	-	-	-	-	-	-	-	.74 <sup>c</sup> -	.70° .56°	.69 <sup>c</sup>
14. BHS 15. CBI	-	-	-	-	-	-	-	-	-	-	-	-	-	-	.54 <sup>c</sup> -

a = p < .05

b = p < .01 c = p < .001

Table 4. Intercorrelations Among Care Recipient Variables, Caregiver/Care Recipient Dyad Variables, Caregiver Variables, and Caregiver Distress (Includes Untransformed Variable Values and Social Problem-Solving Components)

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
Care Recipient 1. ADLS Caregiver/ Recipient	-	.28	45 <sup>b</sup>	.44 <sup>b</sup>	34ª	48 <sup>b</sup>	46 <sup>b</sup>	.17	.01	07	.06	27	.05	.02	12	40 <sup>b</sup>	40 <sup>b</sup>	28	41 <sup>b</sup>
Dyad																			
2. DAS	-	-	66 <sup>c</sup>	67 <sup>c</sup>	55 <sup>c</sup>	84 <sup>c</sup>	42 <sup>b</sup>	.21	.58°	.42 <sup>b</sup>	.23	53 <sup>c</sup>	.09	45 <sup>b</sup>	58 <sup>c</sup>	66 <sup>c</sup>	71 <sup>c</sup>	60 <sup>c</sup>	77 <sup>c</sup>
Caregiver																			
3. BDI-II	-	-	-	88 <sup>c</sup>	.77 <sup>c</sup>	.63 <sup>c</sup>	.59°	31 <sup>a</sup>	33 <sup>a</sup>	43 <sup>b</sup>	49 <sup>b</sup>	.83°	47 <sup>b</sup>	.59 <sup>c</sup>	.70°	.82°	.74 <sup>c</sup>	.68°	.62°
4. BAI	-	-	-	-	.68°	.60°	.54°	31ª	29	34	31 <sup>a</sup>	.73 <sup>c</sup>	36 <sup>a</sup>	.53°	.53°	.74 <sup>c</sup>	.90°	.64 <sup>c</sup>	.57°
5. BHS	-	-	-	-	-	.63°	.42 <sup>c</sup>	43 <sup>b</sup>	35ª	57 <sup>a</sup>	56 <sup>c</sup>	.84 <sup>c</sup>	53 <sup>c</sup>	.66°	.66°	.83 <sup>c</sup>	.71°	.92°	.65°
6. CBI	-	-	-	-	-	-	.49 <sup>b</sup>	32 <sup>a</sup>	43 <sup>b</sup>	38ª	25	.57 <sup>c</sup>	16	.54 <sup>c</sup>	.55°	.68°	.62°	.64 <sup>c</sup>	.95°
7. LES	-	-	-	-	-	-	-	04	.12	.01	31 <sup>a</sup>	.46 <sup>b</sup>	33ª	.32ª	.25	.51°	.50°	.38ª	.42 <sup>b</sup>
8. SF-36 PF	-	-	-	-	-	-	-	-	.10	.29	.19	37 <sup>a</sup>	.30ª	32 <sup>a</sup>	14	28	26	37 <sup>a</sup>	36ª
9. SSQA	-	-	-	-	-	-	-	-	-	.69 <sup>c</sup>	.16	31 <sup>a</sup>	12	27	44 <sup>b</sup>	42 <sup>b</sup>	35 <sup>a</sup>	41 <sup>b</sup>	46 <sup>b</sup>
10. SSQS	-	-	-	-	-	-	-	-	-	-	.36	49 <sup>b</sup>	.19	42 <sup>b</sup>	46 <sup>b</sup>	59 <sup>c</sup>	34ª	61 <sup>c</sup>	47 <sup>b</sup>
11. PPO*	-	-	-	-	-	-	-	-	-	-	-	71 <sup>c</sup>	.77 <sup>c</sup>	49 <sup>b</sup>	61 <sup>c</sup>	51 <sup>c</sup>	22	44 <sup>b</sup>	30 <sup>a</sup>
12. NPO*	-	-	-	-	-	-	-	-	-	-	-	-	64 <sup>c</sup>	.73 <sup>c</sup>	.84 <sup>c</sup>	.83°	.67°	.72°	.60°
13. RPS*	-	-	-	-	-	-	-	-	-	-	-	-	-	56 <sup>c</sup>	40 <sup>b</sup>	44 <sup>b</sup>	24	37 <sup>a</sup>	19
14. ICS*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	.61 <sup>c</sup>	.69°	.58°	.67°	.56°
15. AS*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	.73°	.50 <sup>b</sup>	.53°	.61°
Caregiver																			
Distress																			
16. BDI-II	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	.79°	.81°	.72°
17. BAI	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	.71 <sup>c</sup>	.57°
18. BHS	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	.68°
19. CBI	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

a = p < .05

b = p < .01

c = p < .001

<sup>\*</sup> SPSI-R subscales: PPO – Positive Problem Orientation; NPO – Negative Problem Orientation; RPS – Rational Problem Solving; ICS – Impulsivity/Carelessness Style; AS – Avoidance Style

Table 5. Care Recipient Variables, Caregiver/Care Recipient Dyad Variables, and Caregiver Variables as Predictors of Caregiver Depressive Symptoms; Dependent Variable – Beck Depression Inventory, 2<sup>nd</sup> Edition

