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Intrapersonal Grief as a Clinical Entity Distinct from Depression: Does It Exist Among a Medically Ill Parkinson's Disease Population?

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Intrapersonal grief as a clinical entity distinct from depression: Does it exist among a medically ill Parkinson's disease population?

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in clinical psychology at Virginia Commonwealth University

by

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Table of Contents

List of Tables

List of Figures

Abstract

GRIEF AS A CLINICAL ENTITY DISTINCT FROM DEPRESSION: DOES IT EXIST AMONG A MEDICALLY ILL PARKINSON'S DISEASE POPULATION?

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There has been growing support for the idea that complicated grief symptoms following bereavement are independent of symptoms of depression and anxiety. However, the loss of a loved one is not the only or the most frequent type of loss to be encountered. The onset of an insidious medical illness may trigger a mourning process for the lost function or body part that is posited to also involve feelings of grief. While the risk of depression is high among a medical or rehabilitative population, the impact of grief over functional losses has never been empirically investigated as a contributing factor in the patient's emotional and physical functioning following illness. Currently, many assume that grief and depression are part of the same condition within the medical context. However, it may be that symptoms conceptualized as grief in the bereavement literature can be identified and distinguished from depressive symptoms within a medically ill population.

The aims of the current study were to: 1) investigate the reliability and validity of the *Loss Inventory* (Niemeier, Kennedy, McKinley, & Cifu, 2004), a newly-developed measure used to assess intrapersonal grief, 2) explore the relationship between grief and depression, and their distinction from one another, using principal components analysis among their respective symptom items, and 3) examine the unique and added contribution of grief on concurrent and prospective emotional and physical health outcomes (i.e. self-esteem, intrusive thoughts and avoidant behavior, global well-being, sleep quality, state anxiety, activities of daily living, and number/severity of co-morbid illnesses).

Two hundred and ten Parkinson's disease and Essential Tremor patients recruited from a VAMC Hospital completed questionnaires at baseline and five to six months later. The *Loss Inventory* proved to be a reliable and a valid measure of intrapersonal grief. Principal components analysis supported the distinction between intrapersonal grief and depression symptoms as measured by symptoms from the *Loss Inventory* and *Zung SDS*. Finally, grief symptoms significantly predicted several concurrent and prospective emotional and physical health outcomes after controlling for disease stage, disability, *and* depression. In sum, the present findings lend support to the hypothesis that bereavement-related symptoms can occur and are meaningful after functional losses from medical illness.

Introduction

A loss is the disappearance of something cherished by an individual, like a person or property. Despite the focus both within the general community and the scientific literature on grief and loss associated with interpersonal losses or spousal bereavement, there remains an underlying recognition that loss and resultant grief are also associated with other adverse life events such as illness, unemployment, school failure, and traumatic incidents. Raphael (1984), in defining grief as "the emotional response to loss: the complex amalgam of painful affects including sadness, anger, helplessness, guilt, and despair," alludes to the fact that grief reactions are experienced by those placed in many situations in which something perceived of value is lost.

Thus, losses by death are not the only or the most frequent losses to be encountered, and there is growing literature on the effects of other types of losses (Clarke, Kissane, & Smith, 2005; Clarke, Smith, Dowe, & McKenzie, 2003; Parkes, 1996; Thomas & Siller, 1999; Sapey, 2004; Zarb, 1993). Chronic illnesses and disability are common experiences in the lives of many individuals. They affect the physical, psychological, social, vocational, and economic functioning of those affected and that of their families. It is estimated that currently more than 35 million Americans have some form of chronic illness or a disabling condition that interferes with their daily lives (Eisenberg, Glueckauf, & Zaretsky, 1993). The prolonged course of treatment, the often

uncertain prognosis, the constant and intense psychosocial stress, the gradually increasing interference with the performance of daily activities and life roles, and the associated impact on family and friends all combine to create a profound effect on the lives of persons with chronic illnesses and disabilities (Davidhizar, 1997; Davis, 1987)

Naturally, the onset of an insidious disability constitutes a crisis in the life of the affected person. On a daily basis, healthcare professionals may be unaware that their patients may be significantly emotionally impacted by a loss. These may include the loss of body image, loss of body function, loss of mental function, loss of health through disease and illness, loss of plans, hopes, and dreams for the future and loss of independence. Medical regimens, treatments, and surgical procedures may also inflict loss (Niemeier & Burnett, 2001; Parkes, 1972; Silver & Wortman, 1980; Slaughter, Beck, Johnston, Holmes, & McDonald, 1999). Given this, disability and illness may trigger a mourning process for the lost body part or function that is posited to be evidenced by feelings of grief and despair. Although most writers define mourning as a time-limited, depressive period, the nature and dynamics of the mourning process and the ensuing feelings of depression that follow the onset of disability have never been empirically studied (Niemeier & Burnett, 2001). Davis (1987) for example, speculates that people who become disabled experience grief differently. This is because permanent disabilities or chronic illnesses require extended and unpredictable periods of mourning. She claimed that the traditional stage theories of adaptation to loss distort the grief experienced by persons who must live continuously with their disability. Because the mourning process that follows the onset of a physical disability is cyclical and prolonged, the person with a

disability must gradually come to terms with an altered and suffering self in order to cope optimally (Davis, 1987; Slaughter et al., 1999).

Currently, much research is interested in complicated grief from a spousal bereavement as a nosologic entity that is distinct from major depression, panic disorder, and posttraumatic stress disorder (Engel, 1961; Jacobs, Mazure, & Prigerson, 2000; Marwit, 1996; Prigerson, Bierhals, Kasl, Reynolds, Shear, & Newson, 1996; Prigerson, Frank, Kasl, Reynolds, Anderson, & Zubenko, 1995; Prigerson & Jacobs, 2001; Prigerson, Shear, Jacobs, Reynolds, Maciejewski, & Davidson, 1999; Wijngaards-de Meij, Stroebe, Schurt, Stroebe, van den Bout, & van der Heijden, 2005). However, there is still some debate in the literature concerning the operationalization, specific symptoms, and validation of complicated grief. Recent advances in the spousal bereavement literature, however, have recognized distinct differences between complicated grief and bereavement-related depression (Horowitz, Siegal, Holen, Bonanno, Milbrath, & Stinson, 1997; Jacobs et al., 2000; Pessagno, 1999; Prigerson, Bierhals et al., 1997; Prigerson, Frank et al., 1995; Prigerson & Jacobs, 2001). Instruments have been developed to assess symptoms of complicated grief (Horowitz, Wilner, & Alvarez, 1979; Prigerson, Maciejewski, Reynolds et al., 1995). Still some researchers define complicated grief as nothing more than a "continued depressive symptom" (Ben-Sira, 1983; Clayton, 1990; Stewart & Shields, 1985; Worden, 1991).

While the risk of depression has been documented as high in rehabilitation patient populations, (Cavenaugh, Clark, & Gibbons, 1983; Coetzer, 2004; Gans, 1981; Kreutzer, Seel, &Gourley, 2001), the impact of grief over intrapersonal losses has not been

explored as a contributing factor or alternate diagnosis when a patient is dysphoric following illness or injury (Niemeier & Burnett, 2001; Niemeier, Kennedy, McKinley, & Cifu, 2004). For some patients, they may immediately be given a diagnosis of depression after their acquired injury or diagnosis and consequently not given the opportunity to appropriately grieve for their loss.

Niemeier and Burnett (2001) write that this confusion in diagnoses occurs for several reasons. First and most important, the terms grief and depression are used often and are thought of as interchangeable. Second, there is an overlap between physical symptoms associated with illness or injury and the vegetative symptoms of depression that may lead to an overestimate of depression diagnoses (Hansson, Carpenter, & Fairchild, 1993; Niemeier & Burnett, 2001). Many mood screens such as the Beck Depression Inventory (Beck & Steer, 1987), Center for Epidemiologic Studies-Depression (Radloff, 1977) and the Hamilton Depression Rating Scale (Hamilton, 1960) include somatic items. Additionally, these mood and personality assessment instruments tend to be used to discern the presence or absence of psychopathology (i.e. depression) rather than to characterize the patient's stress and coping responses to his or her losses (Niemeier & Burnett, 2001; Stroebe, von Son, Stroebe, Kleber, Schut, & van den Bout, 2000).

As mentioned earlier, research on bereavement has not focused specifically on the intrapersonal grief experience of medical patients with disabling illnesses or injury. Early researchers have recommended that clinicians in rehabilitation settings treat their patients who are grieving functional losses as if they were undergoing a major depression

(Davidhizar, 1997; Jacobs & Lieberman, 1987), while other authors have relied on stages similar to those delineated in the bereavement literature to explain the emotional journey in adjustment to disability (Belitsky & Jacobs, 1986; Kubler-Ross, 1969). Despite this current application, it is not known if grief for those with intrapersonal losses is even the same process or consists of similar symptoms as it is for persons with extrapersonal losses (i.e. bereavement and spousal loss). Recent advances and understandings in the bereavement field have not been applied to these individuals. Does a rehabilitative population experience grief and are the symptoms similar to what is already known about grief and mourning during spousal bereavement? Could symptoms of grief be distinguished from symptoms of depression in a rehabilitation population? The distinctiveness of symptom clusters has not been investigated with individuals other than recently bereaved elders whose partners died from illness. Replication of this distinction from depression in a rehabilitation population is important since high levels of spousal grief have been found to be associated with physical and mental health impairments (Byrne & Raphael, 1997; Gilewski, Farberow, Gallagher, & Thompson, 1991; Latham & Prigerson, 2004; McDaniel, Brown, & Cole, 2000; Prigerson, Bierhals, Kasl, Reynolds, Shear, & Day, 1997). Treating those suffering from loss in the medical context without being aware of the grief response can have detrimental effects such as incorrect medical diagnoses, inappropriate treatment plans, and non-existent or poor therapeutic responses. Therefore it is important that healthcare professionals learn to recognize the signs and symptoms of a grief response and to distinguish this, if possible, from depressive symptoms secondary to medical illness enabling the proper diagnosis and treatment.

Given this, this study's primary goal is to determine whether symptoms conceptualized as dimensions of grief from a spousal bereaved population could be identified and distinguished from symptoms conceptualized as dimensions of depression secondary to a medical illness or disability within a specific rehabilitation population, specifically Parkinson's disease and Essential Tremor. The use of a Parkinson's disease population is particularly interesting since some research suggests that up to 50% of those diagnosed with PD will potentially experience "depression" though this could potentially be a normal grief reaction to the diagnosis (Leentjens, 2004; Liebermann, 2006; Starkstein, Berthier, Bolduc, Preziosi, & Robinson, 1989; Veazey, Erden, Cook, Lai, & Kunik, 2005). The high prevalence rate of co-morbid depression in Parkinson's disease is thought to be as great or greater than co-morbid depression rates found in other chronic illnesses. About 17 to 27% of cardiac patients, 9 to 26% of type-II diabetes patients, 22 to 29% of cancer patients, and 30 to 54% of chronic pain patients suffer from depression (Anderson, Freedland, Clouse, & Lustman, 2001; Campbell, Clauw, & Keefe, 2003; Raison & Miller; 2003; Rudisch & Nemeroff, 2003). Stroebe et al., (2000, 2001) and others argue that despite many recent advances in the spousal bereavement literature, there remains a need for greater clarity and consensus in defining complicated grief, finer delineation of the overlap and distinction between grief and other symptoms such as depression, and further validation of the concept of complicated grief. If there is support that depressive and grief symptoms are distinguishable in a rehabilitative population, this may suggest that symptoms unique to grief may be overlooked if grief and depression are assumed to be part of the same condition. It may be that treatment interventions with

rehabilitative grieving patients may need to focus on various aspects of grief rather than or in addition to various aspects of depression. This study will thus review several distinct literatures including: background and definition of bereavement, grief, and stage models; current application of grief in a rehabilitative population; qualitative characteristics of grief and depression; empirically validated symptoms of grief and its complications vs. depression in a spousal bereaved population; the recent development of the *Loss Inventory* (Niemeier, Kennedy et al., 2004) and its use in a rehabilitative population; and finally a brief review of depressed mood in Parkinson's disease.

Literature Review

Bereavement, Grief, and Stage Models

Although it is difficult to draw categorical distinctions between the terms of bereavement, grief, or normal versus complicated grief, it is important at the outset to indicate how the literature has used these terms.

The term *bereavement* is understood to refer to the objective situation of having lost someone significant. Although most people manage to come to terms with this over the course of time, it is associated with intense distress for most people. The usual reaction to bereavement is termed *grief*, defined primarily as an emotional reaction to the loss of a loved one through death. Sometimes *mourning* is used interchangeably with grief, particularly among those following a psychoanalytic tradition (Stroebe, Hansson, Stroebe, & Schut, 2001). Grief, however, is more than just emotion. Worden (1991) has suggested that it consists of four dimensions. These are feelings (sadness, anger, guilt and reproach, anxiety, loneliness, fatigue, helplessness, shock, yearning, numbness); physical sensations (hollowness in the stomach, tightness in the chest and throat, oversensitivity to noise, a sense of depersonalization, shortness of breath, muscle weakness, lack of energy and dry mouth); cognitions (disbelief, confusion, preoccupation, sense of presence and hallucinations); and behaviors (sleep and appetite disturbances, absent-minded behavior, social withdrawal, dreams of the deceased, avoiding reminders of the deceased, searching

and calling out, sighing, restlessness, over-activity, crying, visiting places or objects that remind the survivor of the deceased, and treasuring objects that belonged to the deceased).

It is common to conceptualize grief as a progression through stages (Kübler - Ross, 1969). The vast majority of stage or phase models of grief follow a similar pattern: first, a *period of disorganization*, emotional numbness, and denial of the reality of the loss; followed by a period of *extremes*, in which the bereaved search for the one who is now lost to them and also struggles to accommodate to a revised reality; ending in *resolution* of the loss, in which the changed reality is accepted and the bereaved moves on with their lives. A prominent model, developed by Bowlby (1961, 1980) and Parkes (1972, 1983), involves four stages: 1) shock and numbness, 2) searching and yearning, 3) disorientation, and 4) reorganization and resolution. Possibly the most popular stage model is one that was developed by Kübler-Ross (1969) in her work with dying patients. She intended this model to be used in relation to one's grief at one's own death, but it has been adopted by many as the standard by which all grief should be assessed. In this model, the griever moves through five stages of loss, characterized by *denial, anger, bargaining, depression,* and finally *acceptance*. The griever might move through these stages in a varied way, but the ultimate goal is acceptance of the loss (Kübler -Ross, 1969).

These stage models have come under increasing scrutiny. After all, only one recent empirical study examines the stage theory of grief resolution explicitly (Maciewjewski, Zhang, Block, & Prigerson, 2007) The current thinking of stage theories

has shifted toward seeing the stages as benchmarks, but they often are seen as causing more problems than they resolve. Although not intended by the vast majority of writers, they often are seen as prescriptive rather than descriptive; individuals who "haven't gone through the stages" may come to feel that they are not grieving "right." Researchers looking at different types of losses have been unable to find evidence that people move through a consistent set of stages toward recovery (Parkes, 2001). Indeed, common patterns found, especially among parents who had lost a child, include *recurrent grief,* also referred to as *shadow grief* (Peppers & Knapp, 1980). In this, bereaved individuals experience episodes of renewed grief after a period of assumed recovery. Others may experience worsened grief over time, sometimes after they have experienced their initial grief as less intense. There are questions about whether or not people "recover" (Silver & Wortman, 1980) from grief and what that term actually means. Much evidence shows that later losses may trigger earlier grief thought to have been resolved (Stroebe & Stroebe, 1991; Wortman & Silver, 1989, 2001)

Normal and Complicated Grief

Many people experience normal grieving. In fact, approximately 80-90% of bereaved individuals experience *normal* or *uncomplicated grief* (Barry, Kasl, & Prigerson, 2001; Latham & Prigerson, 2004; Prigerson, 2004). As mentioned above, the process of grief can be very painful and disruptive. However, most bereaved survivors overcome the initial sense of disbelief and gradually come to accept the loss as a reality. The vast majority of bereaved people eventually are able to move on with their lives and proceed with their daily functions and activities.

Unfortunately, a significant minority of bereaved persons are not able to adapt to their loss, which can lead to *complicated grief.* In the past, distinctions between normal and complicated grief (also called *traumatic* or *pathological grief*) have been difficult to make, partly because the definition of complicated grief has been empirically rather than theoretically derived (Stroebe, 2000, 2001). Second, some may argue that complicated grief is not a single syndrome with clear diagnostic criteria (Stroebe et al., 2000, 2001). Third, setting a cutoff point between what is normal and what is not is a dubious endeavor (i.e. there are differences in cultural manifestations that need to be taken into account); and finally, because it is sometimes difficult to differentiate complicated grief from related disorders (depression, anxiety disorders, posttraumatic stress disorder (Stroebe et al., 2000, 2001). For simplification, researchers have defined complicated grief as a deviation from the cultural norm in the time course or intensity of specific or general symptoms of grief. For example, in contrast with bereaved survivors with uncomplicated grief (normal grief), those with complicated grief are essentially stuck in a state of chronic mourning (Prigerson, 2004). Mental anguish stems from the protest against the reality of the loss and a general reluctance to make adaptations to life in the absence of the loved one. Overall, complicated grief is regarded as one of two extremes, grief that is avoided or suppressed and grief that the individual will not "let go of."(Stroebe & Stroebe, 1991; Stroebe et al., 2001; Worden, 1991).