Step	Variables	В	sr <sup>2</sup>	R <sup>2</sup> <sub>change</sub>	F <sub>change</sub>	R <sup>2</sup> cumulative	Adjusted R <sup>2</sup>	F
1.	BDI-II	.68 <sup>b</sup>	.62	.62	68.597 <sup>b</sup>	.62	.61	68.597 <sup>b</sup>
2.	LES SF-36 PF ADLS	.01 03 04	.00 .00 .00	.00	.100	.62	.58	16.122 <sup>b</sup>
3.	DAS SSQA SSQS	.08 .01 07 <sup>a</sup>	.01 .00 .08	.12	5.639 <sup>a</sup>	.74	.69	14.917 <sup>b</sup>
4.	SPSI-R	14 <sup>a</sup>	.05	.05	9.517 <sup>a</sup>	.80	.75	17.330 <sup>b</sup>

a = p < .01

b = p < .001

Table 6. Care Recipient Variables, Caregiver/Care Recipient Dyad Variables, and Caregiver Variables as Predictors of Caregiver Anxiety Symptoms; Dependent Variable – Beck Anxiety Inventory

Step	Variables	В	sr <sup>2</sup>	R <sup>2</sup> <sub>change</sub>	F <sub>change</sub>	R <sup>2</sup> cumulative	Adjusted R <sup>2</sup>	F
1.	BAI	.88 <sup>a</sup>	.69	.69	92.968 <sup>a</sup>	.69	.68	92.968 <sup>a</sup>
2.	LES SF-36 PF ADLS	.00 .09 15	.00 .00 .00	.01	.291	.70	.66	22.283 <sup>a</sup>
3.	DAS SSQA SSQS	.12 02 .03	.01 .01 .01	.04	1.856	.74	.68	14.366 <sup>a</sup>
4.	SPSI-R	.00	.00	.00	.005	.74	.68	12.224 <sup>a</sup>

a = p < .001

Table 7. Care Recipient Variables, Caregiver/Care Recipient Dyad Variables, and Caregiver Variables as Predictors of Caregiver Hopelessness Symptoms; Dependent Variable – Beck Hopelessness Scale

Step	Variables	В	sr <sup>2</sup>	R <sup>2</sup> <sub>change</sub>	F <sub>change</sub>	R <sup>2</sup> cumulative	Adjusted R <sup>2</sup>	F
1.	BHS	.81 <sup>a</sup>	.78	.78	147.639 <sup>a</sup>	.78	.77	147.639 <sup>a</sup>
2.	LES SF-36 PF ADLS	01 18 .01	.00 .01 .00	.01	.794	.79	.77	36.962 <sup>a</sup>
3.	DAS SSQA SSQS	.02 .01 02	.00 .00 .01	.02	.980	.81	.77	21.509 <sup>a</sup>
4.	SPSI-R	.04	.00	.00	.912	.81	.77	18.888 <sup>a</sup>

a = p < .001

Table 8. Care Recipient Variables, Caregiver/Care Recipient Dyad Variables, and Caregiver Variables as Predictors of Caregiver Burden Symptoms; Dependent Variable – Caregiver Burden Interview

Step	Variables	В	sr <sup>2</sup>	R <sup>2</sup> <sub>change</sub>	F <sub>change</sub>	R <sup>2</sup> cumulative	Adjusted R <sup>2</sup>	F
1.	СВІ	.95 <sup>a</sup>	.89	.89	351.254 <sup>a</sup>	.89	.89	351.254 <sup>a</sup>
2.	LES SF-36 PF ADLS	01 .09 .06	.00 .00 .00	.01	.782	.90	.89	87.030 <sup>a</sup>
3.	DAS SSQA SSQS	11 .00 02	.01 .00 .01	.02	2.346	.92	.90	55.887 <sup>a</sup>
4.	SPSI-R	03	.00	.00	1.075	.92	.90	49.138 <sup>a</sup>

a = p < .001

#### **APPENDIX 2: CONSENT FORM AND MEASURES**

Identifying #:	
Subject Initials:	
Page 1 of 3	

## MCP Hahnemann University Consent to Take Part In a Research Study

Participant's Name:	
---------------------	--

- 2. **Title of Research**: Social Problem-Solving Ability as a Predictor of Distress in Caregiving Partners to Men with HIV and AIDS
- 3. **Purpose of Research**: You are being asked to take part in a research study. The purpose of this study is to find out how the way you cope affects your experiences being in a relationship with a man with HIV or AIDS.
- 4. Procedures and Duration: You understand that you will be asked to do the following:
  - (a) To provide information about yourself, such as your age, race, and health. Your name will not be on any materials retained in this study and this personal information will be known only to the research team.
  - (b) To fill out some questionnaires asking you about your life experiences, your relationship with your partner, your social support, how you typically solve problems in your life, and some feelings that you may be having about providing care to your partner. You will be asked to fill out some of these questionnaires again three (3) months after you first fill them out.
- 5. **Risks and Discomforts**: You understand that the risks and/or discomforts of being in this study might include the following:
  - (a) You may worry about who will have personal information about you. Since information about you is private, when the researchers discuss the results of this study, all information will be combined with everyone else's information. Only the professionals involved with this study will see any of your answers.
  - (b) Filling out the questionnaires may increase negative feelings by causing me to think about my current problems. If you do have an increase in negative thoughts or feelings, you can discuss them with any professional involved with this study. They will try to understand these feelings and be of help to you.

(See next page)

- 6. **Benefits**: You understand that the following benefits may occur as a result of your participation in this study:
  - (a) Your participation may help future caregivers by helping researchers know more about the importance of problem-solving styles in coping with providing care to men with HIV and AIDS.
  - (b) You understand that you may not directly experience any benefits from participating in this study.
- 7. Alternative Procedures/Treatments: Not applicable in this study.
- 8. **Reasons for Removal from Study**: You may be required to stop the study before the end for any of the following reasons:
  - (a) change in your medical condition
  - (b) if all or part of the study is discontinued for any reason by the sponsor
  - (c) if others in this study experience harmful reactions
- 9. **Voluntary Participation**: You understand that you can refuse to participate in this study or change your mind about continuing to do so at any time. Your right to receive health care will not be affected if you do so.
- 10. **Stipend/Reimbursement**: After you have completed and returned the two sets of questionnaires that is, the first set of questionnaires and the second set that you will complete three months later), the researcher will enter your name, along with the names of the other participants, into a drawing. One hundred dollars (\$100.00) will be distributed to the participant whose name is drawn by the researcher.
- 11. **In Case of Questions or Injury**: You understand that if you have any questions or believe that you have been injured in any way by participating in this research project, you should contact William Good at telephone number 212-946-1369 or Dr. Christine Maguth Nezu at 215-762-4511. If you have an adverse reaction or injury as a result of this study, you should also contact the MCP Hahnemann University Research Administration Office at 215-762-3453.
- 12. **Consent to Use Research Results and Confidentiality of Records**: As a participant in this research project, you have given your permission for MCP Hahnemann University to keep, preserve, publish, use, or dispose of the results of the research study. In any publication, your identity will be kept confidential, but there is the possibility that records that identify you will be inspected by authorized individuals and agencies required by law.
- 13. I hereby certify that I do not fit within any of the following categories:
  - (a) volunteer or formally employed as an HIV/AIDS care provider
  - (b) unable to understand the English language

If I fit into (a) and/or (b) as described above, I will not sign this consent and I will inform the person who gave me this consent that I will not participate in this study.

(See next page)

• I HAVE BEEN INFORMED OF THE REASONS FOR THIS STUDY

Psychology and Medicine

- I HAVE HAD THE STUDY EXPLAINED TO ME
- I HAVE HAD ALL OF MY QUESTIONS REGARDING THE STUDY ANSWERED
- I HAVE CAREFULLY READ THIS CONSENT FORM AND HAVE RECEIVED A SIGNED COPY
- I GIVE MY CONSENT VOLUNTARILY

Participant's Name (PLEASE PRINT)		Date		
Participant's Signature				
Investigator or Individua	al Obtaining this Consent**	Date		
** List of Individuals Au	thorized to Obtain Consent			
<u>Name</u>	<u>Title</u>	Day Phone #	24 Hour Phone #	
William Good, M.A.	Doctoral Candidate, Dept. of Clinical & Health Psycho	(212) 946-1369 ology	(212) 946-1369	
Christine M. Nezu, Ph.D.	Professor of Clinical & Health	(215) 762-7670	(215) 762-7670	

# **DEMOGRAPHICS FORM**

Γoday's Date:	
1) Name:	
2) Telephone Number:	
3) Your Age:	
4) Your Partner's Age:	
5) Your Total Number of Years of Education Completed:	
8 <sup>th</sup> grade or less	
some high school	
high school diploma	
partial college or vocational training	
college degree	
some graduate/professional training	
graduate/professional degree	
6) What is your ethnic background?	
7) Are you currently employed? Yes No	
If yes, what is your current occupation?	
8) Is your partner currently employed? Yes No	
9) Current total family income:	
10) How long have you been in your current relationship with your partner (in months)?	
11) Are you:  HIV negative?  HIV positive – How long have you been HIV positive?  diagnosed with AIDS – How long have you had AIDS?	
12) Is your partner: HIV positive – How long has your partner been HIV positive? diagnosed with AIDS – How long has your partner had AIDS?	_

(13) If you are HIV positive or have AID medications?	S, are yo	u currently tak	king any l	HIV or AIDS-related
	Yes	No		
If yes, please list these medications belo	ow:			
(14) Is your partner currently taking any	HIV or A	DS -related m	nedicatio	ns?
If yes, please list these medications belo	ow:			
(15) Do you currently have health insura	ance?		Yes	No
(16) Does your partner currently have h	nealth insu	ırance?	Yes	No
(17) On the average, how many hours p	oer week	do you provid	e care to	your partner?
less than 5 hour 6-10 hours per v 11-20 hours per 21-30 hours per 31-40 hours per greater than 40 h	veek week week week			
(18) Are you currently receiving profess responsibilities (for example, a support				
	Yes	No		
If yes, please indicate what type of supp	port you a	re receiving b	elow:	
(20) How often does providing care to y to you if you would need it? (Circle one			hink abo	ut who will provide care
1 2 never	3 someti	mes	4	5 most of the time

**Impact** 

### THE LIFE EXPERIENCES SURVEY

Listed below are events that sometimes can bring about change in one's life. Please read this list and **for those events that you have actually experienced sometime during the** *past year*: (a) note how long ago this event occurred (*how many months ago did it happen?*), and (b) using the scale described below, indicate the extent to which you viewed the event as having either a *positive* (+1, +2, or +3), *negative* (-1, -2, or -3), or *neutral* (0) impact on your life. **Remember:** only indicate the event and its impact on you if it occurred during the *past year*. Thank you.

# **Impact Ratings**

+3 = very positive

+2 = somewhat positive

+1 = a little positive

0 = neutral (no impact at all)

How Long Ago Did It Occur

-1 = a little negative

-2 = somewhat negative

-3 = very negative

	(Number of Months)?	Rating
(1) Marriage		
(2) Detention in jail or comparable institution		
(3) Death of spouse		
(4) Death of a close family member		
a. mother		
b. father c. brother		
d. sister		
e. grandmother		
f. grandfather		
g. other (relationship to you:		
(5) Foreclosure on mortgage or loan		
(6) Death of a close friend		
(7) Outstanding personal achievement		
(8) Minor law violations (e.g., traffic tickets)		
(9) Male: Wife/girlfriend pregnancy		
(10) Female: Pregnancy		

# How Long Ago Did It Occur Impact (Number of Months)? Rating

(11) Changed work situation (different work responsibility, major change in work conditions, working hours, etc.)		
(12) New job		
(13) Serious illness or injury of close family member:     a. father     b. mother     c. sister     d. brother     e. grandmother     f. grandfather     g. other (relationship to you:)		
(14) Trouble with employer (in danger of losing job, being suspended, demoted, etc.)		
(15) Trouble with in-laws		
(16) Major change in financial status (a lot better off or a lot worse off)		
(17) Major change in closeness of family members (increased or decreased closeness)		
(18) Gaining a new family member (through birth, adoption, family member moving in, etc.)		
(19) Change of residence		
(20) Marital separation from mate (due to conflict)		
(21) Major change in church activities (increased or decreased attendance)		
(22) Marital reconciliation with mate		
(23) Major change in number of arguments with spouse (a lot more or a lot less arguments)		
(24) <i>Married Male</i> : Change in wife's work outside the home (beginning work, ceasing work, changing to a new job, etc.)		
(25) <i>Married Female</i> : Change in husband's work (loss of job, beginning new job, retirement, etc.)		