Does grief occur in rehabilitative patients?

Rehabilitation patients have a variety of diagnoses (i.e. amputation, spinal cord injury, Parkinson's disease, etc.) and thus frequently and potentially will have many

losses to grieve (Niemeier & Burnett, 2001; Niemeier et al., 2004). Although never directly studied before, a likely outcome of experiencing functional loss is grief. An early study by Parkes & Weiss (1983) examined 37 men and 9 women under the age of 70 who were recent amputees. They were interviewed one month and 13 months after the amputation of an arm or leg. Although the loss of a leg is not the same as the loss of a loved one, many of this study's patients repeatedly referred to their "grief". Alarm, feelings of anxiety, tension, and restlessness were common during the year after amputation. Feelings of bitterness and anger are also commonly expressed by those with amputation. Interviews with patients showed that intense anger may be directed towards doctors or others whose actions might have helped to bring about the amputation, and like the widow or widower, these amputees often blame themselves (Parkes, 1996; Parkes & Weiss, 1983). Parkes & Weiss (1983) also found that like the bereaved, the amputees do tend to be preoccupied with thoughts of loss. They mourn for their lost intactness. These patients are likely to be self-conscious about being seen in public in their present state. In Parkes and Weiss's study 67% of the amputees attempted to take their mind off their loss, but they were constantly being reminded of it. In conclusion, many of the pathological reactions to amputation resembled those to bereavement or loss of a spouse. They commonly reflect distortion or prolongation of the process of realizing the loss and, although additional research is needed to clarify the picture, it does appear that one of the main types of reactions (i.e. grief) found among disturbed widows and widowers is also found in amputees and possibly other rehabilitative patients.

Given these observations, Parkes' study qualitatively allows for the possibility that the transition from being an intact person to being an amputee is a painful and time-consuming process that is, in many ways, similar to the transition from married person to widow or widower. It would seem justifiable, therefore, to regard these two situations as parts of the same field of study.

Current Application of the Grief Literature in Rehabilitative Patients

Researchers and clinicians in the field of rehabilitation have relied on bereavement terms and theories as mentioned earlier (from spousal loss) to explain the adjustment to disability. Consequently, the adjustment to disability literature has focused on grief following disablement in several ways. Authors have relied on stages similar to those delineated in the bereavement literature to explain the emotional journey in adjustment to disability (Ben-Sira, 1983; Niemeier & Burnett, 2001; Stewart & Shields, 1985). Over the past two decades, the descriptions of stage models (i.e. denial, anger, bargaining, etc.) of reactions to loss have appeared in numerous articles written for clinicians. As a result, these models have become firmly entrenched among health care professionals. In fact, professionals sometimes use the stages as a kind of yardstick to assess progress and evaluate how a given individual is doing. The consequences of applying the stage models in this manner are not always positive. Some clinicians now think dying persons who did not follow these grieving stages as "deviant" or "neurotic" (McDaniel, Brown, & Cole, 2000; Stewart & Shields, 1985).

Attempts have been made to relate these early theories with the concept of stages and phases of grief to individuals with losses other than through death. In the area of

rehabilitation counseling, several theorists assert that working through stages, similar to those set forth in bereavement models, is essential for facilitation of adjustment to disability and thus to overall successful rehabilitation efforts. Gualtieri and Johnson's review (as cited in Niemeier & Burnett, 2001), addressed grieving within the brain injury patient population and recommended a working through process to facilitate adjustment to disabilities. Despite this, criticism of the inflexibility of these stage/models has been raised. Sports psychologists disagree about the adequacy of many of these stages for conceptualizing the process of grieving that athletes experience when an injury prevents them from playing their sport (Niemeier & Burnett, 2001). Thomas and Siller (1999) point out that the application of the traditional bereavement stages to adjustment to disability has not accomplished much in the way of understanding the emotional experience of patients grieving lost functions and body parts.

Chronic Sorrow and Rehabilitative Patients

Olshansky (1962) first used the term "chronic sorrow" to describe a pervasive psychological phenomenon observed in parents of children with mental retardation. His work was based on his clinical experience as a counselor. He contends that chronic sorrow is a natural and understandable response to a tragic event, and is manifested throughout the lifespan of the parent-child relationship. This is in contrast to previous theorists who believe the non-resolution of mourning to be an unhealthy response. Olshansky (1962) disputed the closure stage of other theorists as it symbolizes acceptance, which he sees as a "simplistic and static concept". He argues that sorrow is a normal response to an overwhelmingly tragic event and that acceptance may not be

achieved. In recent years, the concept of chronic sorrow has been analyzed by nurses (Burke, Hainsworth, Eakes, Lindgren, 1992; Eakes, Burke & Hainsworth, 1998; Lindgren, 1996) who have applied it to different groups: parents who have chronically ill children or premature babies, adults who have multiple sclerosis, adults with a cancer diagnosis, or elderly caregivers of spouses with dementia. Recent literature has generalized this concept as a framework for understanding the responses to losses by the chronically ill and their caregivers (Burke et al., 1992; Eakes et al., 1998; Hainsworth, Eakes, & Burke, 1994; Lindgren et al., 1992; Lindgren, 1996). It has been defined as a pervasive sadness that is permanent, periodic, and progressive in nature. Thus far, the concept has mainly been explored in the literature qualitatively and has focused on how medical care staff can help those with chronic sorrow cope with their situation or illness (Burke et al., 1992; Hainsworth et al., 1994; Lindgren et al., 1992; Lindgren, 1996).

Disenfranchised Grief in Rehabilitative patients

Disenfranchised grief is the result of a loss for which a patient does not have a socially recognized right, role, or capacity to grieve (Doka, 1989). These socially ambiguous losses are not or cannot be openly mourned, or socially supported. Essentially, this is grief that is restricted by "grieving rules" ascribed by culture and society. The bereaved may not publicly grieve because, somehow, some element or elements of the loss prevent a public recognition. Thus, disenfranchised grief occurs in three primary ways: 1) the relationship is not socially recognized (a partner in a gay or lesbian relationship), the relationship exists primary in the past (ex-spouse), 2) the loss is not socially recognized or is hidden from others (hidden losses include abortion, the loss

of pet (fear of ridicule), and 3) the griever is not socially recognized (very old, very young, or mentally disabled) (Doka, 1989).

Unfortunately, early researchers recommended that clinicians in rehabilitation settings treat their patients who are grieving functional losses as if they were undergoing major depression (Niemeier & Burnett, 2001). Thus, for some patients, they are immediately given a diagnosis of depression after their acquired disability or illness and consequently not given the opportunity to appropriately grieve for their losses. Because of the lack of social recognition by healthcare professionals and others, disenfranchised grief for this population is a hidden grief and this "hiddenness" can paradoxically increase the reaction to loss. It can intensify feelings of anger, guilt and/or powerlessness, thus resulting in a more complicated grief response. Disenfranchised grief may also lead to a chronic grief reaction where grief is never resolved, life becomes stagnant, denial of the illness predominates, and new emotional growth cannot take place (Doka, 1989).

Qualitatively Distinguishing between Bereavement-Related Grief and Depression

Although this study will focus on grief in a rehabilitative population, all current empirical research that has been studied on grief is mostly related to loss of a loved one or bereavement-related extrapersonal losses. Therefore, the following sections will review the literature related to grief and spousal bereaved loss making the argument that grief symptoms can be differentiated from depression symptoms in a bereaved population. Confusion between grief and depression still exists. According to Gans (1981), depression in an acute care setting is often misdiagnosed as grief, while in a chronic care setting depression may be overdiagnosed. In his research, Gans (1981),

using six accepted criteria of clinical depression, diagnosed only 19 of 44 suspected cases of depressed mood with clinical depression. An added problem is the ambiguity of terms used to describe depressed mood. The affective disorder by definition must manifest at least four of the following symptoms nearly every day for at least two weeks: poor appetite or significant weight loss, insomnia or hypersomnia, psychomotor agitation or retardation, loss of interest in usual pleasure or activities, fatigue, sense of worthlessness, slowed cognition, and suicidal thoughts. Similarly, grief may involve some or all of these symptoms and may be as severe as the affective disorder. To differentiate the two, clinicians have used their experience in observing the following characteristics:

- A temporal variation of mood is normal in grief, a mixture of "good and bad" days. In contrast, persistent flat affect or dysphoria is characteristic of depression. Depression is a pathological state; patients may "get stuck" in this state without treatment.
- A disturbed self-esteem is not typically seen in grief while this is a common feature of depression; overwhelming and persistent feelings of worthlessness to others and of being a burden are common in depression.
- Distressing guilt is usually generalized to all facets of life in depression, while in grief, the guilt is focused around specific issues (e.g. not being able to attend a child's wedding).
- A grieving patient's hope shifts, but is not lost. (Hope may shift from a hope for cure to hope for life prolongation to hope for dying well). The ability to feel

pleasure is not lost in preparatory grief. In contrast, the depressed patient will comment on feelings of hopelessness and helplessness.

- Grieving patients often need social interaction to help them through the grief process. Social support helps provide the acceptance and assistance necessary for completion of grief work. While social interaction may be helpful in some depressed patients, it will typically not provide the assistance necessary to resolve the depression.
- While suffering associated with uncontrolled symptoms such as pain, concern over being a burden and a desire to be in control of one's dying, may all result in thoughts of an earlier death, an active desire for an early death is not typical of preparatory grief. A persistent, active desire for an early death in a patient, whose symptomatic and social needs have been reasonably met, is suggestive of clinical depression.

For further summary of these two related yet distinct affective states refer to Table 1. These characteristics have been observed between grief and depression at least in situations regarding the loss of a loved one (Burnett, Middleton, Raphael, & Martinek, 1997) However, within a rehabilitative population, it may still be difficult to differentiate between grief and depression secondary to the patient's medical illness or injury. Depressed mood (grief or major depression) may also be a manifestation of illness or drug therapy. Numerous conditions, from influenza to neurologic disorders to heart

Table 1

Differentiating qualitative characteristics between bereavement-related grief and depression

Characteristic	Grief	Depression
Vegetative Signs of Symptoms	Subsides with time	Persist>2 months after the loss
Pathology in Mental Function	Lacks	Severe, distorted, negative perceptions of self, world, and future
Loss	Recognized and acknowledged	Unrecognized and denied
Energy Level	Agitated, restless, transient	Retarded, no energy, persists
Suicide Gestures	Rare in uncomplicated grief	Not atypical
Reaction by Others	Elicits sympathy, concern, a desire to embrace	Potential to elicit irritation, frustration, and a desire to avoid
Responds to Warmth and Support	Yes	Often No
Past of Family History of Depression	None	Common
Preoccupation	Deceased or Situation	Self
Mood	Fluctuates	Stays Down
Over expression of Anger	More Common	Less Common
View of Pain	Acknowledgement of the Loss	Useless or Meaningless
Gender	Equal	More Females

disease, anemia, and chronic pain, can decrease mood and complicate the diagnosis. Drugs such as steroids, antihypertensives, anti-parkinsonians, and tranquilizers, can cause depression (Neimeier & Burnett, 2001). As a stroke resolves, so do the mental changes. When the person begins to realize the severity of the illness, the grieving process may be superimposed upon the mental changes, making differentiation between grief and depression even more difficult (Neimeier & Burnett, 2001). Some rehabilitative patients may even experience both grief and illness-related depression simultaneously.

Empirically validated symptom criteria Bereavement-Related Complicated Grief

As described above, there are clearly numerous phenomena that could be considered complications of grief in dealing with bereavement-related extrapersonal losses. However, only a subset of researchers has developed complicated grief symptom criteria empirically (Enright & Marwit, 2002; Horowitz, Siegal, Holen, Bonanno, Milbrath, & Stinson, 1997; Marwit, 1996; Prigerson, Frank, Kasl, Reynolds, Anderson, Zubenko et al., 1995; Prigerson, Bierhals et al., 1996). In 1993, Horowitz and colleagues argued that "complicated/pathological grief disorder" should be a separate diagnosis in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 1994; 2000), which was being developed at the time (Horowitz, Bonanno, & Holen, 1993; Horowitz, Stinson, Fridhandler, Milbrath, Redington, & Ewert, 1993). They proposed that a single category should be developed to prevent further confusion and to facilitate research.

Horowitz and colleagues (Horowitz, Marmar, Weiss, DeWitt, & Rosenbaum, 1984) were able to demonstrate that prolonged grief reactions were in fact characterized

by intrusions, avoidance, and problems with adaptations to the loss. Dysfunctional adaptation involved failure to resume responsibilities and/or somatic symptoms beyond 1 month after bereavement, and /or failure to form new relationships beyond 13 months after bereavement.

Based on the findings of this study, Horowitz and colleagues (1997) constructed operational definitions of these symptoms and created a structured diagnostic interview evaluating 30 potential symptoms of complicated grief (CG) as a supplement to the Structured Clinical Interview for DSM-III-R—Non-Patient Edition (SCID-NP; Spitzer, Williams, Gibbon, & First, 1990). They administered this interview module along with self-report measures to 70 bereaved spouses and partners 6 and 14 months following the loss of their significant other. Latent class model analyses and signal detection procedures were used to calibrate the data against global clinical ratings and self-report measures of grief-specific distress. The complicated grief symptoms were then characterized by a smaller set of the assessed symptoms. Additionally, these researchers found that the group of individuals demonstrating severe symptoms remained fairly consistent at 6 months post-loss and 14 months post-loss. Also, subjects who matched these symptom patterns did not significantly overlap with subjects who received a diagnosis of major depressive disorder.

Overall, the proposed diagnostic criteria required a combination of the following symptoms for more than a year after the loss: intense intrusive thoughts, pangs of severe emotion, distressing yearnings, feeling excessively alone and empty, excessively avoiding tasks reminiscent of the deceased, unusual sleep disturbances, and maladaptive

levels of loss of interest in personal activities (Horowitz et al., 1997). Furthermore, the 30 original symptoms were able to be statistically divided into three categories of symptoms: (1) intrusion, e.g., unbidden memories, emotional spells, strong yearning; (2) avoidance, e.g., avoiding places that are reminders of the deceased, emotional numbness towards others; and (3) failure to adapt symptoms, e.g., feeling lonely or empty, having trouble sleeping. These categories exhibited low to satisfactory internal consistency to one another supporting differences among the symptom categories (Horowitz et al., 1997).

Another group of researchers, Prigerson and colleagues (1995) also began to empirically evaluate symptoms of complicated grief (CG) after observing a cluster of symptoms following bereavement as qualitatively different from those of bereavement-related depression and anxiety. They evaluated symptoms that were associated with poorer adjustment in prior bereavement studies; that were clinically and intuitively related to long-term dysfunction; and that clustered together in a principal components analysis with varimax rotation, but that were separate from depressive symptoms. A review of the literature yielded a list of 12 depressive symptoms associated with poor bereavement-related outcome, including depressed mood, guilt, hypochondriasis, low self-esteem, worthlessness, suicidal ideation, psychomotor retardation, apathy, loneliness, pessimism, anxiety, and insomnia. There were 10 grief-related symptoms that were considered maladaptive, including crying, difficulty accepting the loss, preoccupation with thoughts of the deceased, anger, lack of closure, yearning for the deceased, searching for the deceased, disbelief, numbness, and being stunned by the loss. These symptoms were assessed in a sample of late-life widows and widowers using an

assessment instrument composed of items from a variety of scales. The researchers conducted a principal components analysis of these symptoms. Factor 1, accounted for 26.2% of the variance and was interpreted as the bereavement-related depression factor. Factor 2, accounted for 20% of the variance and was interpreted as the CG factor. Yearning for and preoccupation with thoughts of the deceased loaded more heavily on the CG factor, suggesting these are key features of CG.

Prigerson and her team have continued to replicate these findings (Burnett, Middleton, Raphael, & Martinek, 1997; Chen et al., 1999; Marwit, 1991, 1996; Prigerson, Frank et al., 1995; Prigerson, Maciewjewski et al., 1995; Prigerson, Bierhals et al., 1996) in several independent samples of mid to late-life widows and widowers. They have even developed an empirically validated instrument, the Inventory of Complicated Grief (ICG; Prigerson, Maciewjewski et al., 1995), to assess the symptoms of CG in this population. Since completion of these initial studies, there exists a sizeable and growing body of evidence indicating that complicated grief symptomatology meets the DSM-IV definition of a mental disorder and as will be described later, differs from both Major Depressive Disorder and Posttraumatic Stress Disorder among the those with bereavement-related losses (Boelen, van den Bout & de Keijser, 2003; Chen et al., 1999; Horowitz et al., 1997; Ogrodniczuk et al., 2003; Prigerson, Frank et al., 1995, Prigerson, Maciewjewski et al., 1995, Prigerson, Bierhals et al., 1996, Prigerson, Shear et al., 1996).