**Impact** 

**How Long Ago Did It Occur** 

# (Number of Months)? Rating (26) Major change in usual type and/or amount of recreation (27) Borrowing more than \$10,000 (buying a home, business, etc.) (28) Borrowing less than \$10,000 (buying car, TV, getting school loan, etc.) (29) Being fired from a job (30) Male: Wife/girlfriend having an abortion (31) Female: Having an abortion (32) Major personal illness or injury (33) Major change in social activities e.g., parties, movies, visiting (increased or decreased participation) (34) Major change of living conditions of family (building new home, remodeling, deterioration of home, neighborhood, etc.) (35) Divorce (36) Serious illness or injury of close friend (37) Retirement from work (38) Son or daughter leaving home (due to marriage, college, etc.) (39) Ending of formal schooling (40) Separation from spouse (due to work, travel, etc.) (41) Engagement (42) Breaking up with boyfriend/girlfriend (43) Leaving home for the first time (44) Reconciliation with boyfriend/girlfriend

	How Long Ago Did It Occur (Number of Months)?	Impact Rating
Other experiences which have had an impact or not mentioned above. Please list and rate.	n your life	
(45)		
(46)		

(47) \_\_\_\_\_

# SF - 36 HEALTH STATUS SURVEY

**Instructions:** This survey asks for your views about your health. This information will help keep track of how your feel and how well you are able to do your usual activities. Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

- 1. In general, how would you say your health is: (circle one)
  - 1 Excellent
  - 2 Very Good
  - 3 Good
  - 4 Fair
  - 5 Poor
- 2. <u>Compared to one year ago.</u> how would you rate your health in general <u>now</u>? (circle one)
  - 1 Much better than one year ago
  - 2 Somewhat better now than one year ago
  - 3 About the same as one year ago
  - 4 Somewhat worse than one year ago
  - 5 Much worse than one year ago
- 3. The following items are about activities you might do during a typical day. Does <u>your</u> <u>health now limit you in these activities</u>? If so, how much?

	<u>ACTIVITIES</u>	Yes Limited A Lot		Yes Limited A Little	No, Not Limited At All
a.	Vigorous activities such as running, lifting heavy objects, participating in strenuous sports	y 1		2	3
b.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing	golf	1	2	3
c.	Lifting or carrying groceries	1		2	3
d.	Climbing several flights of stairs	1		2	3
e.	Climbing one flight of stairs	1		2	3
f.	Bending, kneeling, or stopping	1		2	3
g.	Walking more than one mile	1		2	3
h.	Walking several blocks	1		2	3
i.	Walking one block	1		2	3
j.	Bathing or dressing yourself	1		2	3

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

		circle one number on each line		
		<u>Yes</u>	<u>No</u>	
a.	Cut down the amount of time you spent on work other activities	or 1	2.	
b.	Accomplished less than you would like	1	2	
c.	Were limited in the kind of work or activities	1	2	
d.	Had difficulty performing the work or other activiti (for example, it took extra effort)	ies 1	2	

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number on each line)

Yes No

Cut down the amount of time you spent on work or other activities 1 2

Accomplish less than you would like 1 2

2

1

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors or groups? (circle one)

Not at all
 Slightly
 Moderately
 Quite a bit
 Extremely

Didn't do work or other activities as carefully as usual

- 7. How much bodily pain have you had during the past 4 weeks? (circle one)
  - 1 None

a.

b.

c.

- 2 Very mild
- 3 Mild
- 4 Moderate
- 5 Severe
- 6 Very severe

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? (Circle one)

- 1 Not at all
- 2 A little bit
- 3 Moderately
- 4 Quite a bit
- 5 Extremely

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks:

	All of the time	Most of the time	A Good bit of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of pep?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt down- hearted or blue?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

- 10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)? (Circle one)
  - 1 All of the time
  - 2 Most of the time
  - 3 Some of the time
  - 4 A little of the time
  - 5 None of the time
- 11. How TRUE or FALSE is each of the following statements for you?

	Definitely True	Mostly True	Not Sure	Mostly True	Definitely True
I seem to get sick a     little easier than other     people.	1	2	3	4	5
b. I am as healthy as anybody I know.	1	2	3	4	5
c. I expect my health to get worse.	1	2	3	4	5
d. My health is excellent.	1	2	3	4	5

12. The statements below concern your personal health beliefs about your present health condition. Please circle the number beside each statement that best describes how you feel about the statement. There are no right or wrong answer. Please answer even if you are not currently experiencing a health condition.