Overall, Prigerson and colleagues' consensus criteria for complicated grief differentiate between two categories of symptoms (Prigerson & Jacobs, 2001; Prigerson,

Shear et al., 1999). These are the following: (1) separation distress, e.g., preoccupation with thoughts of the deceased, longing and searching for the deceased, loneliness; and (2) traumatic distress, e.g., feeling disbelief about the death, mistrust, anger, feeling shocked by the death, and the experience of somatic symptoms of the deceased. In addition there must be clinically significant daily activity disturbance for more than six months before a diagnosis can be made. Despite Horowitz's and Prigerson's two slightly different diagnostic systems for complicated grief, recent reviews have gathered evidence in favor of both Prigerson's and Horowitz's criteria sets to measure complicated grief distinct from depression. Overall, this research would suggest a general agreement about the symptoms that complicated grief would comprise (Forstmeier & Maercker, 2007; Jacobs, Mazure, & Prigerson, 2000; Lichtenthal, Cruess, & Prigerson, 2004; Stroebe et al., 2000).

Quantitatively distinguishing bereavement-related Grief and Depression

Distinct risk factors and correlates. To explore risk factors of CG, van Doorn, Kasl, Beery, Jacobs, & Prigerson, (1998) examined individuals caring for their terminally ill spouses prior to and following their spouses' death. They demonstrated that a close, security-enhancing relationship with the significant other, which had been implicated in other reports (Carr, House, Kessler, Neese, Sonnega, & Wortman, 2000; Cleiren, Diekstra, Kerkhof, & van der Wal, 1994; Johnson, Vanderwerker, Borstein, Zhang, & Prigerson, 2007; Vanderwerker, Jacobs, Parkes, & Prigerson, 2006), predicted CG symptoms. Insecure attachment styles, including excessive dependency, compulsive caregiving, defensive separation, were also related to CG (Carr et al., 2000; Cleiren et al., 1994; van Doorn et al., 1998). Risk factors for parental bereavement (loss of a child)

include the number of remaining children (i.e. greater grief reactions for those who have lost a child and do not have other children) (Wijngaards-de Meij et al., 2005). In a recent study of 346 bereaved older adults, African-American bereaved subjects were nearly five times more likely than Caucasian subjects to meet criteria for Complicated Grief (Odds Ratio = 4.9, 95% CI 1.3-18.4) (Goldsmith, Morrison, Vanderwerker, & Prigerson, in press, 2007). A very recent study examining the correlates of complicated grief in parentally bereaved children and adolescents found that complicated grief (as measured by the Inventory of Complicated Grief-Revised) was significantly related to functional impairment (i.e. Children's Global Assessment Scale (r = -.38); depression (r = .47), anxiety (r = .44), PTSD (r = .62), hopelessness (r = .31), and suicidal ideation (r = .32) (Melham, Moritz, Walker, Shear, & Brent, 2007). These findings are consistent with findings in adults in whom CG was found to be associated to predict functional impairment after controlling for depression (Prigerson, 1997). Overall, it would seem that CG is associated with interpersonal factors, including the relationship with the deceased and with other measures of psychopathology. Additionally, both a security-enhancing marriage and an insecure attachment style are two predictors of complicated grief that have not been found to explain symptoms of depression (Sanders, 1993; van Doorn et al., 1998).

Biological Clinical Correlates. The biological associated features of CG are also different from those of bereavement-related depression (Enright & Marwit, 2002; Prigerson & Jacobs, 2001). In their study of EEG sleep variables, McDermott and colleagues (1997) distinguished CG from bereavement-related depression among late-life

spousal bereaved individuals. Depressive symptoms were independently associated with particular electroencephalographic (EEG) sleep measures (i.e. sleep efficiency and maintenance). Complicated grief symptoms, on the other hand were only independently associated with mild subjective sleep impairment (McDermott et al., 1997). Thus, it appears that complicated grief symptoms do not entail the changes of EEG sleep physiology seen in depression. Bereaved individuals also appear to have a unique response to the Dexamethasone Suppression Test (DST; Schucter, Zisook, Kirkorowicz, & Risch, 1986). Cortisol levels normally decrease in response to the administration of dexamethasone, a synthetic compound similar to cortisol, and therefore abnormal responses to the DST may indicate overproduction of cortisol in the body. Failure to suppress when given the DST has been associated with depressive symptoms (Goodkin et al., 2001). Interestingly, Schuchter et al., (1986) found that rates of nonsuppression to the DST were associated with the severity of anxiety rather than to the severity of depression among bereaved individuals. In addition, Jacobs (1987) reported that symptoms of acute separation distress, a core component of CG, were related to increases in urinary free cortisol and plasma growth hormone among widowed individuals. However, depressive symptoms were not associated with these clinical markers in this study sample (Jacobs, 1987).

Distinct courses and outcomes. The course of bereavement-related depression also may be different from the course of CG (Pasternak et al., 1991; Pasternak et al., 1993; Prigerson, Bierhals et al., 1996; Prigerson, Frank et al., 1995; Zisook & Devaul, 1983). Pasternak et al., (1993) found that grief did not resolve as quickly as depression in their

study of elderly spousal bereaved individuals; depressive and grief symptoms were evaluated over a period of 18 months. Although depressive symptoms appeared to remit as is typical in the course of depression, grief symptoms assessed by the *Texas Revised Inventory of Grief* (TRIG; Fashingbauer, Zisook, & DeVaul, 1987) remained more severe and stable over time (Pasternak et al., 1993). Prigerson, Frank, and colleagues (1995) similarly found that bereavement-related depression decreased over time significantly more among participants who were treated with nortriptyline for depression than for nontreated participants, but that there were no differences between the treated and nontreated participants in CG over time. Additionally, even when taking into the account the effects of depressive and anxiety symptoms, those with CG have been associated with an increased risk of cancer, hypertension, cardiac events and suicidal ideation (Latham & Prigerson, 2004; Prigerson et al., 1997; Prigerson et al., 1999). CG has been associated with future disability, functional impairments (social, family, and occupational dysfunction), depressive symptoms, hospitalizations, adverse health behaviors such as increased alcohol and cigarette consumption, and reduced quality of life (Latham & Prigerson, 2004; Prigerson, Frank et al., 1995, Prigerson et al., 1997; Prigerson et al., 1999; Ott, 2003; Reich, Zautra, & Guarnaccia, 1990; Rosenzweig, Prigerson, Miller, & Reynolds; 1997; Stroebe et al., 2001; Simon et al., 2005)

Differences in response to assessment and treatment. Assessment of depressive and CG symptoms has revealed that although they are frequently comorbid, they can occur independently (Enright & Marwit, 2002; Horowitz, Bonanno et al., 1993; Prigerson, 1997). Prigerson, Frank et al., (1995) reported, for example, that 46% of individuals

diagnosed with CG did not meet criteria for Major Depressive Disorder. This finding suggests that CG is a distinct entity not fully accounted for in assessing for existing mental disorders. Another key distinguishing factor between bereavement-related depression and CG is their independent responses to treatments. Prior studies have found that grief symptoms (as assessed by the TRIG) were not reduced through treatment with tricyclic antidepressants, suggesting that they are distinctive from depressive symptoms and require a different type of intervention (Jacobs & Lieberman, 1987; Pasternak et al., 1991). Reynolds et al., (1999) conducted post hoc analyses of a placebo-controlled trial comparing nortriptyline, interpersonal therapy (IPT), and their combination to treat bereavement-related depression. CG was assessed using the *Inventory of Complicated Grief*, and for those individuals likely to have a CG diagnosis (scores >25), scores decreased approximately 20% over the 16-week study period. There were no effects on rates of decline due to IPT, nortriptyline, or a combination of the two. The antidepressant medication and the combination of medication plus IPT did, however, reduce depressive symptoms when compared to placebo. In other words, individuals with bereavement-related depression, responded to traditional treatments of Major Depressive Disorder (i.e. antidepressant and IPT), whereas individuals with CG appeared to need a different approach to alleviate their suffering (Frank, Prigerson, Shear, & Reynolds; 1997; Prigerson, Bierhals et al., 1996; Prigerson & Jacobs, 2001). These results provide further support that symptoms of grief are distinct from those of depression and suggest that additional research is needed to demonstrate the efficacy of pharmacotherapy for the reduction of symptoms of grief.

With respect to psychological interventions, Shear and colleagues (2005) recently published a randomized, controlled trial of a manualized psychotherapy treatment developed specifically for those with CG. They compared the newly developed Complicated Grief Treatment with Interpersonal Psychotherapy (IP) among patients from a university-based psychiatric research clinic among an African-American community. Participants found to meet criteria for CG were randomized to receive IP (n=46) or Complicated Grief Treatment (n=49). Treatment response was defined as either an independent evaluator-rated clinical global improvement score of 1 or 2 or as time to a 20-point or better improvement in the self-reported *Inventory of Complicated Grief.* All raters were blind to participants' treatment condition. Results indicated that both treatments significantly reduced CG symptoms, but the response rate was much greater for the Complicated Grief Treatment (51%) than for Interpersonal Psychotherapy (28%; $p < .05$) (Shear, Frank, Houck, & Reynolds, 2005).

Current Measures of Mood in a Rehabilitation Population and the Loss Inventory

As mentioned earlier, there are a variety of scales developed to assess for grief and its complication in the bereaved population, however, assessing for grief in the rehabilitative setting is dramatically different currently. Because grief and depression are still used interchangeably in this population, measures used to assess grief are also the measures used to assess for depression. The most frequently used mood measures used by rehabilitation psychologists, include the *Beck Depression Inventory* (BDI), the *Zung Self-Rating Depression Scale* (Zung-SDS), the *Hamilton Rating Scale for Depression* (Ham-D), the *Geriatric Depression Scale* (GDS), and the *Center for Epidemiological Studies*

Depression Scale (CES-D). However, the validity and appropriateness of these measures for use with medical patient populations has been challenged by investigators (Niemeier & Burnett, 2001; Stroebe et al., 2000) in part since they do not assess emotional responses to intrapersonal loss directly. Many scales are instead used during routine evaluations of patients in rehabilitation. Niemeier and Burnett (2001) write that depending on the theoretical view of the examiner, results may primarily be used to discuss the presence or absence of psychopathology rather than to characterize the patient's stress and coping responses to his or her losses. Similarly, these measures have items having to do with somatic complaints that are often endorsed because of the patient's physical symptoms rather than mood symptoms, leading to an over diagnosis of depression (Gabriel & Kirschling, 1989; Hall & Johnston, 1994). Scales that grief researchers currently use for the assessment of physically healthy bereaved individuals are naturally worded to reflect reactions to the loss of a loved person rather than an ability or body part.

To rectify this problem, Niemeier et al., (2004) have recently developed a tool, called the *Loss Inventory* (LI), for the assessment of grief reactions and intensity experienced by patients in rehabilitation. The authors of the LI hope that the inventory will diagnose accurately by characterizing those symptoms that may occur during grief and not depression related to medical illness. This is an area of continued concern for clinicians wishing to correctly diagnose and treat depression in this population and, at the same time, not recommend unnecessary treatment (i.e. antidepressant medication) if a patient is having a *normal reaction* to loss rather than an episode of depression. The

potential indicators of complicated grief for the Loss Inventory (LI) came from a review of literature on positive symptoms of complicated grief within a spousal bereaved population (Niemeier & Burnett, 2001; Niemeier et al., 2004). Example items include the following: "I feel myself longing for the time before my loss", "I feel guilty about having this loss", and "My situation seems unreal to me." Niemeier et al., (2004) completed a study using the LI with 103 hospitalized patients with a variety of acute rehabilitative diagnosis (multiple sclerosis, stroke, brain injury, amputation, etc.) and found preliminary findings showing respectable internal consistency (Cronbach's Alpha = .95, Spearman-Brown = .94) as well as divergent validity between the LI and the Zung SDS (a measure of depression most often used in medical populations). Scores from the LI and the Zung SDS were significantly different (r=.59, p<.05) indicating that the LI is indeed measuring some construct different from depression, yet similar enough to yield a .59 correlation. Despite this finding, the sample size of the study was small and more extensive statistical analyses needs to be done.

Parkinson's disease and Essential Tremor

One particular rehabilitative group of concern is that of Parkinson's disease patients. Parkinson's disease (PD) is a chronic degenerative neurological illness. Tremor, muscular rigidity, bradykinesia, postural instability, and a loss of facial expression are the disease's most characteristic physical symptoms (Dakof & Mendelsohn, 1986). Patients may also suffer from cognitive deficits, concentration and memory problems. Those diagnosed with PD are often given their diagnosis unexpectedly. Furthermore, to suffer from Parkinson's disease in most cases interferes with a large spectrum of action goals

people have set for themselves. Although the disorder does not cause death, an increased risk of morbidity in persons with Parkinson's disease (PD) is associated with complications of inactivity. The following characteristics are common as PD progresses (Dakof & Mendelsohn, 1986; MacCarthy & Brown, 1989): self-care activities require more time, communication becomes more difficult because of slowness of speech and writing, dependency on others increases, intellectual functioning (decision making, memory, judgment) gradually deteriorates, withdrawal from interpersonal relations increases, and depression and anxiety intensify. Thus, a combination of these symptoms is likely to lead to feelings of loss within the PD patient and their family. Loss of functionality is also common to those with Essential Tremor (ET), another very common movement disorder characterized by a slowly progressive postural and/or kinetic tremor, usually affecting both upper extremities. Unlike Parkinson's disease, however, Essential tremor doesn't usually lead to serious health complications or is linked to other diseases (Louis, Barnes, & Albert, 2001; Putzle, Whaley, Baba, Wszolek, & Uitti, 2006) For some people, however, Essential tremor may be distressing but not as debilitating, though still likely to lead to feelings of loss.

Parkinson's disease and Depression

Parkinson's disease is frequently complicated by depression. The comorbidity of an episode of major depression in PD is a common clinical finding, with a mean prevalence of 50% and a range of 2.7% to 70% (Cummings, 1992; Dooneief et al., 1992; Leentjens, 2004). Several reasons for this variation in prevalence can be given. One reason is that different criteria have been used when diagnosing depression in patients

with PD. A review of the PD and depression literature revealed some proposed unique characteristics of depression complicating PD. It is thought that depression probably reflects a complex interplay of psychological reaction to the onset of PD symptoms as well as neurochemical brain changes. Perhaps more than any other medical disorder, the symptoms of PD overlap with the symptoms of depression (Leentjens, 2004). Patients with advanced PD often have significant sleep disturbances, fatigue, psychomotor slowing, difficulty concentrating, and diminished sexual function. PD patients can appear withdrawn from social activities, because they are unable to participate due to disabling dyskinesias and may be socially uncomfortable with their appearance. Even the appearance of a patient with PD (bradykinetic movements and flat facial expressions) may be similar to that of someone with a severe melancholic depression. Dementia symptoms too, may cloud the diagnosis of depression in PD. Apathy, concentration, attention, and memory problems associated with dementia can be misdiagnosed as comorbid depression. As mentioned earlier, most scales overdiagnose depression in PD because they do not distinguish the physical and neurologic symptoms of depression. Furthermore, the accurate diagnosis of depression in PD is further complicated by the observation that a majority of depressed PD patients are given diagnoses of less severe forms of mood disturbances, such as minor depression, dysthymic disorder, and subsyndromal symptoms. Thus, the DSM diagnostic criteria for major depression do not adequately describe the PD patients with subsyndromal levels of depression.

This observation in the literature raises two important points. First, the high rates of comorbid depressive symptoms in PD support the hypothesis that mood disturbances

may be a symptom of the neurodegenerative process in PD. Second, the fact that the rates of depressive symptoms are so high, yet the incidence of major depression is relatively low, highlights the importance of reexamining the diagnosis of depression in PD. Some researchers have demonstrated that comorbid depression in PD may be qualitatively different since these patients typically have increased anxiety, dysphoria, pessimism, and somatic symptoms but do not have guilt or self-blame (Brown & MacCarthy, 1990) Others have noted symptoms such as "lowered arousal" involving apathy and diminished self-initiated planning, psychomotor retardation, and irritability (Ehmann, Beninger, Gawel, & Riopelle, 1990a, 1990b; Frazier, 2000). Starkstein and colleagues (1992) had a series of 105 patients (21 with Major Depression, 20 with minor depression, and 64 with no depression), and observed that major depression significantly correlated with longer duration of PD and greater frequency of a personal history of depression prior to the onset of PD. Although PD patients may experience more suicidal ideation, suicide is not common in the PD patient population. Nevertheless, these subsyndromal depressive disorders can cause significant disability, and research should focus on defining the nature of this "depression" in PD and developing reliable screening tools. Since DSM diagnostic criteria for major depression do not adequately describe the PD patients with "subsyndromal depression", investigators have instead described a number of subtypes of depression in this population (i.e. apathetic and anxious subtypes), and it is unclear how these subtypes are related to primary mood disorders or if they are responsive to medication (Brown & Jahanshahi, 1995; Brown & MacCarthy, 1990; Cummings, 1992; Dooneief et al., 1992; Leentjens, 2004). It might be that in the case of Parkinson's

disease, these patients are in fact experiencing grief in response to their diagnosis and loss of functioning, instead of or in addition to a major depressive episode or depressive symptoms.

Current Study and Significance

The *Loss Inventory* (LI) was designed to measure grief intensity in a rehabilitative population. Its items are similar to items of measures of grief from a spousal bereaved population but are worded to refer to the patient's intrapersonal losses. This study intends to further assess for the validity and reliability of the *Loss Inventory* using a rehabilitative Parkinson's disease and Essential Tremor population. Since grief and depression have been used interchangeably in a rehabilitative population, it is necessary to distinguish symptoms of grief and depression especially since grief alone or in addition to depression can have a negative impact on the immune system and physical health, and high levels of grief could lead to adverse health sequalae for patients who are already physically compromised. The opportunity to differentially diagnose clinical depression versus grief and its complications may also allow for more appropriate interventions to be administered. Early identification of grief in these medical patients might allow clinicians to refer their patients for potential psychological interventions that would reduce costs of prolonged or more complicated care due to secondary comorbidities and/or lack of treatment compliance. Similarly, early identification of normal grieving or more complicated grieving might allow clinicians to avoid inappropriately intervening with unnecessary probing and referrals to psychotherapy and/or medication.

Individuals with Parkinson's disease, in particular, because of their physical symptoms of bradykinesia, tremor, and rigidity, may feel grief in association with their increasing functional losses and dependency on others. Grief in this rehabilitative population may or may not resemble grief reactions from the loss of a loved person. Due to the current controversy in diagnosis among Parkinson's disease patients (i.e. most have symptoms of "subsyndromal depression"), this study will also explore the amount of grief intensity experienced and explore the impact of both grief and depression symptoms on various psychosocial health outcomes (i.e. activities of daily living, sleep quality, self-esteem, number of medical illnesses and severity, general health and well-being, and anxiety). High intensity grief rather than depression or in combination with depression may contribute to the PD patient's overall well-being and functioning.

Overall, goals of the study include to first provide additional data on the validity and reliability of the *Loss Inventory*, a measure designed to examine intrapersonal grief. Second, the study explored the relationship between grief and depression among a medical population. Do specific symptoms of grief differ from symptoms of depression among a rehabilitative population as has been seen among those with spousal bereavement? Third, the study aimed to determine the independent or interactive influence of grief and depression on various psychosocial outcomes at Time 1 and also examined the potential influence of grief and depression or their interaction on subsequent mental and physical health outcomes at Time 2.

Hypotheses

Reliability of the Loss Inventory. It is hypothesized that items from the *Loss Inventory* will show high internal consistency (Cronbach'Alpha) similar to that found in an earlier study (Niemeier et al., 2004). This suggests that the *Loss Inventory* measures a distinct and homogenous domain: grief and loss. It is also hypothesized that the *Loss Inventory* will also have a high (.80 - .90) split-half reliability, which provides another measure of internal consistency with regard to content sampling (Anastasi & Urbina, 1997). Lastly, long-range test-retest reliability will show the extent to which scores from the *Loss Inventory* can be generalized over time. Because it is expected that changes in *Loss Inventory* scores will be minimal, this reliability coefficient is expected to be high (.80 - .90).

Convergent and Divergent Validity of the Loss Inventory. The *Loss Inventory* is hypothesized to be a valid tool for measuring grief intensity in this population. In order to demonstrate that the *Loss Inventory* in fact measures a construct most similar to grief, the LI must show that it is correlated highly with other variables or constructs with which it should theoretically correlate. It must also show that it does not correlate significantly with variables from which it should differ. The former process is called convergent validation and the latter called discriminant validation (Anastasi & Urbina, 1997). To estimate the degree to which any two measures are related to each other, the correlation coefficient will be used. That is, the intercorrelations among various measures should be "high" between theoretically similar measures and "low" between theoretically dissimilar measures. Unfortunately, the definition of "high" or "low" is controversial and is

dependent on the size of the study population. In general, convergent correlations should be as high as possible and discriminant correlations should be as low as possible. For example "*r*" ranging from zero to .20 may be regarded as indicating no or negligible correlation, "*r*" ranging from about .40 to .60 may be regarded as indicating a moderate degree of correlation, "*r*" from about .60 to .80 may be regarded as indicating a marked degree of correlation and finally "*r*" ranging from about .80 to 1.00 may be regarded as indicating a high correlation (Franzblau, 1958; Hinkle, Wiersma, & Jurs, 1988).

Regarding convergent validity, high correlations are expected between the *Loss Inventory* and Horowitz's *Impact of Events Scale* (IES), which measures amounts of intrusion and avoidance in response to a stressful situation. Symptoms of intrusion and avoidance have been thought to be symptoms of grief at least in a spousal bereaved population and may similarly be symptoms of grief in a rehabilitative Parkinson's population. Secondly, if the *Loss Inventory* measures grief intensity, then total LI scores should be positively correlated with the patient's functional loss as measured by the self-reported *Activities of Daily Living* (ADL) subscale of the *Unified Parkinson's Disease Rating Scale* (UPDRS) and the objective movement disability subscale of the UPDRS (UPDRS part III). Higher LI scores should indicate worse ADL functioning and disease severity. Length of diagnosis years is also hypothesized to positively correlate with the *Loss Inventory*, assuming that greater grief is associated with a longer duration of the illness. Finally, although reduced self-esteem has not been empirically shown to be associated with bereavement-related grief, this study hypothesized that lowered self-

esteem is associated with greater LI scores given the intrapersonal losses of chronic illness.

A .59 correlation found between the LI and Zung from Niemeier et al.,'s (2004) study suggests overlap in symptoms of depression and grief. However, while some correlation between *Zung SDS* and LI scores is expected, the study hypothesizes that grief and depression are not interchangeable. The LI is hypothesized to show divergence or a moderate correlation with the *Zung SDS*. The LI is also hypothesized to not correlate with cognitive impairment (MMSE) or self-report satisfaction of the patient's marriage, also showing divergent validity. Finally, divergent validity between the LI and *Zung SDS* will be assessed via principal component analyses. Here, the entire set of items from both scales, the LI and *Zung SDS*, will be combined. It is hypothesized that symptoms of grief (from the LI) will load highly on one factor while loading very poorly on the other extracted factor, which would contain mostly items from the depressive *Zung SDS* scale. It is hypothesized that at least two factors will be extracted that can be separately interpreted as symptoms of grief and depression. The LI and the *Zung SDS* are likely to have shared measurement variance because they both are of similar length and use the same method of administration. In addition, both measure constructs that involve affective distress. Thus, if the two questionnaires differ it will likely be because of actual differences between the two constructs. The LI will be measuring something different from the Zung's depression construct.

Factorial Validity. No a priori hypothesis regarding the factorial structure of the *Loss Inventory* will be made. However, it is expected that if experiencing intrapersonal losses

is similar to experiencing interpersonal losses (such as in spousal bereavement), then potential extracted components would be related to at least one or more of the following symptoms of bereavement-related grief: a yearning or longing over the loss, trouble accepting the loss, bitterness, inability trusting others since the loss, feeling uneasy moving on with one's life, feeling emotionally numb, feeling that life and the future is meaningless after the loss, feeling anger, and feeling agitated since the loss (Horowitz et al., 1997; Prigerson et al., 2000; Prigerson, 2004; Prigerson, Bierhals et al., 1996; Prigerson & Jacobs, 2001; Prigerson, Jacobs, Rosenheck, & Maciewjewski, 1999; Prigerson, Shear et al., 1996; Prigerson, Shear et al., 1999; Zhang, El-Jawahri, & Prigerson, 2006).

Prevalence of Depression and Intrapersonal Grief among a PD population. It is hypothesized that the study population will report varying levels of grieving symptoms as measured by the *Loss Inventory*. Varying levels of grief as measured by the LI will demonstrate the LI's ability to distinguish between patients who are experiencing a great amount of grief from those who are not. As mentioned earlier, many with Parkinson's disease are diagnosed with "subsyndromal depression" or dysthymia. Instead of a depression diagnosis, it is hypothesized that a majority of patients may instead experience relatively high amounts of intrapersonal grief and loss with few symptoms of depression. As mentioned earlier, a moderate correlation will exist between the LI and the Zung SDS, similar to what was found in the Niemeier et al., (2004) study.

Independent influence of Depression and Intrapersonal Grief on Psychosocial Outcomes. If grief and depression are different clinical entities, then one or both may influence various psychosocial outcomes such as self-esteem, state anxiety, intrusive and avoidant thoughts and behavior, subjective overall health and well-being, sleep quality, ADL functioning, and the number and severity of medical illnesses. Furthermore, grief (as a separate entity) is hypothesized to contribute additional variance in predicting the aforementioned health outcomes above that of baseline depression. Specifically, high intensity grief scores are hypothesized to predict greater IES (intrusive and avoidant behavior), ADL dysfunction, and medical co-morbidity and severity beyond the effects of depression. Additionally, interactive effects of grief and depression on the psychosocial outcomes may exist. Few, if any, studies have examined the interactive effects of grief and depression on psychosocial outcomes, even within a spousal bereaved population, therefore this analysis is exploratory and no hypotheses in this area were made.

Depression and Intrapersonal Grief as Risk Factors for Subsequent Mental and Physical Morbidity. Although the role of intrapersonal grief on overall health in a rehabilitative Parkinson's population is speculative and exploratory, it is also hypothesized that intense grief will be significantly related to the aforementioned health indicators over time. For example, high grief scores from Time 1 may contribute to global health dysfunction, increased sleep difficulty, and increased state-anxiety at Time 2, while controlling for the effects of physical status (movement disability and disease stage), concurrent levels of depression and the health outcome's prior health score. This is hypothesized since research has shown an association between high grief scores and

global health dysfunction in a spousal bereaved population, and it is thought that this association will be similar in this population (Bonanno & Kaltman, 1999; Beem, Hooijkaas, Cleiren, Schut, Garssen, & Croon, 1999; Beery, Prigerson, Bierhals, Santucci, Newsom, & Maciewjewski, 1997; Carr et al., 2000; Chen et al., 2000; Prigerson et al., 1997). However, it is possible that low amounts of grief within this medical population is reflective of non-resolved grief or unwillingness to express grief, and may subsequently lead to increased health consequences in the future. It is hypothesized that greater baseline depressive symptoms predict subjective global health dysfunction, low self-esteem, and increased number of medical illnesses (CIRS) at Time 2 while also controlling for the influence of physical status (movement disability and disease stage), concurrent grief scores, and the health outcome's prior health score. An interaction between baseline grief and depression scores may also predict subsequent health outcomes, though this analysis is exploratory and no specific hypothesis in this area were made.

Method

Participants

Participants were veterans seeking outpatient care at the Richmond McGuire Veteran's Hospital in Richmond, Virginia. All participants had a confirmed primary diagnosis of idiopathic Parkinson's disease or Essential Tremor as diagnosed by the clinic's neurologist. A review of the clinic's patient database showed that at the time of the study's initiation, the Parkinson's Disease Research, Education, and Clinical Center (PADRECC) had 728 patients, however 422 patients were diagnosed with PD and another 145 were diagnosed with Essential Tremor. Limited exclusionary criteria will yield a greater number of potential participants. The study's only exclusionary criterion was a cognitive Mini-Mental status exam (Folstein, Folstein, & McHugh, 1975) total score of less than 24, indicating possible dementia.

Five-hundred and sixty seven patients were eligible for the study (i.e. MMSE $\geq$ - 24, were diagnosed with Parkinson's disease (PD, N=422) or Essential Tremor (ET, N=145), and had not died since their initial clinic visit). These 567 existing patients were mailed study questionnaires to their homes. Information about the study and questionnaires were also given to 65 new clinic patients at their initial appointment at the VA hospital from January to September 2006. Overall, a total of 632 PADRECC potential patients were identified and a total of 250 questionnaires were returned. Seventeen of these questionnaires were ineligible for the study since these questionnaires

were less than 50% completed. An additional twenty-one spouses of patients returned their questionnaires incomplete due to the recent death of the patient. Two patients returned questionnaires incomplete due to a recent acute illness. A total of 210 participants (35.7% response rate) were included in the study analyses. Since this study mainly focuses on Parkinson's disease patients, only those PD patients who had completed their questionnaires within six weeks of the first questionnaire mail-out were given follow-up questionnaires at Time 2. Out of 160 mail-out questionnaires at Time 2, 100 (62.5% response rate) were returned completed within one month later. Two additional study participants returned questionnaires stating they were unable to participate due to an acute illness at that time.

The study population (N=210) at Time 1 consisted of 95.2% males. All, regardless of gender, were United States military veterans. The mean age of the total sample was 71.1 years (SD = 9.9; range = 35 to 89). The ethnic composition was 88.2% Caucasian, 8.8% African-American, 0.5% Hispanic, 0.5% Asian, 0.5% Native American, and 1.5% other. About 13% of the sample did not complete high school or receive a GED equivalent and another 22.3% completed high school only. The majority of the study population was retired and/or receiving disability benefits at the time of the study (87.3%). See Table 2 for additional demographic characteristics.

Medically, all participants had received or were currently receiving medical care for idiopathic Parkinson's disease or Essential Tremor. The clinic sees a majority of Parkinson's disease patients and consequently 87.6% of the study population had this diagnosis. Those with Parkinson's disease reported a longer disease history compared to

Table 2

Demographic characteristics for the total, PD, and ET study populations

	Total (n=210)	PD (n=184)	ET (n=26)
Gender:	95.2% male	95.1% male	96% male
Age:	71.1 (9.9)	71.5 (9.7)	67.9 (11.5)
Race:			
Caucasian	88.2%	89.3%	80.8%
Non-Caucasian	11.8%	9.6%	19.2%
Education:			
Did not graduate HS	13.6%	12.8%	19.2%
HS graduate	22.3%	22.2%	23.1%
Trade School/some college classes	32.5%	33.3%	26.9%
College graduate	14.6%	13.3%	23.1%
Some Graduate School	17.0%	18.3%	7.7%
Employment:			
Retired	87.3%	87.7%	84%
Part-time	4.9%	4.5%	8%
Full-time	7.8%	7.8%	8%
Marital Status:			
Married/coupled	73.2%	76%	53.8%
Divorced	12.9%	11.5%	23.1%
Widowed	8.1%	8.2%	7.7%
Separated	3.3%	2.2%	11.5%
Never Married	2.4%	2.2%	3.8%
Length of Marriage	40.6 (16.8)	41.3 (16.6)	34.4 (17.9)
Living Arrangement:			
Live with spouse	63.8%	66.3%	46.2%
With child only	2.9%	2.8%	3.8%
With wife and child	6.8%	6.6%	7.7%
With a friend	5.3%	4.4%	11.5%
Assisted living facility	4.3%	5.0%	-----
Live Alone	13.0%	11.6%	23.1%
Other relative	3.9%	3.3%	7.7%

those with Essential Tremor, (PD: M = 9.18; ET: M = 4.18; $t(14.5) = 3.395, p<.005$). The average disease stage rating from the *Modified Hoehn and Yahr Staging* for Parkinson's disease patients at the patient's initial clinic visit (i.e. anywhere between less than one year to three years prior to study participation) was 2.65 (Range = 0 to 5) indicating mild to moderate bilateral disease. The average *Schwab and England Activities of Daily Living scale* (S&E ADL) for Parkinson's Disease patients was 78.6% (Range = 20 to 100) indicating "independence in most chores, but takes twice as long" (van Hilten et al., 1994). This score was significantly worse than the average Essential Tremor patient's total S&E ADL score (M=86.3%, Range = 70 to 90; $t(105) = 2.99, p<.005$). Scores from the movement examination of the UPDRS at the initial clinic visit was 23.62 (Range = 4 to 51). This shows moderate amounts of movement disability for Parkinson's patients. Essential Tremor patients scored better (M = 14.2, Range = 2 to 21) showing improved movement ability compared to PD patients, $t(36.95) = 6.73$, $p<.001$). There were no significant differences found between the two diagnosis groups on number of medical illnesses (CIRS), number of moderate to severe medical illnesses (CMI), or cognitive ability (MMSE). Table 3 presents additional medical information for the total, PD, and ET study populations.

Of the total sample population, nearly 15% self-reported having had the diagnosis of a Major Depressive Disorder prior to their study participation and diagnosis of PD or ET. Nearly 31% reported currently using anti-depressant medications. About 31%

reported seeking emotional support from their medical doctor ranging from once to weekly and 19.5% reported seeking emotional support from a mental health professional. Those with a prior history of self-reported MDD were younger in age, $t(200) = -4.09$, $p<.001$, and had a shorter PD disease history, $t(37.31) = -2.65$, $p<.05$, than those with no history of MDD. Those who currently use anti-depressant medication were also younger, $t(81.64) = -4.701$, $p<.001$, and self-reported worse ADL dysfunction on the UPDRS ADL scale, $t(199) = 2.55$, $p<.05$, compared to those not using anti-depressant medication. See Table 4 for more information regarding differences in those with a prior MDD history versus those without a history and Table 5 for those who currently use anti-depressant medication versus those who do not.

Setting

The Hunter Holmes McGuire Veterans Affairs Medical Center in Richmond, Va., is one of six Veterans Health System Centers of Excellence for the treatment of Parkinson's disease. Patients referred to Parkinson's Disease Research, Education, and Clinical center undergo a comprehensive interdisciplinary evaluation that includes examination by a neurologist, neuropsychologist, nurse, and physiatrist. A diagnosis of PD was confirmed by the PADRECC neurologist (i.e. appropriate clinical findings and confirmed responsiveness to dopamine or dopamine-agonists).