	Strongly Disagree Disagree		Do Not Agree or Disagree	Agree	Strongly Agree	
a. My condition is controlling my life.	1	2	3	4	5	
<ul> <li>b. I would feel helpless   I couldn't rely on other   people for help with r   condition.  </li> </ul>	er	2	3	4	5	
c. No matter what I do, on how hard I try, I just on seem to get relief from my condition.	can't	2	3	4	5	

	Strongly Disagree	Disagree	Do Not Agree or Disagree	Agree	Strongly Agree
d. I am coping effectively with my condition.	y 1	2	3	4	5
e. It seems as though far and other factors beyo my control affect my condition.		2	3	4	5

# **ACTIVITIES OF DAILY LIVING**

**Directions:** For each activity listed below, please circle the number next to the statement that best describes **your PARTNER'S level of functioning over the past month.** 

## 1. **FEEDING** Eats without assistance 0 Requires assistance or special preparation (cutting food), is untidy, or requires help cleaning up N/A Does not apply; reason: 2. **DRESSING** Dresses, undresses and selects clothes without assistance 1 Requires assistance for dressing, undressing, selecting clothes or buttoning 0 N/A Does not apply; reason: 3. **GROOMING** Always neatly dressed and well groomed without assistance 0 Requires assistance with for shaving, combing or general grooming N/A Does not apply; reason 4. **BATHING** Bathes self (tub, shower, sponge bath) without assistance 1 0 Requires assistance to bathe body, wash hair, regulate water, undress or dry self N/A Does not apply; reason 5. **TOILETING** 1 Cares for self at toilet completely independently; no incontinence 0 Needs help cleaning self or is incontinent N/A Does not apply; reason **AMBULATION** 6. Ambulation without physical assistance 0 Requires physical assistance (cane, physical support, walker, wheelchair) to ambulate within or outside residence N/A Does not apply; reason 7. **TRAVELING** Travels independently (public transportation, motor vehicle, other vehicle or 1

Requires supervision to travel outside of residence

Does not apply; reason

0

N/A

# 8. FINANCES

- Manages financial matters independently (banking, bills, checks) or manages day-to-day purchases independently
- 0 Is incapable of handling money even for day-to-day purchases

N/A Does not apply; reason

\_\_\_\_\_

## 9. TELEPHONE

- 1 Operates or answers a telephone independently
- O Does not use a telephone independently

N/A Does not apply; reason

# 10. FOOD PREPARATION

- 1 Plans, prepares and serves simple meals independently
- Requires assistance to plan or serve meals (others must supply ingredients or cook meals ahead of time), or does not maintain an adequate diet

N/A Does not apply; reason

\_\_\_\_\_

#### 11. HOUSEKEEPING

- 1 Performs light daily housekeeping tasks (cleaning, making bed, dishwashing) independently
- O Requires assistance to perform **all** housekeeping tasks

N/A Does not apply; reason

## 12. LAUNDRY

- 1 Launders small items (e.g., socks) independently
- O All laundry must be done by others

N/A Does not apply; reason

# 13. SHOPPING

- 1 Takes care of all shopping needs independently
- Needs to be accompanied on any shopping trip, or shops only for small purchases

N/A Does not apply; reason

## 14. MEDICATIONS

- 1 Is responsible for taking medications in the correct doses at the correct time
- 0 Is not capable of dispensing own medications or requires reminders or preparation of medication in advance

N/A Does not apply; reason

# DYADIC ADJUSTMENT SCALE

**Instructions:** Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list. **Circle the star (\*) under one answer for each item.** 

	Always Agree	Almost Always Agree	Occasionally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree
1. Handling family finance	es *	*	*	*	*	*
2. Matters of recreation	*	*	*	*	*	*
3. Religious matters	*	*	*	*	*	*
4. Demonstrations of affection	*	*	*	*	*	*
5. Friends	*	*	*	*	*	*
6. Sex relations	*	*	*	*	*	*
7. Conventionality (correct/proper behavior	or) *	*	*	*	*	*
8. Philosophy of Life	*	*	*	*	*	*
9. Ways of dealing with por in-laws	arents *	*	*	*	*	*
10. Aims, goals and thing believed important	, , ,	*	*	*	*	*
11. Amount of time spent	t *	*	*	*	*	*
12. Making major decisions	*	*	*	*	*	*
13. Household tasks	*	*	*	*	*	*
14. Leisure time interests	and					
activities	*	*	*	*	*	*
15. Career decisions	*	*	*	*	*	*

	All The Time	Most of The Time	More Often Than Not	Occasionally	Rarely	Never
16. How often do you						
discuss or have you						
considered divorce, separation or						
termination of your relationship?	*	*	*	*	*	*
17. How often do you or your mate						
leave the house after a fight?	*	*	*	*	*	*
18. In general, how often do you						
think that things between you						
and your partner are going well?	*	*	*	*	*	*
19. Do you confide in your mate?	*	*	*	*	*	*
20. Do you ever regret that you lived together?	*	*	*	*	*	*
21. How often do you and your partner quarrel?	*	*	*	*	*	*
22. How often do you and your mate get on each other's nerves?	*	*	*	*	*	*
get on each other's herves?						
	Every Day	Almost Every Day	Occasionall	y Rarely	Ne	ver
23. How often do you kiss your mate?	*	*	*	*		•
	All of Them	Most of Them	Some of Them	Very Fev of Then		ne of em
24. Do you and your mate engage in outside interests together?	*	*	*	*	3	k

For Numbers 25-28, How often do the following occur between you and your mate?	Never	Less than Once a Month	Once or Twice a Month	Once or Twice a Week	Once a Day	More Often
25. Have a stimulating exchange of ideas?	*	*	*	*	*	*
26. Laugh together	*	*	*	*	*	*
27. Calmly discuss something	*	*	*	*	*	*
28. Work together on a project	*	*	*	*	*	*

Numbers 29 and 30 are some things about which couples sometimes agree and disagree. Please indicate "yes" or "no" if either item caused differences of opinions or were problems in the past few weeks.

	Yes	No
29. Being too tired for sex	*	*
30. Not showing love	*	*

31. The stars on the following line represent different degrees of happiness in your relationship. The middle star, "happy", represents the degree of happiness of most people's relationships. Please circle the star above the phrase which best describes the degree of happiness, all things considered, of your relationship.