Procedure

All possible participants were sent letters to their home explaining that they had an opportunity to participate in a study that examined emotional well-being in

Table 3

Medical and psychosocial characteristics for the total, PD, and ET study populations

	Total (n=210)	PD (n=184)	ET (n=26)
Diagnosis:	-------	87.6%	12.4%
DBS surgery:			
Yes	12.4%	13.1%	7.7%
No	87.6%	86.9%	92.3%
***Length of diagnosis: n=175	8.41(6.8)	8.69(6.8)	3.70(4.4)
Initial Clinic Visit:			
***H&Y n=107	2.65(.817)	2.69 (.779)	1.0 (1.4)
***S&E ADL n=152	79.74(12.4)	78.6 (12.9)	86.3 (5.8)
***UPDRS movement n=162	23.39(11.79)	23.62 (9.45)	14.2 (7.0)
MMSE n=139	28.06(2.9)	28.1 (3.0)	27.7 (2.8)
Medical Questionnaires:			
Illness burden (CIRS) n=179	9.68(7.71)	9.41 (7.0)	11.4 (11.3)
Co-morbidity (CMI) n=179	2.59(2.86)	2.44 (2.6)	3.5 (3.9)
***ADL functioning n=207	16.3(7.87)	17.10 (7.9)	10.7 (4.4)
Psychosocial Variables:			
Loss Inventory n=197	65.23 (26.63)	66.29 (26.1)	58.2 (29.5)
Zung Depression Index n=199	55.49 (12.3)	55.8 (11.6)	53.1 (16.1)
Rosenberg Self-esteem n=201	28.0 (5.97)	27.9 (5.9)	28.7 (6.4)
Impact of Events Scale n=191	24.2 (17.6)	25.1 (17.7)	18.6 (16.0)
STAI-state anxiety n=205	42.4 (14.9)	42.9 (14.9)	38.6 (14.4)
**General Health n=199	14.49 (7.73)	15.04 (7.6)	10.3 (7.4)
***PSQI: Sleep n=202	5.7 (4.0)	5.4 (3.8)	8.2 (4.3)

DBS = Deep Brain Stimulation, H&Y = Hoehn and Yahr Disease Staging, S&E ADL = Schwab & England Activities of Daily Living, UPDRS = Unified Parkinson's Disease Rating Scale, CIRS = Current Illness Rating Scale, CMI = Co-morbidity Illness Rating Scale, PSQI = Pittsburgh Sleep Quality Index. STAI = State-Trait Anxiety Inventory

*** = $p \leq .005$, ** = $p < .01$ * = $p \leq .05$; n = total sample population

Table 4

Medical and psychosocial characteristics for those with a prior MDD history versus no prior MDD history

	Prior MDD (n=30)	No prior history (n=176)
***Age	64.4 (9.0)n=30	72.2 (9.7) n=172
Diagnosis:		
PD	13.8% (n=25)	----------
ET	20% (n=5)	----------
Total Sample	14.6% (n=30)	
*Length of diagnosis:	6.0 (5.5) n=23	8.8 (6.8) n=149
Initial Clinic Visit:		
H&Y	2.74 (.986)n=29	2.63 (.779) n=88
S&E ADL	80.0 (10.4)n=25	79.76 (13.0) n=124
UPDRS– movement	25.24 (12.56)n=24	22.84 (11.3) n=132
MMSE	27.3 (2.49)n=20	28.1 (3.1) n=116
Medical Questionnaires:		
***Illness burden (CIRS)	14.3 (7.3)n=26	8.91 (7.5) n=150
***Co-morbidity (CMI)	4.46 (3.1)n=26	2.29 (2.7) n=150
ADL functioning	17.8 (7.75)n=29	16.1 (7.85) n=174
Psychosocial Variables:		
***Loss Inventory	88.38(26.62)n=29	61.25 (24.59) n=165
***Zung depression Index	69.1 (13.3)n=29	53.5(10.9)n=167
***Rosenberg Self-esteem	23.7 (5.92)n=30	28.68 (5.6) n=167
***Impact of Events Scale	38.93 (17.6)n=28	21.67 (16.5)n=160
***STAI-state anxiety	54.63 (16.3)n=30	40.34 (13.7) n=172
***General Health	21.7 (8.39)n=27	13.36 (7.0) n=169
***PSQI: Sleep	9.25 (4.49)n=28	5.18 (3.67)n=170

DBS = Deep Brain Stimulation, H&Y = Hoehn and Yahr Disease Staging, S&E ADL = Schwab & England Activities of Daily Living, UPDRS = Unified Parkinson's Disease Rating Scale, CIRS = Current Illness Rating Scale, CMI = Co-morbidity Illness Rating Scale, PSQI = Pittsburgh Sleep Quality Index. STAI = State-Trait Anxiety Inventory
*** = $p \leq .005$, ** = $p < .01$ * = $p \leq .05$; n = total sample population

Table 5

Medical and psychosocial characteristics for those currently using anti-depressant medication versus those who are not.

	Using Anti-Dep Meds (n=62)	No Anti-Dep meds (n=139)
*Age:	68.22(10.8)n=60	72.04 (9.4)n=137
Diagnosis:		
PD	31.4% (n=55/184)	----------
ET	26.9% (n=7/26)	----------
Total Sample	30.8% (n=62/210)	
Length of diagnosis:	8.98 (7.25)n=52	8.32 (6.6) n=115
Initial Clinic Visit:		
H&Y	2.83 (.71)n=35	2.57 (.87)n=68
*S&E ADL	76.88 (12.74)n=48	81.31(12.4) n=99
UPDRS movement	25.87 (11.44)n=51	21.98 (11.9)n=103
*MMSE	27.3 (3.23)n=42	28.39 (2.86)n=93
Medical Questionnaires:		
**Illness burden (CIRS)	12.16 (7.22)n=51	8.71 (7.82)n=121
**Co-morbidity (CMI)	3.51 (2.97)n=51	2.24 (2.78)n=121
*UPDRS ADL functioning	18.47 (7.82)n=35	15.43 (7.71)n=68
Psychosocial Variables:		
***Loss Inventory	81.98(26.63)n=60	58.99(23.78)n=130
***Zung depression Index	60.51 (13.93)n=59	53.22 (10.87)n=133
***Rosenberg self-esteem	26.11 (6.57)n=61	29.04 (5.44)n=134
***Impact of Events Scale	30.07 (17.53)n=59	20.81 (16.92) n=124
***STAI-state anxiety	48.45 (15.59)n=62	39.41 (13.35) n=135
***General Health	17.75 (8.22)n=60	12.83 (6.94) n=132
***PSQI:Sleep	7.52 (4.90)n=61	4.90 (3.26) n=133

DBS = Deep Brain Stimulation, H&Y = Hoehn and Yahr Disease Staging, S&E ADL = Schwab & England Activities of Daily Living, UPDRS = Unified Parkinson's Disease Rating Scale, CIRS = Current Illness Rating Scale, CMI = Co-morbidity Illness Rating Scale, PSQI = Pittsburgh Sleep Quality Index

*** = $p \leq .005$, ** = $p < .01$* = $p \leq .05$

Parkinson's disease patients (see Appendix A). Guest lectures given by this investigator and fliers were prepared for added recruitment of participants (see Appendix B). Study participants were given limited details related to the hypotheses or specific objectives of the study. Packages of questionnaires were mailed to all potential patients by the VA staff. Stamped and addressed envelopes were provided to all participants to mail back to the VA hospital. If participants had not completed questionnaires within 3 to 4 weeks, then follow-up letters were mailed to these participants (see Appendix C). All new patients seen for the first time at the clinic with a confirmed diagnosis of Parkinson's disease or Essential Tremor were also given questionnaires and were able to return them by mailing them back to the VA hospital. Questionnaires took up to one hour to complete (see Appendix D). They included the following: *The Loss Inventory* (30 items), *Zung Self-Report Depression Scale* (20 items), *Impact of Events Scale* (15 items), *Rosenberg's Self-Esteem scale* (10 items), *Pittsburgh Sleep Quality Index* (19 items), *State-Trait Anxiety Scale* (State only, 20 items), *Unified Parkinson's Disease Rating Scale*; *Activities of Daily Living* (14 items), *General Health Questionnaire-12* (12 items), and *Cumulative Illness Rating Scale* (14 items). Participants were instructed that they may complete questionnaires at intervals (i.e. allow for breaks). Because this study mainly focuses on Parkinson's disease patients (given the study's research questions and potential limited availability of Essential Tremor patients), only the PD patients were requested to complete the package of questionnaires again (Time 2) at five months after they have returned the original questionnaires. All patients were informed that participating or not

participating in the study would not affect their care at the VA Hospital. Questionnaires did not contain any identifying information. All potential participants were later identified with a three-digit code listed on their returned questionnaires that corresponded to each participant's medical data from their medical records. Medical variables were obtained from the patient's physician and medical records/PADRECC databases at the time of the patient's initial visit and clinic follow-up visits.

Measures: Demographic, Antecedant and Background

Antecedent and background factors consist of demographic variables (age, SES indicators, race/ethnicity, living arrangements, marital status, recent loss of loved one), expectedness of diagnosis, and measures of health status (i.e. past psychiatric history, taking antidepressant medications, has had Deep Brain Stimulation surgery, recent medical diagnosis). Participants were asked to rate their health (from poor to excellent) and complete the corresponding health measures as described below. The expectedness of loss/diagnosis was assessed on the basis of five response alternatives from 1 (completely expected) to 5 (not at all expected).

Patient Objective Health and Disability Measures

Information was gathered from patient records regarding basic medical information with respect to their Parkinson's disease diagnosis. This included the patient's self-report of date of diagnosis, current stage of disease process, activities of daily living, motor ability, and treatments received. These data were collected at each patient's initial visit to the PADRECC clinic. Time points for any particular patient's initial visit ranged from two months to three years prior to completing the study's

questionnaire packet. Motor disability data was also collected at a time point closer (within one year) of completion of the study questionnaires. These data were all assessed by the following questionnaires:

Unified Parkinson's Disease Rating Scale (Fahn & Elton, 1987). The Unified Parkinson's Disease Rating Scale (UPDRS) is currently the most widely accepted reliable and valid scale for measuring the different components of PD (Richards, Marder, Cole, & Mayeux, 1994; van Hilten, van der Zwan, Zwindmerman, & Roos, 1994). It is used in clinical research and drug trials to follow the longitudinal course of PD, and allows the physician to assess easily the course of PD with treatment and time. Its major strength is that it provides a detailed and accurate assessment of PD in different respects. It is divided into four sections. For this study, only the activities of daily living (ADL) and motor examination sections will be used; other sections include Mentation (mental activity), behavior, and mood, and Complications of therapy.

The *motor examination* is conducted by the physician and is a detailed motor examination that evaluates 14 items with 27 distinct functions. Each item is scored on a scale from 0 to 4. A total of 108 points is possible, with 108 representing maximal or total disability and 0 representing no disability. Each patient's initial clinical evaluation score and the most recent (to the current study) follow-up clinic visits will be included for use in this study.

The *ADL scale* component measures the impact of PD on 14 categories, including speech, swallowing, handwriting, cutting food, dressing, hygiene, turning in bed, falling, walking, right and left sided tremor, salivation, and sensory complaints. Each category is

scored on a 0-4 scale, with 0 indicating normal or unaffected functioning, and 4 signifying a patient who is helpless or non-ambulatory. For example, the response scale for cutting food and handling utensils is as follows: 0 = Normal, 1 = Somewhat slow and clumsy, but no help needed, 2 = Can cut most foods, although clumsy and slow; some help needed, 3 = Food must be cut by someone, but can still feed slowly, 4 = Needs to be fed. The scores for the 14 categories are summed to give an overall ADL score. The overall score ranges from 0 to 56, with higher scores reflecting greater disability and the need for assistance. This is a self-report scale and was given to the patient in the study packet of questionnaires.

The Modified Schwab and England Capacity for Daily Living Scale (S&E ADL Scale, Fahn & Elton, 1987). This scale is widely used to assess disability in performing activities of daily living for people with PD. It is a percentage scale divided into deciles, with 100% representing completely normal function and 0% representing total dependency. This score is usually determined by the clinic nurse and is given only during the clinic's initial visit.

Modified Hoehn and Yahr Staging Scale (Hoehn, 1992; Hoehn & Yahr, 1967). The Modified Hoehn and Yahr Staging Scale is also widely used and designed to give an estimate of PD disease staging based on the following categories:

0 No evidence of disease

1.0 Unilateral disease only

1.5 Unilateral disease plus axial involvement

2.0 Bilateral mild disease, without impairment of balance

2.5 Mild bilateral disease with recovery on pull test

3.0 Mild-to-moderate bilateral disease, with some postural instability but physically independent

4.0 Severe disease, but still able to walk or stand unassisted

5.0 Wheelchair bound or bedridden unless aided

It is usually determined by either the clinic nurse or neurologist during the initial clinic visit.

Measures of self-reported mood

Loss Inventory (LI, Niemeier et al., 2004). The *Loss Inventory* was designed to assess unique grief symptoms following disablement. It has shown promise but needs further establishment of its reliability and validity. The 30 items of this self-report scale were developed from the bereavement literature. Preliminary findings using the LI with 103 hospitalized patients undergoing acute rehabilitation for functional and cognitive deficits included respectable internal consistency (Cronbach's Alpha = .95, Spearman-Brown = .94) as well as reliability and validity (.59 correlation with the Zung SDS). Gender and ethnic differences were significant with both minority and male patients scoring lower (less grief intensity) than Caucasian and female patients.

Zung Self-Rating Depression Scale (Zung-SDS, 1965a, 1965b). The *Zung SDS* consists of 20 items that address each of four most commonly found characteristics of depression: the pervasive effect, the physiological equivalents, other disturbances, and psychomotor activities. Ten items are worded positively and ten items are worded negatively. Each item is scored on a 1-4 point scale (1= little of the time – 4=most of the

time) with reverse scoring. In an analysis of the discriminatory power of the *Zung SDS*, scores for clinically depressed patients were significantly higher than normal controls (Zung, 1965b).

The Impact Events Stress Scale (IES, Horowitz, Wilner, & Alvarez, 1979). This 15-item scale measures stress associated with traumatic events. It consists of two subscales one reflecting intrusive stress experiences such as stress-related thoughts, feelings) and the other reflecting avoidance of thoughts, feelings, or reminders of the event. The intrusive subscale consists of seven items. The avoidance subscale consists of 8 items each requesting endorsements using a four-point scale to rate how frequently the intrusive or avoidance reaction occurred. Higher scores reflect more stressful impact. Both the intrusion and avoidance scales have displayed acceptable reliability (alpha of .79 and .82, respectively), and a split-half reliability for the whole scale of .86 (Horowitz et al., 1979). The IES has also displayed the ability to discriminate a variety of traumatized groups from non-traumatized groups (Briere & Elliott, 1998).

Measures of General Health and Functioning

Rosenberg Self-esteem Scale (Rosenberg, 1965). This scale consists of 10 Likert-type items that are summed for a possible range of 10 (low) to 40 (high). Although originally designed for adolescent populations, this scale has been shown to be a useful measure for older populations in which a score of 29 or less is indicative of low self-esteem for this age group (Ward, 1977). Blascovic & Tomaka (1991) reported test-retest coefficients equal to .85, and validity coefficients ranging from .59 to .83.

Pittsburgh Sleep Quality Index (PSQI; Buysse, Reynolds, Monk, Berman, & Kupfer, 1989). The PSQI (Buysse et al., 1989) is a self-rated questionnaire that assesses sleep quality and disturbances over a 1-month time interval. Nineteen individual items lead to seven component scores: subjective sleep quality, sleep onset latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleep medication, and daytime dysfunction. The sum of scores for these seven subscales yields one global score of overall sleep quality. The PSQI has internal consistency and has a reliability coefficient (Cronbach's alpha) of .83 for all of its seven components. Numerous studies using the PSQI have supported high reliability and validity (Backhaus, Junghanns, Broocks, Riemann, & Hohagen 2002; Beck, Schwartz, Towsley, Dudley, & Barsevick, 2004; Knutson, Rathouz, Yan, Liu, & Lauderdale, 2006).

State Trait Anxiety Inventory-State (STAI-state, Spielberger, 1983). This measure is a self-rated questionnaire that assesses one's current level of tension and apprehension. It is the most frequently used scale designed to study anxiety. It consists of 20 items with a range of four possible responses to each. A higher score means more state anxiety and low scores mean less. The reliability of the STAI was assessed on male and female high school and college students. The test-retest range for the State-anxiety scale was .16 to .62, which is expected since responses to these items are thought to reflect transient situational factors existing at the time of testing.

Short General Health Questionnaire (GHQ-12, Goldberg & Blackwell, 1970). The GHQ-12 is designed to be self-administered. The questionnaire comprises twelve questions, asking participants about their general level of happiness, experience of

depressive and anxiety symptoms and sleep disturbance over the last four weeks. Thus, the questionnaire concerns itself with an inability to carry out one's normal healthy functions and an appearance of new phenomena of a distressing nature. Interpretation of the answers is based on a four-point response scale (symptom present = 0, same as usual = 1, more than usual = 2, and much more than usual = 3; with a total range of 0-36). Higher scores suggest greater distress. The questionnaire has been used in the National Health Survey for many years and has been thought to be valid among older age groups despite its presence of physical symptoms items. Values for the scales' internal consistency, Cronbach's alpha, range from .82 to .93 (Shek, 1987) depending on the particular version used. The scale has shown appropriate criterion-related validity in its correlation to measures of psychiatric illness derived from the *Clinical Interview Schedule* (CIS) (Goldberg & Blackwell, 1970).

Cumulative Rating Illness Scale (CIRS, Linn, Linn, & Gurel, 1968). This scale uses 5-point ordinal scales (0-4 points) to estimate the self-reported severity of pathology in each of 14 systems, including cardiac, respiratory, renal, musculo-skeletal, and psychiatric. Based on the ratings, two scores are derived. The total cumulative Illness (CIRS) rating score, which reflects the overall burden of illness and is based on the sum of the ratings for all 14 categories (0 to 56). The *comorbidity index* (CMI) reflects the diversity of illnesses and is the total number of categories in which moderate (3) or severe (4) levels of pathology are noted (0 to 13). Higher scores for both the CIRS and CMI indicate greater medical complexity. The instrument has shown adequate test-retest reliability, construct and discriminative validity. The CIRS has also shown validity within

a geriatric and geriatric rehabilitation population (Miller et al., 1992; Parmalee, Thuras, Katz, & Lawton, 1995) and among patients with cancer (Wedding et al., 2007).

Data Analysis

Missing Data. Missing data is common in questionnaire-based research studies. For this study, returned questionnaire packages with less than 50% total completion were not used in any analyses. A mean substitution score for each individual questionnaire was imputed if data was missing for less than 50% of the total individual questionnaire. For all medical variables (Hoehn & Yahr Disease Stage, UPDRS movement disability, and Schwab & England ADL), data was considered missing if it was not collected by the clinic (missing H&Y=82, UPDRS=48, S&E ADL=54). T-tests were completed to determine if missing data was at random for each of the outcome variables; analyses showed that these data were missing at random. Outlying scores for each questionnaire were also identified and defined as any score greater than three standard deviations from the mean on any of the variables of interest (Hair, Anderson, Tatum, & Black, 1998). These outliers were considered missing as well. The only skewed variable, length of diagnosis, was log transformed. Efforts were made to collect all questionnaires administered at Time 2.

Reliability of the Loss Inventory. Cronbach's alpha was used to determine internal consistency. Regarding split-half reliability, the *Loss Inventory* was divided into odd and even items as is common in many reliability analyses. Correlation coefficients were calculated to determine test-retest reliability from Time 1 and Time 2 using only

participants who completed questionnaires at both time points. A paired t-test was used to determine a difference in total scores at Time 1 and Time 2.

Convergent and Divergent Validity of the Loss Inventory. Regarding the validity of the Loss Inventory, the assessment of convergent validity was limited by the fact that there exists no known scale of this construct of grief for a rehabilitative population. However, as explained earlier, some research has shown that symptoms of intrusion and avoidance are characteristic of grief in at least a spousal bereaved population. The IES, thus, is used as a distal construct to assess for convergent validity, and the two are expected to have a high and significant correlation. Amount of functionality as measured by the ADL scores (UPDRS part 1), motor examination (UPDRS part 3), length of diagnosis, as well as self-esteem were also used to assess for convergent validity. Cognitive impairment (MMSE) and self-reported marriage satisfaction were used to assess for divergent validity. Pearson and Spearman rho correlation coefficients were calculated to establish the relationship between these variables (as well as other study collected variables) and the Loss Inventory. Given the use of multiple correlation analyses, an adjusted Bonferroni correction (Miller, 1966; Perneger, 1998) was used separately for Time 1 and Time 2 variables.

A low to moderate correlation between the LI and *Zung SDS* was also assessed to establish divergent validity. The study also used principal-components analysis (PCA) with an oblique promax rotation to determine how the selected pool of symptoms (items from both the *Loss Inventory* and *Zung SDS*) taken at Time 1 would cluster together. A PCA is needed so that it can be determined how many distinct factors can be extracted

from combining the LI and *Zung SDS* items. Since the LI and *Zung SDS* are expected to be somewhat associated and moderately correlated, an oblique rotation (a common rotation as part of a PCA analysis) was conducted. Overall, it was thought that at least two factors from the combined LI and Zung items will likely be extracted. Items within the LI and the *Zung SDS* separately will have high intercorrelations suggesting the presence of two distinct questionnaires. A high internal consistency from the LI items, assessed by Cronbach's alpha coefficient, will essentially measure homogeneity and thus also add to the LI's construct validity. Overall, this type of analysis is needed to determine if particular symptoms asked within the LI or *Zung SDS* are more prominently symptoms of one factor versus another (ideally intrapersonal grief versus depression) by examining which factor each item loads onto. Regarding power, a conservative analysis of this type is thought to need at least 5-8 persons for each individual item. The LI and *Zung SDS* combined yielded 50 questions. It is estimated that about 250 individuals were needed for sufficient power (Cohen, 1988).

Similar studies using bereaved participants have used a principal component analysis to answer a similar research question regarding distinguishing symptoms of grief versus depression (Boelen, van den Bout & de Keijser, 2003; Chen et al., 1999; Prigerson, Frank et al., 1995; Prigerson, Maciewjewski et al., 1995; Prigerson, Bierhals et al., 1996; Prigerson, Shear et al., 1996; Prigerson, Jacobs et al., 1999; Prigerson, Shear et al., 1999; and Ritsher & Neugebauer, 2002). In these studies, two factors were extracted, and were interpreted to be grief and depression. The grief factor had more items relating to yearning, loss, and avoidance of past thoughts, whereas the depression factor had more

items relating to loss of appetite, sleep difficulty, suicidal ideation, etc. A similar arbitrary interpretation was used for this study.

Factorial Validity of the Loss Inventory. Items from the *Loss Inventory* were subjected to an exploratory principal component analysis as well. Because of the possibility of a significant correlation among extracted components, both an oblique promax and orthogonal varimax rotation will be conducted. Only those items with a component loading of greater than 0.5 were included when placing items on the extracted components. Extracted components were determined by the Kaiser-Gutman eigenvalue greater-than-one rule and by examination of the scree plot.

Prevalence of Intrapersonal Grief and Depression among a PD population. Descriptive statistics (means and standard deviations of all variables) at Time 1 and Time 2 were calculated. Raw score frequencies from the *Loss Inventory* were used to assess if the LI was able to show varying levels of grief. Using PD patients only, participants were categorized as experiencing depression (ranging from mild to severe symptoms as validated by the *Zung SDS*, a cutoff score ≥ 50) or little to no symptoms of depression (*Zung SDS* <50). Since limited research has been done with the *Loss Inventory*, no cut-off score indicating high intensity grief has been validated. For purposes of this study only, those who scored above the sample's median were defined as experiencing higher grief intensity and those who scored below the sample's median were defined as experiencing lower grief intensity. The distribution of participants for each category (e.g. depression/low loss, depression/high loss, no depression/low loss, and no depression/high

loss) was displayed in a contingency table. A Pearson correlation was also used to examine the relationship between depressive and intrapersonal grief intensity scores.

Influence of Depression and Intrapersonal Grief on Psychosocial Outcomes. Psychosocial outcomes included the following: self-esteem, self-reported global health, state anxiety, intrusive thought and avoidant behavior, sleep quality, number of co-morbid medical illnesses, number of moderate to severe medical illnesses, subjective activities of daily living (UPDRS ADL component), and depressed mood. These questionnaires were assessed at Time 1 and at Time 2. All questionnaires were centered on their mean by subtracting the mean from each individual variable score to produce variables with a mean close to zero (Aiken & West, 1991). This was done in order to place each of the variables on a common metric. Hierarchical multiple regressions were used to test the influence of depression and intrapersonal grief on the concurrent psychosocial health outcomes. Since the study sample mainly consisted of older males of Caucasian race, age, sex, and race were not treated as demographic covariates. Instead, initial UPDRS movement disability scores and Hoehn & Yahr disease stage were controlled for (entered onto Step 1) since both of these variables are likely to significantly influence health outcomes. Next, Time 1 depression scores were entered onto Step 2, followed by Time 1 grief scores entered onto Step 3. Lastly, their interactive term was entered onto Step 4. Significant interactions will be interpreted by solving the regression equations at one standard deviation above and below the mean for each of the components of the interaction. Overall, this order of forced entry will allow the opportunity to assess the influence of *Zung SDS* scores to predict concurrent health

outcomes beyond physical disability and disease stage (step 2) and examine if grief scores predict health outcomes while controlling for physical disability, disease stage, and depression (step 3). Because of the large number of models that were estimated, a more stringent significance threshold ($p < 0.01$) for interpreting the regression results was used to correct for Type 1 error. Probabilities between 0.01 and 0.05 were considered marginally significant for these regression models. If intrapersonal grief additionally contributes to various health outcomes beyond that of depression, then assessing for both in a medical setting may offer clinical utility for clinicians and patients.

Depression and Intrapersonal Grief as Risk Factors for Subsequent Mental and Physical Morbidity. In order to evaluate future (Time 2) health consequences (i.e. self-esteem, self-reported global health, state anxiety, intrusive thought and avoidant behavior, sleep impairment, number of co-morbid medical illnesses, number of moderate to severe medical illnesses, subjective ADL functioning (UPDRS ADL component), and depressed mood), the multiple regression procedure was used. Again, all questionnaires were centered and only those who completed both sets of questionnaires were used in these analyses (N = 100). In these analyses, each health outcome was predicted by the *Loss Inventory* and *Zung SDS*, while prior history of the dependent variable reported at baseline Time 1, physical disability, and disease stage were controlled. Specifically, physical disability, disease stage, the dependent variable's Time 1 score, Time 1 depression, Time 1 grief scores, and the interaction term were all entered simultaneously. This method of forced entry allowed examination of the potential differential roles of depression, loss, and their interaction on health outcomes at Time 2, while taking into

account physical disability, disease, and the dependent variable's baseline scores. Again, because of the large number of models that were estimated, a more stringent significance threshold ($p< 0.01$) for interpreting the regression results was used. Probabilities between 0.01 and 0.05 were considered marginally significant for these regression models as well.

Results

Validity and Reliability of the Loss Inventory

Reliability. One item from the *Loss Inventory* was deleted from all data analyses due to a clerical error on the mail-out questionnaires (Question #9: I feel disbelief about what had happened). The resulting 29-item *Loss Inventory*'s internal consistency (Cronbach's alpha) was 0.975 at Time 1 and 0.976 at Time 2. The scale's Spearman-Brown's split half reliability for the 29-item scale at Time 1 was 0.952. As expected, these findings were similar to Niemeier et al.,'s (2004) study findings with a diverse rehab population. For those participants who completed the LI at both Time 1 and five to six months later (N=100), the questionnaire's test-retest reliability was .728 ($p< .001$). This suggests that the questionnaire measured the same construct over the two test occasions. A paired t-test of Time 1 and Time 2 *Loss Inventory* scores was not significant, indicating that scores at Time 1 and Time 2 were not significantly different from one another, (Time 1 M: 62.96, SD = 26.39; Time 2 M: 60.29, SD = 24.44; $t(89) = 1.324$, $p=.189$). In order to determine if change in physical functioning (as measured by self-report ADL scores) over time (Time 1 to Time 2) would predict Time 2 LI scores, a multiple regression analysis was completed. Specifically, Time 1 LI scores and the change score were entered simultaneously into the model predicting Time 2 LI. This was done to determine if the LI was sensitive to physical functioning change. Results showed that changes in ADL functioning did not predict Time 2 LI scores. The LI was not sensitive to physical functioning change over a 5-6 month time span within this population (See Table 6).

Table 6

Change in self-report ADL functioning as a predictor in Time 2 Loss Inventory scores

DV: Time 2 Grief

	B	SE	*B*	Sig.
Step 1				
**T1 Grief	.678	.067	.734	.000
Change in ADL	.258	.426	.044	.546
Overall model fit: F(2,89) = 50.822, p=.000				

** p<.01 * $p \leq .05$

Convergent Validity. In order to examine symptoms of depression (as measured by the *Zung SDS*) and intrapersonal grief (as measured by the *Loss Inventory*) separately, it is first important to determine if the *Loss Inventory* is in fact measuring intrapersonal grief. For these analyses both ET and PD participants were used, since the groups did not significantly differ in their total *Loss Inventory* or *Zung SDS* scores (see Table 3). Regarding convergent validity, the *Loss Inventory* total scores were significantly correlated with both subscales of the *Impact of Events Scale* (Intrusive Thought and Avoidance) and the scale's total score. These significant positive correlations were expected from the study's hypotheses. Similar to a spousal bereaved population, greater grief and loss is correlated with greater distress, intrusive thought, and avoidance of the stressor. As expected, The *Loss Inventory*'s total scores were also significantly correlated with self-esteem, such that greater intrapersonal grief was associated with worse self-esteem. On self-reported medical measures, the *Loss Inventory* was correlated, as expected, with a greater number of medical illnesses (CIRS), greater number of moderate to severe medical illnesses (CMI), and greater difficulty with ADL functioning (UPDRS ADL subscale). Data from the patient's medical charts showed a significant positive correlation between the *Loss Inventory* and the UPDRS movement disability subscale at the patient's initial clinic visit.

Most of these correlations were also observed between the LI and the aforementioned outcomes at Time 2 with the exception of a marginally significant finding between the *Loss Inventory* and the number of medical illnesses (CIRS). See

Table 7 for correlations between the *Loss Inventory*, *Zung SDS* and all outcome measures at both time points.

Unexpected from the study's hypotheses, the *Loss Inventory* did not correlate with the number of years since diagnosis (log transformed) or with expectedness of the illness. Other significant *Loss Inventory* total score correlations included a negative correlation with age and a trend toward significance with education. These results suggests that those who are younger or those with less education have higher grief intensity scores. Additionally, the *Loss Inventory* was significantly correlated at both time points with the *STAI-State Anxiety Scale*, the *General Health Questionnaire*, and the *Pittsburgh Sleep Quality Index*, suggesting that greater state anxiety, worse general health, and greater sleep impairment is associated with greater loss/grief intensity. See Table 7 for more information.

Divergent Validity. As expected, no significant correlation was found between the LI and total *Mini-Mental Status Exam* scores (r = -.128, p=.141) or a 1 through 7-point self-report scale of happiness of the patient's marriage (r =-.09, p=.248). The overall sample correlation (both PD and ET patients) between the *Loss Inventory* and the *Zung SDS* was r= .610, p< .001 and r= .586, p< .001 for a PD population alone. These correlations show a moderate correlation and are higher than what was expected.

To examine divergent validity between the *Loss Inventory* and the *Zung SDS*, all items from these two scales were combined and subjected to a principal component analysis using an oblique promax rotation (delta = 4). An oblique promax rotation was necessary given the known correlation between the two scales. Again, both PD and ET

Table 7

Correlations between the Loss Inventory, Zung SDS and various outcome measures at two time points.