Extremely Fairly A Little Happy Very Extremely Perfect Unhappy Unhappy Unhappy Happy

- 32. Which of the following statements best describes how you feel about the future of your relationship? Please circle the letter for **one** statement.
  - A. I want desperately for my relationship to succeed, and would go to almost any length to see that it does.
  - B. I want very much for my relationship to succeed, and will do all I can to see that it does.
  - C. I want very much for my relationship to succeed, and will do my fair share to see that it does.
  - D. It would be nice if my relationship succeeded, but I can't do much more than I am doing now to keep the relationship going.
  - E. It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.
  - F. My relationship can never succeed, and there is no more that I can do to keep the relationship going.

# SOCIAL SUPPORT QUESTIONNAIRE

**Instructions:** The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part (part A), please list all of the people you know (excluding yourself) whom you can count on for help or support in the manner provided. List the persons (initials only) and how they are related to you (see the example below).

For the second part (part B), please circle how satisfied you are with the overall support you have. If you cannot identify anyone whom you can count on for help or support for a particular question(s), please put an "X" next to the words "No one", but still rate your level of satisfaction for that question(s).

Plasca	anewor	all of	tha	following	questions.	
ı ıcasc	answei	an or	เมเต	IOIIOWIIIG	questions.	

#### **EXAMPLE:**

(a) Who do you know whom you can trust with information that could get you in trouble?

No one	(1) <b>T.N. (sister)</b>	(4) F.L. (mother)	(7)
	(2) L.M. (friend)	(5) <b>B.L. (cousin)</b>	(8)
	(3) R.S. (friend)	(6)	(9)

(b) How satisfied were you?

Very			Moderately		Very	
Satisfied			Satisfied		Dissatisfied	
6	5	4	3	2	1	

No o	ne (1 (2 (3	)	(4) (5) (6)		(7) (8) (9)		
(b)	How satisfied	were you?					
Very Satisfied			Moderately Satisfied		Very Dissatisfied		
6	5	4	3	2	1		
	2. (a) Whom can you really count on to help you feel more relaxed when you are tense or under pressure? No one (1) (4) (7) (5) (8) (3) (6) (9)						
(b) How satisfied were you?							
Very Satisfied			Moderately Satisfied		Very Dissatisfied		
6	5	4	3	2	1		

(a) Whom can you really count on to be dependable when you need help?

1.

3. (a)	vvno accepts	s you totally, inc	ciuaing both your t	worst and your bes	st points?
No o	ne	(1) (2) (3)	(4) (5) (6)	(7 (8 (9	3)
(b)	How satisfie	d were you?			
Very Satisfied			Moderately Satisfied		Very Dissatisfied
6	5	4	3	2	1
4. (a)	to you?	(1) (2) (3)	(4) (5) (6)	you, regardless of (7 (8 (9	3)
(b)	How satisfie	d were you?			
Very Satisfied			Moderately Satisfied		Very Dissatisfied
6	5	4	3	2	
			3	2	1

5. (a	Who can yo down?	ou really count on to	o help you feel better	when you	ı are ger	nerally feeling		
No (	one	(1) (2) (3)	(4) (5) (6)		(7) (8) (9)			
(b) How satisfied were you?								
Very Satisfied			Moderately Satisfied			Very Dissatisfied		
6	5	4	3	2		1		
6. (a	6. (a) Whom can you count on to console you when you are upset?							
No	one	(1) (2) (3)	(4) (5) (6)		(7) (8) (9)			
(b) How satisfied were you?								
Very Satisfied			Moderately Satisfied			Very Dissatisfied		
6	5	4	3	2		1		

#### SOCIAL PROBLEM-SOLVING INVENTORY - REVISED

#### **INSTRUCTIONS**

Below are a series of statements that describe how some people might think, feel, and act when faced with important **PROBLEMS** in everyday living. We are **not** talking about the ordinary hassles and pressures that you deal with successfully everyday. In this questionnaire, a **problem** is something important in your life that bothers you a lot but you don't immediately know how to make it better or stop it from bothering you so much. You know that you have a problem when you feel confused, uncertain, puzzled or stumped about something. The problem could be something about yourself (e.g., your thoughts, feelings, behavior, health, appearance), your relationships with other people (e.g., family, friends, employer, co-workers), or your physical environment and possessions (e.g., your house, car, property, money). Read each statement carefully and select one of the numbers below that indicates how true the statement is of you. Consider yourself as you **typically** think, feel, and act when you are faced with important problems **these days**. Place the appropriate number in the parentheses ( ) next to the number of the statement.

0 = Not at all true of me

1 = Slightly true of me

2 = Moderately true of me

3 = Very true of me

4 = Extremely true of me

1. I spend too much time worrying about my problems instead of trying to solve ( them. 2. I feel threatened and afraid when I have an important problem to solve. 3. When making decisions, I do **not** evaluate all my options carefully enough. 4. When I have a decision to make, I fail to consider the effects that each option is likely to have on the well-being of other people. When I am trying to solve a problem, I often think of different solutions and 5. then try to combine some of them to make a better solution. 6. I feel nervous and unsure of myself when I have an important decision to make. 7. When my first efforts to solve a problem fail, I know if I persist and do not give up too easily, I will be able to eventually find a good solution. 8. When I am attempting to solve a problem, I act on the first idea that occurs to me. 9. Whenever I have a problem, I believe that it can be solved. 10. I wait to see if a problem will resolve itself first, before trying to solve it myself. 0 = Not at all true of me

1 = Slightly true of me 2 = Moderately true of me 3 = Very true of me 4 = Extremely true of me

11.	(	)	When I have a problem to solve, one of the first things I do is analyze the situation and try to identify what obstacles are keeping me from getting what I want.
12.	(	)	When my first efforts to solve a problem fail, I get very frustrated.
13.	(	)	When I am faced with a difficult problem, I doubt that I will be able to solve it on my own no matter how hard I try.
14.	(	)	When a problem occurs in my life, I put off trying to solve it for as long as possible.
15.	(	)	After carrying out a solution to a problem, I do <b>not</b> take the time to evaluate all of the results carefully
16.	(	)	I go out of my way to avoid having to deal with problems in my life.
17.	(	)	Difficult problems make me very upset.
18.	(	)	When I have a decision to make, I try to predict the positive and negative consequences of each option.
19.	(	)	When problems occur in my life, I like to deal with them as soon as possible.
20.	(	)	When I am attempting to solve a problem, I try to be creative and think of new or original solutions.
21.	(	)	When I am trying to solve a problem, I go with the first good idea that comes to mind.
22.	(	)	When I try to think of different possible solutions to a problem, I cannot come up with many ideas.
23.	(	)	I prefer to avoid thinking about the problems in my life instead of trying to solve them.
24.	(	)	When making decisions, I consider both the immediate consequences and the long-term consequences of each option.
25.	(	)	After carrying out my solution to a problem, I analyze what went right and what went wrong.
26.	(	)	After carrying out my solution to a problem, I examine my feelings and evaluate how much they have changed for the better.
27.	(	)	Before carrying out my solution to a problem, I practice the solution in order to increase my chances of success.

0 = Not at all true of me

1 = Slightly true of me 2 = Moderately true of me 3 = Very true of me 4 = Extremely true of me

28.	(	)	When I am faced with a difficult problem, I believe I will be able to solve it on my own if I try hard enough.
29.	(	)	When I have a problem to solve, one of the first things I do is get as many facts about the problem as possible.
30.	(	)	I put off solving problems until it is too late to do anything about them.
31.	(	)	I spend more time avoiding my problems than solving them.
32.	(	)	When I am trying to solve a problem, I get so upset that I cannot think clearly.
33.	(	)	Before I try to solve a problem, I set a specific goal so that I know exactly what I want to accomplish.
34.	(	)	When I have a decision to make, I do <b>not</b> take the time to consider the pros and cons of each option.
35.	(	)	When the outcome of my solution to a problem is not satisfactory, I try to find out what went wrong and then I try again.
36.	(	)	I hate having to solve the problems that occur in my life.
37.	(	)	After carrying out a solution to a problem, I try to evaluate as carefully as possible how much the situation has changed for the better.
38.	(	)	When I have a problem, I try to see it as a challenge, or opportunity to benefit in some positive way from having the problem.
39.	(	)	When I am trying to solve a problem, I think of as many options as possible until I cannot come up with any more ideas.
40.	(	)	When I have a decision to make, I weigh the consequences of each option and compare them against each other.
41.	(	)	I become depressed and immobilized when I have an important problem to solve.
42.	(	)	When I am faced with a difficult problem, I go to someone else for help in solving it.
43.	(	)	When I have a decision to make, I consider the effects that each option is likely to have on my personal feelings.

44. When I have a problem to solve, I examine what factors or circumstances in my environment might be contributing to the problem. When making decisions, I go with my "gut feeling" without thinking too much 45. about the consequences of each option. 46. When making decisions, I use a systematic method for judging and comparing alternatives. 47. When I am trying to solve a problem, I keep in mind what my goal is at all 48. When I am attempting to solve a problem, I approach it from as many different angles as possible. 49. When I am having trouble understanding a problem, I try to get more specific and concrete information about the problem to help clarify it. When my first efforts to solve a problem fail, I get discouraged and 50. depressed. 51. When a solution that I have carried out does not solve my problem satisfactorily, I do not take the time to examine carefully why it did not work. 52. I am too impulsive when it comes to making decisions.

0 = Not at all true of me
1 = Slightly true of me
2 = Moderately true of me
3 = Very true of me
4 = Extremely true of me

# PLEASE MAKE SURE THAT YOU ANSWERED EVERY QUESTION THANK YOU

#### BDI-II

**Instructions:** This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the **one statement** in each group that best describes the way you have been feeling during the **past two weeks, including today.** Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

# 1. Sadness

- 0 I do not feel sad.
- 1 I feel sad much of the time.
- 2 I am sad all the time.
- I am so sad or unhappy that I can't stand it.

# 2. Pessimism

- 0 I am not discouraged about my future.
- 1 I feel more discouraged about my future than I used to be.
- 2 I do not expect things to work out for me.
- 3 I feel my future is hopeless and will only get worse.

#### 3. Past Failure

- 0 I do not feel like a failure.
- 1 I have failed more than I should have.
- 2 As I look back, I see a lot of failures.
- 3 I feel I am a total failure as a person.

Items 1 through 3 reprinted with the permission of The Psychological Corporation.

# BAI

Below is a list of common symptoms of anxiety. Please carefully read each item in the list. Indicate how much you have been bothered by each symptom during the PAST WEEK, INCLUDING TODAY, by placing an X in the corresponding space in the column next to each symptom.

NOT	MILDLY	MODERATELY	SEVERELY
AT	It did not	It was very unpleasant,	I could barely
ALL	bother me much	but I could stand it.	stand it.

- 1. Numbness or tingling
- 2. Feeling hot.
- 3. Wobbliness in legs.

Items 1 through 3 reprinted with the permission of The Psychological Corporation.

# **BHS**

This questionnaire consists of 20 statements. Please read the statements carefully one by one. If the statement describes your attitude for the **past week including today**, darken the circle with a 'T' indicating TRUE in the column next to the statement. If the statement does not describe your attitude, darken the circle with an 'F' indicating FALSE in the column next to this statement. **Please be sure to read each statement carefully.** 

I look forward to the future with hope and enthusiasm.	Т	F
I might as well give up because there is nothing I can do about making things better for myself.	Т	F
3. When things are going badly, I am helped by knowing that they cannot stay that way forever.	T	F

Items 1 through 3 reprinted with the permission of The Psychological Corporation.