Variable	LI 1	Zung 1	LI 2	Zung 2
Age	-.270 .000*** 192	-.168 .019 194	-.193 .066 92	-.104 .324 91
#Education	-.172 .016 194	-.035 .630 196	-.248 .021 88	-.079 .461 89
Expectedness of Illness	-.002 .974 182	-.070 .342 185	-.172 .104 90	-.154 .160 89
Length of Diagnosis Log transformed	.088 .277 155	-.037 .644 156	-.018 .868 91	-.082 .442 91
Zung SDS	.610 .000*** 192	----------	.619 .000*** 94	----------
Self-Esteem	-.562 .000** 195	-.615 .000*** 195	-.665 .000*** 96	-.720 .000*** 98
IES Avoidance Subscale	.621 .000*** 186	.468 .000*** 190	.498 .000*** 92	.422 .000*** 92
IES: Intrusive Thoughts	.680 .000*** 186	.549 .000*** 187	.743 .000*** 91	.705 .000*** 91
IES Both Total subscale	.693 .000*** 185	.542 000*** 186	.731 .000*** 91	.705 .000*** 91
STAI anxiety	.681 .000*** 194	.648 .000*** 196	.620 .000*** 95	.740 .000*** 94
General Health Questionnaire	.731 .000*** 191	.697 .000*** 192	.652 .000*** 94	.707 .000*** 93
Subjective sleep Quality	.456 .000*** 191	.502 .000*** 193	.415 .000*** 89	.558 .000*** 88

LI 2 and Zung 2 are correlated to Outcomes taken at Time 2 and are among PD pts only
uses nonparametric correlations: Spearman's rho. Bottom numbers are total Ns
*** = $p<.005$; ** = $p<.01$; * = $p<.05$ with Adjusted Bonferroni corrections

Table 7 (Continued)

Variable	LI Time 1	Zung Time 1	LI Time 2	Zung Time 2
#H&Y Initial Clinic Visit	.173 .081 103	.233 .018 103	.337 .008 56	.343 .007 56
S& E ADL Initial Clinic Visit	-.118 .157 145	-.125 .134 146	-.225 .05 76	-.290 .011 76
UPDRS Initial Clinic Visit	.278 .000*** 154	.286 .000*** 154	.283 .009 85	.229 .036 84
MMSE Initial Clinic Visit	-.128 .141 134	-.092 .287 135	-.105 .382 71	-.386 .001*** 71
#H&Y Closer to Time 1	.264 .013 88	.283 .007 89	.380 .004 54	.193 .159 52
S&E ADL Closer to Time 1	-.202 .042 101	-.199 .044 102	-.261 .044 60	-.292 .026 58
UPDRS : Closer to the Time 1	.267 .025 70	.311 .008 72	.523 .001*** 35	.193 .268 35
CIRS (burden of illness)	.290 .000*** .174	.315 .000*** .174	.277 .009 89	.339 .001*** 88
CMI (co-morbidity of illnesses)	.240 .001*** -174	.280 .000*** 174	.359 .001*** 89	.445 .000*** 88
ADL function	.422 .000*** 194	.430 .000*** .196	.490 .000*** 94	.423 .000*** 93
Overall self-report of health	-.386 .000*** 192	-.425 .000*** 194	-.390 .000*** 89	-.378 .000*** 90

LI 2 and Zung 2 are correlated to Outcomes taken at Time 2
uses nonparamtric correlations: Spearman's rho. Bottom numbers are total Ns
*** = p<.005; ** = p<.01; * = p<.05 with Adjusted Bonferroni corrections

participants were used in these analyses since the groups' LI and Zung SDS scores did not differ. Using this method, the Kaiser-Meyer-Olkin measure of sampling adequacy was .938, which was a more than acceptable value to continue with the analysis given a final sample size of 210 PD and ET participants (Kaiser & Rice, 1974). This statistic reflects the degree to which it is likely that common components explain the observed correlation between variables. Bartlett's test was significant, $X^2 = 6575.073$, df=1176, $p<$ .001, suggesting that the item correlation matrix was not an identity matrix. Principal component analysis generated an eleven-factor solution to the 49-items combined LI (29 items) and *Zung SDS* (20 items). This solution accounted for 70.2% of the variance in item intercorrelations. The first component between the two scales accounted for 40.2% of the variance and the second accounted for 6.1% of the variance; the 11th factor accounted for 2.1% of the variance (See Table 8). However, examination of the scree plot (see Figure 1) supported a three-factor solution that accounted for 50.5% of the variance in item intercorrelations. When examining individual items, all of the items from the LI loaded together on the first component, which was arbitrarily named the "grief" component. The majority of the *Zung SDS* items also loaded together onto the second or third components. Only one *Zung SDS* item, "I feel down-hearted and blue", loaded higher onto the "grief" component. Four other *Zung SDS* items loaded onto the "grief" component, but with lower than the .5 loading. This pattern of LI and *Zung SDS* items loading separately on components was seen among the four through eleven-factor solution as well. (See Table 9 for the pattern matrix loadings for the three-factor forced extraction solution).

Factorial Validity of the Loss Inventory

Because no a priori hypothesis regarding the number of factors likely to emerge from the 29-item *Loss Inventory* was made, an exploratory principal component factor analysis was used to extract a factor solution. The solution was first subjected to an orthogonal varimax rotation to minimize the overlap between different factors. A varimax rotation was conducted since there are no prior data to suggest a moderate correlation between factors within the *Loss Inventory*. However, given the chance of a correlation between factors, a promax rotation was also conducted and evaluated.

Both Bartlett's test of sphericity (Bartlett, 1950) and the Kaiser-Meyer-Olkin test results were favorable and suggested that given the items from the LI and the sample size, the questionnaire could be factor analyzed. Bartlett's test was significant, $X^2 = 5037.8$, df=406, $p < .001$, suggesting that the item correlation matrix was not an identity matrix, and the Kaiser-Meyer-Olkin measure of sampling adequacy was .963, which is considered exceptional. For the entire scale, the item-to-total scale correlations ranged from .60 ("I feel the need to talk about my loss") to .86 ("I get upset when I remember having what I lost."). This range of item-total correlations is considered acceptable (Nunnally & Bernstein, 1994) and no items were eliminated because of redundancy or lack of homogeneity with the construct.

Using an orthogonal varimax rotation, the number of potential factors extracted was initially determined using the eigenvalue >1 rule. The rotation yielded a three-factor solution (see Table 10). This solution accounted for 67.1% of the variance. The three-factor solution generated factors, each composed of between six and twelve items. Items

were considered to load on a factor if the factor loading was at least 0.5. One item "I feel stunned and dazed over what has happened" had a factor loading of 0.49, but was still retained in its placement on a factor because it was logically consistent with the derived factors. An additional six items from the *Loss Inventory* loaded on two of the three derived factors. However, their final placement on a particular factor was determined by the factor that had the highest factor loading. See Table 11 for the varimax-rotated structure matrix, item loadings, and placements.

The first factor was composed of eleven items and appeared to primarily reflect cognitive symptoms of loss such as thinking of the loss and reflecting on life before the diagnosis. This factor, which accounted for 25.5% of the variance after rotation, included the following items: "I think about what I have lost." (Item 2), "Memories of how I was before my loss upset me." (Item 4), "I am longing to have what I lost again" (Item 8), "I don't feel like a whole person since my loss." (Item 11), "I feel stunned and dazed over what has happened." (Item 12), "I feel myself longing for the time before my loss" (Item 13), "It is hard for me to believe that what I lost is gone." (Item 23), "I can't help thinking about the "good old days" before my loss." (Item 25), "My situation seems unreal to me." (Item 26), "I am upset by reminders of my loss." (Item 27), and "I feel sad about my loss." (Item 29). This factor had a high degree of internal consistency within these eleven items, with an alpha coefficient of 0.953.

The second factor was composed of twelve items and appeared to primarily reflect symptoms of anxiety, crying, intrusive thoughts, difficulty sleeping, difficulty

Table 8

Initial eigenvalues and explained variance of the combined LI and Zung items from a PCA

Component	Initial eigenvalues	%Variance	Cumulative%
1	19.728	40.262	40.262
2	3.031	6.185	46.446
3	1.977	4.034	50.481
4	1.471	3.003	53.484
5	1.375	2.805	56.289
6	1.300	2.653	58.942
7	1.229	2.507	61.449
8	1.160	2.367	63.816
9	1.102	2.249	66.065
10	1.044	2.130	68.196
11	1.028	2.099	70.294

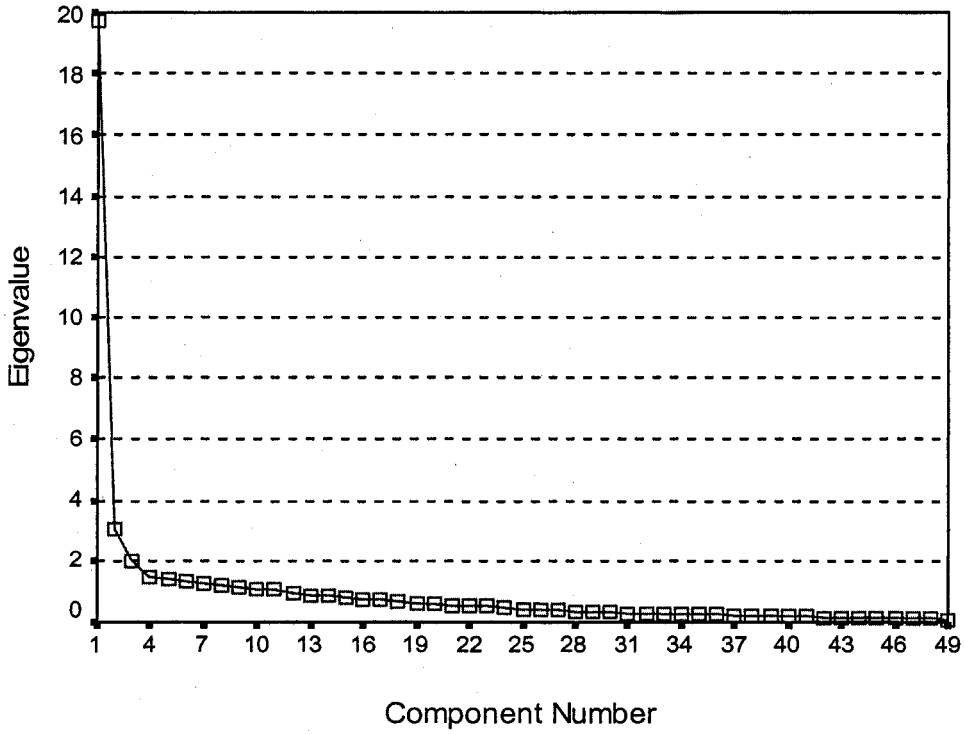

Figure 1 Scree plot from a PCA with combined LI and Zung Items

Table 9

Item-Level principal components analysis (PCA) of the combined Loss Inventory and Zung SDS items

LI and Zung Items Combined	PCA pattern matrix loadings on three forced components C1	C2	C3
LI1 I feel like crying when I think about my loss	.605		
LI2 I think about what I have lost.	.742		
LI3 I think about my loss so much it is hard for me to do things I normally do.	.722		
LI4 Memories of how I was before my loss upset me.	.786		
LI5I feel I cannot accept my loss.	.757		
LI6 I think it is unfair that I have this loss.	.735		
LI7 I am angry about my loss.	.753		
LI8 I am longing to have what I lost again.	.774		
LI10 I feel envious of others who have not had a loss like this.	**.849**		-.233
LI11 I don't feel like a whole person since my loss.	.813		
LI12 I feel stunned and dazed over what has happened	.774		
LI13 I feel myself longing for the time before my loss.	.898		
LI14 I feel bitter about having this loss.	.828		
LI15 I feel anxious.	.681		
LI16 I have had dreams about what I lost.	.742		
LI17 I feel the urge to cry when I think about my loss.	.627		
LI18 I feel the need to talk about my losses.	.594		
LI19 Thoughts of what I lost come to me when I don't expect them.	.858		
LI20 I get upset when I remember having what I lost.	.917		
LI21 I feel panic	**.532**		.259
LI22 I feel guilty about having this loss.	.620		
LI23 It is hard for me to believe that what I lost is gone	.843		
LI24 I have trouble sleeping because of thoughts about what I have lost.	.690		
LI25 I can't help thinking about the "good old days" before my loss.	.827		
LI26 My situation seems unreal to me.	.876		
LI27 I am upset by reminders of my loss.	.907		
LI28 I have dreams that I still have what I lost.	.701		
LI29 I feel sad about my loss.	.825		
LI30 I feel numb since my loss.	.820		
Z1 I feel down-hearted and blue.	**.443**		.324
Z2 Morning is when I feel the best.		.251	
Z3 I have crying spells or feel like it.	.224		**.362**
Z4 I have trouble sleeping at night.			.524
Z5 I eat as much as I used to.	-.201	**.241**	
Z6 I still enjoy sex.		.417	
Z7 I notice that I am losing weight.	-.224		**.525**
Z8 I have trouble with constipation.			.658
Z9 My heart beats faster than usual.			.544
Z10 I get tired for no reason.			.489
Z11 My mind is as clear as it used to be.		.676	
Z12 I find it easy to do the things I used to do.	.244	**.345**	
Z13 I am restless and can't keep still.			.699
Z14 I feel hopeful about the future.		.661	-.238
Z15 I am more irritable than usual.			.494
Z16 I find it easy to make decisions.		.755	
Z17 I feel that I am useful and needed.			.848
Z18 My life is pretty full.		.766	
Z19 I feel that others would be better off if I were dead			.273
Z20 I still enjoy the things I used to do.			.780

**Loadings Below .20 are omitted for ease of reading*

accepting the loss, and numbness. This factor accounted for an additional 22.2% of the variance after rotation. The following items were included in the second factor: "I feel like crying when I think about my loss." (Item 1), "I think about my loss so much it is hard for me to do things I normally do." (Item 3), "I feel I cannot accept my loss." (Item 5), "I feel anxious" (Item 15), "I have had dreams about what I lost" (Item 16), "I feel the urge to cry when I think about my loss." (Item 17), "I feel the need to talk about my loss." (Item 18), "Thoughts of what I lost come to me when I don't expect." (Item 19), "I feel panic" (Item 21), "I have trouble sleeping because of thoughts about what I lost." (Item 24), "I have dreams that I still have what I lost" (Item 28), and "I feel numb since my loss" (Item 30). These items also had a high degree of internal consistency with an alpha coefficient of 0.942.

The third factor was composed of six items and reflected feelings of unfairness, anger, bitterness, and guilt. This third factor accounted for 18.9% of the variance after rotation. Items contained in this factor include: "I think it is unfair that I have this loss." (Item 6), "I am angry about my loss." (Item 7), "I feel envious of others who have not had a loss like this." (Item 9), "I feel bitter about having this loss." (Item 14), "I get upset when I remember having what I lost." (Item 20), and "I feel guilty about having this loss." (Item 22). Despite being composed of only six items, this scale also revealed a high degree of internal consistency, with an alpha coefficient of 0.913.

Using the promax rotation also revealed a three-component solution that accounted for 67.1% of the variance. Items loading and ultimate placements onto each of the three components were similar to that seen in the varimax rotation solution. Most

items loaded onto only one component and those that loaded onto two components were placed with the highest component loading. One item "I feel stunned and dazed over what has happened." had the lowest component loading overall, but was still placed onto the same component as in the varimax rotation. Excluding this item, component loadings ranged from .548 to .901 for the first component, .410 to .852 for the second component, and .505 to .817 for the third component. See Table 12 for the promax rotated pattern matrix and item loadings. Table 13 has additional information on each scale component.

When examining the total score correlations of each of these three extracted subscale components with outcome measures such as the GHQ-12, STAI-state anxiety, PSQI, etc., correlations were in the expected direction and of similar significance when compared to the total LI scale score correlations with the same outcome measures. However, each component is highly inter-correlated with the other components with correlations ranging from .821 to .873. This suggests that these components are more similar than not and a distinct three-factor solution may not optimally describe the *Loss Inventory* items. See Table 14 for correlations among the three extracted components and the outcome variables.

Further examination of the PCA's scree plot (see Figure 2) and the greater than 5% variance rule yielded the potential for a single factor solution. This solution accounted for 59.1% of the variance. All item loadings were greater than .5 and ranged from .613 ("I have dreams that I still have what I lost.") to .863 ("I am upset by reminders of my loss."). Given the evidence from the scree plot, greater than 5% variance rule, and the large amount of variance contributed from one component, a one-factor

Table 10

Initial eigenvalues and explained variance from the varimax-rotated PCA of the Loss Inventory

Component	Extraction Sums of Squared Loadings·		
	Eigenvalue	%Variance	%Cumulative
C1:	17.150	59.138	59.138
C2	1.286	4.433	63.572
C3	1.050	3.621	67.192

Component	Rotated Sums of Squared Loadings		
	Eigenvalue	%Variance	%Cumulative
C1:	7.414	25.566	25.566
C2:	6.564	22.635	48.201
C3:	5.507	18.991	67.192

Table 11

Varimax-rotated structure matrix for the Loss Inventory items only

LI Items	C1	C2	C3
LI2 I think about what I have lost.	**.614**	.461	
LI4 Memories of how I was before my loss upset me.	**.638**	.410	
LI8 I am longing to have what I lost again.	**.660**		
LI11 I don't feel like a whole person since my loss.	**.643**		
LI12 I feel stunned and dazed over what has happened.	**.494**	.457	.420
LI13 I feel myself longing for the time before my loss.	**.731**		
LI23 It is hard for me to believe that what I lost is gone.	**.664**		.406
LI25 I can't help thinking about the "good old days" before my loss.	**.769**		
LI26 My situation seems unreal to me.	**.724**		.407
LI27 I am upset by reminders of my loss.	**.620**		.528
LI29 I feel sad about my loss.	**.658**	.425	
LI1 I feel like crying when I think about my loss.		**.742**	
LI3 I think about my loss so much it is hard for me to do things I normally do.	.536	**.575**	
LI5 I feel I cannot accept my loss.	.446	**.557**	.457
LI15 I feel anxious.		**.517**	
LI16 I have had dreams about what I lost.		**.635**	
LI17 I feel the urge to cry when I think about my loss.		**.721**	
LI18 I feel the need to talk about my losses.		**.617**	
LI19 Thoughts of what I lost come to me when I don't expect them.	.455	**.540**	.462
LI21 I feel panic.		**.693**	.430
LI24 I have trouble sleeping because of thoughts about what I have lost.		**.563**	.428
LI28 I have dreams that I still have what I lost.	.521	**.562**	
LI30 I feel numb since my loss.	.518	**.576**	
LI6 I think it is unfair that I have this loss.			**.668**
LI6 I am angry about my loss.			**.748**
LI10 I feel envious of others who have not had a loss like this.			**.666**
LI14 I feel bitter about having this loss.	.417		**.645**
LI20 I get upset when I remember having what I lost.	.503	.425	**.604**
LI22 I feel guilty about having this loss.	.441	**.571**	