# **BURDEN INTERVIEW**

**Directions:** 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 wrong answers.

1.	How often	do you	feel that yo	our partner as	sks for more help th	nan he needs?				
		1	2	3	4	5				
		Never	Rarely	Sometimes	Quite Frequently	Nearly Always				
	2. How often do you feel that because of all your time spent with your partner that you don't enough time for yourself?									
		1 Never	2 Rarely	3 Sometimes	4 Quite Frequently	5 Nearly Always				
3. How often do you feel stressed between caring for your partner and trying to meet other responsibilities for your family or work?										
		1 Never	2 Rarely	3 Sometimes	4 Quite Frequently	5 Nearly Always				
4.	How often	do you	feel embar	rassed over	your partner's beha	vior?				
		1 Never	2 Rarely	3 Sometimes	4 Quite Frequently	5 Nearly Always				
5.	How often	do you	feel angry	around your	partner?					
		1 Never	2 Rarely	3 Sometimes	4 Quite Frequently	5 Nearly Always				
6. How often do you feel that your partner affects your relationship with other family members or friends in a negative way?										
		1 Never	2 Rarely	3 Sometimes	4 Quite Frequently	5 Nearly Always				
7.	How often	do you	feel afraid	about what th	ne future holds for	your partner?				
		1 Never	2 Rarely	3 Sometimes	4 Quite Frequently	5 Nearly Always				
8.	How often	do you	feel that yo	our partner is	dependent upon ye	ou?				
		1 Never	2 Rarely	3 Sometimes	4 Quite Frequently	5 Nearly Always				

9. How often do you feel strained when you are around your partner?							
	1	2	3	4	5		
	Never	Rarely	Sometimes	Quite Frequently	Nearly Always		
10. How ofter		u feel that	your health ha	as suffered becaus	e of your involvement with		
	1	2	3	4	5		
	Never	Rarely	Sometimes	Quite Frequently	Nearly Always		
11. How often do you feel that you don't have as much privacy as you would like because of your partner?							
	1	2	3	4	5		
	Never	Rarely	Sometimes	Quite Frequently	Nearly Always		
12. How often partner?	en do yo	u feel that	your social life	e has suffered beca	ause you are caring for your		
	1	2	3	4	5		
	Never	Rarely	Sometimes	Quite Frequently	Nearly Always		
13. How often do you feel uncomfortable about having friends over because of your partner?							
	1	2	3	4	5		
	Never	Rarely	Sometimes	Quite Frequently	Nearly Always		
14. How ofte were the only				seems to expect yo	u to take care of him, as if you		
	1	2	3	4	5		
	Never	Rarely	Sometimes	Quite Frequently	Nearly Always		
15. How often do you feel that you do not have enough money to take care of your partner, in addition to the rest of your expenses?							
	1	2	3	4	5		
	Never	Rarely	Sometimes	Quite Frequently	Nearly Always		
16. How ofte	en do yo	u feel that	you will be ur	able to take care o	of your partner much longer?		
	1	2	3	4	5		
	Never	Rarely	Sometimes	Quite Frequently	Nearly Always		
17. How ofte illness?	en do yo	u feel that	you have lost	control of your ow	n life since your partner's		
	1	2	3	4	5		
	Never	Rarely	Sometimes	Quite Frequently	Nearly Always		
18. How ofte someone els	-	u feel that	you wish you	could just leave th	e care of your partner to		
	1	2	3	4	5		
	Never	Rarely	Sometimes	Quite Frequently	Nearly Always		

19.	How ofte	How often do you feel uncertain about what to do with your partner?					
		1	2	3	4	5	
		Never	Rarely	Sometimes	Quite Frequently	Nearly Always	
20.	How ofte	en do yo	u feel you	u should be doi	ng more for your p	artner?	
		1	2	3	4	5	
		Never	Rarely	Sometimes	Quite Frequently	Nearly Always	
21.	How ofte	n do yo	u feel you	ı could be doin	g a better job in ca	ring for your partner?	
		1	2	3	4	5	
		Never	Rarely	Sometimes	Quite Frequently	Nearly Always	
22.	Overall.	how ofte	en do vou	feel burdened	when caring for yo	our partner?	
	,	now one	on ao you	Tool bardoned		p	
	,	1	2	3	4	5	

# **VITA**

I. Name: William David Good, Jr.

II. Education: 1994 Youngstown State University

A.B. (Psychology/Sociology)

Magna cum Laude

1996 Hahnemann University

M.A. (Clinical Psychology)

2000 Beth Israel Medical Center/

Albert Einstein College of Medicine

Department of Psychiatry

Predoctoral Internship in Clinical Psychology

American Psychological Association-accredited program

2003 Drexel University (formerly MCP Hahnemann University)

Ph.D. (Clinical Psychology) – Degree in Progress

#### III. Publications:

Nezu, A.M., Nezu, C.M., Saad, R., & Good, W. (1999). Clinical decision making in behavior therapy. *Gedragstherapie* (Dutch Journal of Behavior Therapy).

# IV. Teaching and Training Experience:

January-May 1997 Instructor: Undergraduate course in abnormal psychology;

Allegheny University of the Health Sciences.

Developed syllabus, lesson plans, lectures, weekly quizzes and midterm and final examinations. Served as instructor for

the course for the Spring 1997 semester.

October 1997 Assistant: Training Program for Visiting Psychologist;

Allegheny University of the Health Sciences.

Assisted in the training of a visiting rehabilitation psychologist from the University of Alabama School of Medicine. The training focused on the application of social problem-solving based therapy approaches in various contexts. Training included observation of social problem-solving based group

therapy session and a didactic portion.

September 1998-June 1999 Assistant Student Director: University Student Counseling

Center; Allegheny University of the Health Sciences. Coordinated scheduling of intake assessments and therapy cases. Provided training and supervision to practicum

students.