*Loadings below .40 are omitted for ease of reading

Table 12

Oblique promax rotated pattern matrix for the Loss Inventory

LI Items	C1	C2	C3
LI2 I think about what I have lost.	**.598**		
LI4 Memories of how I was before my loss upset me.	**.649**		
LI8 I am longing to have what I lost again.	**.723**		
LI11 I don't feel like a whole person since my loss.	**.628**		
LI12 I feel stunned and dazed over what has happened.	**.357**		
LI13 I feel myself longing for the time before my loss.	**.813**		
LI23 It is hard for me to believe that what I lost is gone.	**.676**		
LI25 I can't help thinking about the "good old days" before my loss.	**.901**		
LI26 My situation seems unreal to me.	**.812**		
LI27 I am upset by reminders of my loss.	**.548**		
LI29 I feel sad about my loss.	**.662**		
LI1 I feel like crying when I think about my loss.		**.852**	
LI3 I think about my loss so much it is hard for me to do things I normally do.	.441	**.499**	
LI5 I feel I cannot accept my loss.		**.439**	
LI15 I feel anxious.		**.454**	
LI16 I have had dreams about what I lost.		**.657**	
LI17 I feel the urge to cry when I think about my loss.		**.815**	
LI18 I feel the need to talk about my losses.		**.688**	
LI19 Thoughts of what I lost come to me when I don't expect them.		**.410**	
LI21 I feel panic.		**.773**	
LI24 I have trouble sleeping because of thoughts about what I have lost.		**.499**	
LI28 I have dreams that I still have what I lost.	.546	**.589**	-.485
LI30 I feel numb since my loss.		**.484**	
LI6 I think it is unfair that I have this loss.			**.681**
LI7 I am angry about my loss.			**.817**
LI10 I feel envious of others who have not had a loss like this.			**.732**
LI14 I feel bitter about having this loss.			**.625**
LI20 I get upset when I remember having what I lost			**.505**
LI22 I feel guilty about having this loss.			**.577**

*Loadings below .40 are omitted for ease of reading

Table 13

Loss Inventory components: means, SD and internal consistency coefficients

Component	1	2	3
Number of Items	11	12	6
Scale Mean	28.17	24.57	12.45
Standard Deviation	11.43	10.61	6.09
Item Mean	2.56	2.05	2.07
Range of Item-Total correlation	.734-.835	.604 -.808	.643-.817
Subscale Internal Consistency Alpha	.953	.942	.913

Table 14

Correlations among items corresponding to LI components and outcome variables

Variable	Component 1	Component 2	Component 3
Loss Inventory	.961 .000*** 197	.955 .000*** 197	.915 .000*** 197
Component 1	1 204	.873 .000*** 204	.836 .000*** 203
Component 2	.873*** .000 204	1 . 204	.821*** .000 203
Component 3	.836*** .000 203	.821*** .000 203	1 . 203
Age	-.236*** .001 199	-.297*** .000 199	-.314*** .000 198
Education	-.140 .048 201	-.162 .022 201	-.141 .046 200
Self-Esteem	-.553*** .000 197	-.545*** .000 197	-.499*** .000 197
Zung SDS Depression	.566*** .000 196	.608*** .000 196	.539*** .000 196

*** = $p<.005$, ** = $p<.01$, * = $p<.05$ with Adjusted Bonferroni corrections
Bottom numbers are total Ns

Table 14 (Continued)

Variable	Component 1	Component 2	Component 3
Impact of Events Scale	.615*** .000 190	.700*** .000 190	.591*** .000 189
STAI anxiety	.598** .000 201	.671** .000 201	.606** .000 200
General Health	.672*** .000 196	.722*** .000 196	.617** .000 196
Sleep Quality	.423*** .000 198	.490*** .000 198	.389*** .000 197
CIRS (Number of Illnesses)	.295*** .000 177	.301*** .000 177	.281*** .000 176
CMI (Co-morbidity of illnesses)	.250*** .001 177	.256*** .001 177	.212 .005 176
ADL Function	.435*** .000 177	.431*** .000 201	.349*** .000 200
Initial H&Y	.117 .234 106	.114 .243 106	.076 .441 106
Initial S&E ADL	-.154 .062 148	-.124 .132 148	-.112 .175 148
Initial UPDRS	.252*** .001 156	.315*** .000 156	.217 .007 156

*** = $p<.005$, ** = $p<.01$, * = $p<.05$ with Adjusted Bonferroni corrections
Bottom numbers are total Ns.

Table 14 (Continued)

Variable	Component 1	Component 2	Component 3
Initial MMSE	-.165 .055 137	-.117 .175 137	-.104 .225 137
Closer to Time 1 H&Y	.251 .016 91	.143 .176 91	.208 .047 91
Closer to Time 1 S&E ADL	-.227 .021 104	-.159 .107 104	-.169 .086 104
Closer to Time 1 UPDRS	.302 .010 71	.189 .114 71	.209 .080 71

*** = $p<.005$, ** = $p<.01$, * = $p<.05$ with Adjusted Bonferroni corrections
Bottom numbers are total Ns.

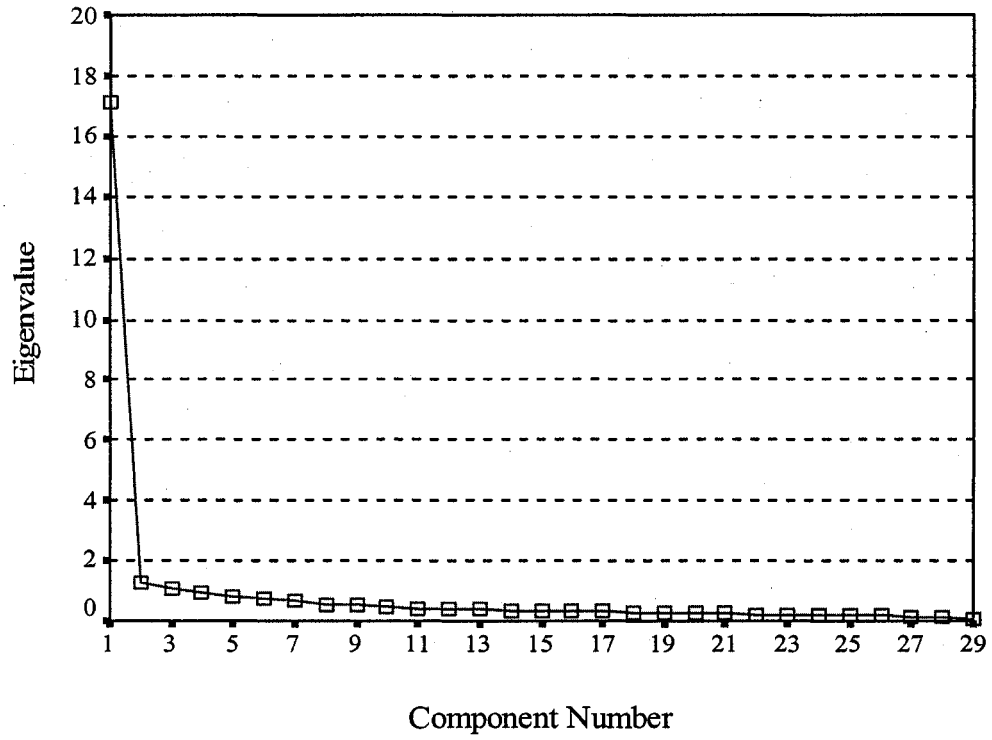

Figure 2 Promax and varimax scree plot for LI items only

Table 15

Item-loadings for each Loss Inventory item from a single factor solution

LI Items	Item loadings C1
LI1 I feel like crying when I think about my loss	.732
LI2 I think about what I have lost.	.784
LI3 I think about my loss so much it is hard for me to do things I normally do.	.788
LI4 Memories of how I was before my loss upset me.	.776
LI5I feel I cannot accept my loss.	**.840**
LI6 I think it is unfair that I have this loss.	.766
LI7 I am angry about my loss.	.765
LI8 I am longing to have what I lost again.	.735
LI10 I feel envious of others who have not had a loss like this.	.672
LI11 I don't feel like a whole person since my loss.	.817
LI12 I feel stunned and dazed over what has happened	.793
LI13 I feel myself longing for the time before my loss.	.797
LI14 I feel bitter about having this loss.	.794
LI15 I feel anxious.	.718
LI16 I have had dreams about what I lost.	.729
LI17 I feel the urge to cry when I think about my loss.	.737
LI18 I feel the need to talk about my losses.	.632
LI19 Thoughts of what I lost come to me when I don't expect them.	**.839**
LI20 I get upset when I remember having what I lost.	**.877**
LI21 I feel panic	.727
LI22 I feel guilty about having this loss.	.664
LI23 It is hard for me to believe that what I lost is gone	.806
LI24 I have trouble sleeping because of thoughts about what I have lost.	.773
LI25 I can't help thinking about the "good old days" before my loss.	.778
LI26 My situation seems unreal to me.	.782
LI27 I am upset by reminders of my loss.	**.863**
LI28 I have dreams that I still have what I lost.	.613
LI29 I feel sad about my loss.	.811
LI30 I feel numb since my loss.	.817

Table 16

Individual Loss Inventory item means and standard deviations, N=197

LI Items	Item Mean	Std.Dev
LI1 I feel like crying when I think about my loss	2.01	1.14
LI2 I think about what I have lost.	2.85	1.15
LI3 I think about my loss so much it is hard for me to do things I normally do.	2.27	1.23
LI4 Memories of how I was before my loss upset me.	2.64	1.31
LI5I feel I cannot accept my loss.	1.95	1.12
LI6 I think it is unfair that I have this loss.	2.22	1.28
LI7 I am angry about my loss.	2.22	1.28
LI8 I am longing to have what I lost again.	3.05	1.41
LI10 I feel envious of others who have not had a loss like this.	2.01	1.24
LI11 I don't feel like a whole person since my loss.	2.51	1.38
LI12 I feel stunned and dazed over what has happened	2.11	1.14
LI13 I feel myself longing for the time before my loss.	2.57	1.22
LI14 I feel bitter about having this loss.	2.03	1.20
LI15 I feel anxious.	2.59	1.29
LI16 I have had dreams about what I lost.	1.81	1.05
LI17 I feel the urge to cry when I think about my loss.	1.86	1.06
LI18 I feel the need to talk about my losses.	2.19	1.07
LI19 Thoughts of what I lost come to me when I don't expect them.	2.17	1.07
LI20 I get upset when I remember having what I lost.	2.18	1.21
LI21 I feel panic	1.94	1.14
LI22 I feel guilty about having this loss.	1.75	1.02
LI23 It is hard for me to believe that what I lost is gone	2.38	1.27
LI24 I have trouble sleeping because of thoughts about what I have lost.	1.98	1.20
LI25 I can't help thinking about the "good old days" before my loss.	2.80	1.25
LI26 My situation seems unreal to me.	2.38	1.27
LI27 I am upset by reminders of my loss.	2.28	1.28
LI28 I have dreams that I still have what I lost.	1.76	1.03
LI29 I feel sad about my loss.	2.62	1.15
LI30 I feel numb since my loss.	1.98	1.19

Table 17

29-item Loss Inventory scale statistics for Time 1 and Time 2

TIME 1 N = 197	
Loss Inventory Scale Mean	65.2
Standard Deviation	26.63
Item Mean	2.24 (1.75 – 3.05)
Total Scale Variance	708.1326
Cronbach's Alpha	.9748
Total Scale Spearman-Brown Coefficient	.952
TIME 2 N = 100	
Loss Inventory Scale Mean	60.44
Standard Deviation	23.94
Item Mean	2.08 (1.54 – 2.79)
Total Scale Variance	573.1378
Cronbach's Alpha	.9755
Test-Retest Reliability	.728

solution for the *Loss Inventory* is the most parsimonious solution. See Table 15 for each item's loadings for this single factor solution. Tables 16 and 17 show additional scale statistics for the *Loss Inventory* at Time 1 and Time 2.

Prevalence of Intrapersonal Grief and Depression among a PD population

One goal of this study was to determine if the *Loss Inventory* measured varying levels of grief intensity and to determine if PD patients experience high amounts of grief and loss rather than depression. It was hypothesized that a majority of participants would report high levels of grief while reporting none to minimal levels of depression. Although the study population was able to report varying levels of grief symptoms as measured by the *Loss Inventory* (see Figure 3), no validated cut-off score suggesting true high intensity grief as measured by the *Loss Inventory* exists. An arbitrary cut-off score of 62 (50^{th} percentile) was chosen to distinguish those with higher versus lower grief intensity from within this sample only. With this arbitrary grief definition, the majority of participants (N =71; 41%) endorsed symptoms of *at least* mild depression (*Zung SDS* > 50) *and* higher grief intensity levels (*Loss Inventory* >62). This, like the Pearson correlation of 0.586 between total grief scores and depression scores, suggests that depression and higher grief intensity are highly associated with one another. This is contrary to the study's hypothesis that the majority of PD patients may experience high grief symptoms with little to no depression symptoms; few participants endorsed higher grief symptoms and little to no depressive symptoms (*Zung SDS* $\leq$50) (N = 15, 8.7%). About 24.3% of the sample endorsed little to no depressive symptoms *and* lower grief symptoms (N = 42)

and another 26% endorsed depressive symptoms only (N = 45). See Table 18 for more information.

Influence of Grief and Depression on Psychosocial and Health Outcomes at Time 1

These reuslts are designed to evaluate the utility of the *Loss Inventory* as a clinical and research tool by examining the effects of depression, grief, and their interaction on various psychosocial health outcomes when controlling for disease stage and physical disability. If grief contributes to the PD patient's physical and psychosocial health outcomes beyond what is contributed by depression, disease stage, and movement disability, then this is added evidence for the usefulness of the *Loss Inventory* as both a clinical and research tool. To accomplish this goal, all variables are centered and only Parkinson's disease patients are used since significant physical and mental health differences were found between PD and Essential Tremor patients. Because of the large number of models estimated, a more stringent significance threshold ($p < .01$) for interpreting the regression results was used. Probabilities between 0.01 and 0.05 were considered marginally significant for these regression models. Disease stage (H & Y) and movement disability (UPDRS) were entered onto the first step to control for disease characteristics that are believed to impact the health outcomes. Depression (*Zung SDS*) was entered onto the second step, followed by grief (LI) entered onto the third step to determine any additional influence of grief on the health outcomes while controlling for

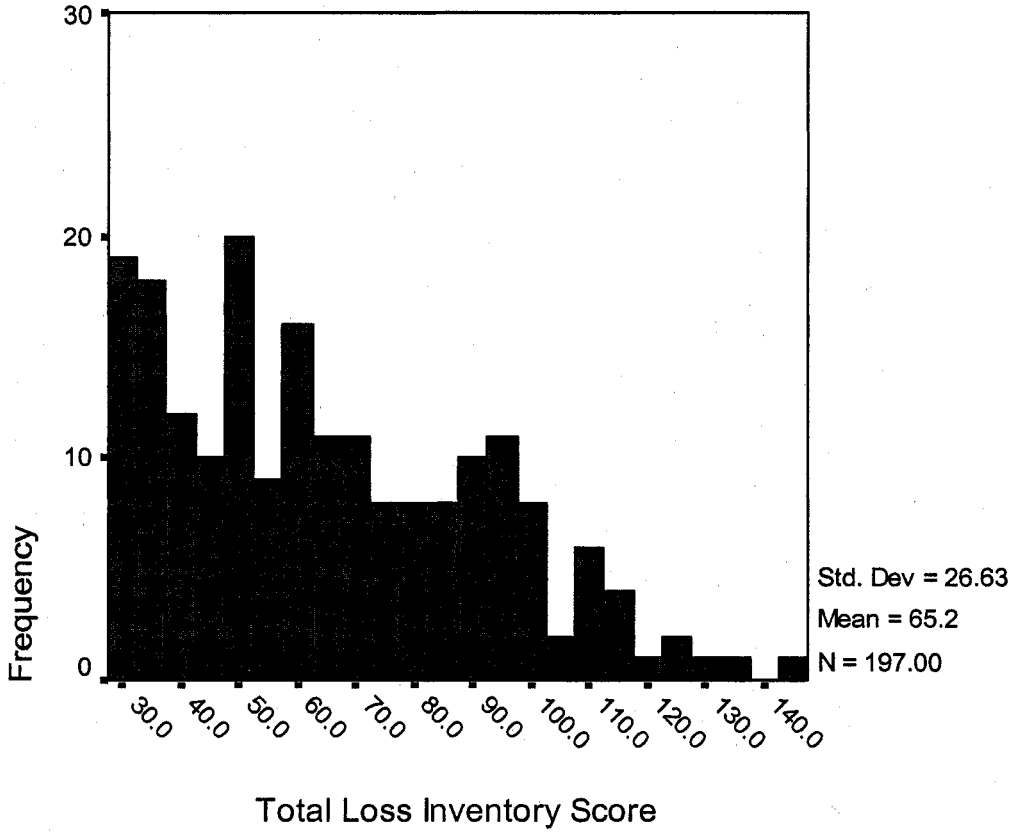

Figure 3 Histogram of frequencies of Loss Inventory total raw scores

Table 18

Cross-tabulation of depression (Yes/No) by Loss Inventory scores (above and below sample median) at Time 1 for 173 Parkinson's disease patients*

0=≤62; 1=>62 on *Loss Inventory* Raw Score			0=≤50; 1= >50 on *Zung SDS* Index score		Total
			No Depression symptoms (0)	Have Depression Symptoms (1)	
	Lower Loss Scores (0)	N	42	45	87
		% of Total	24.3%	26.0%	50.3%
	Higher Loss Scores (1)	N	15	71	86
		% of Total	8.7%	41.0%	49.7%
Total		N	57	116	173
		% of Total	32.9%	67.1%	100.0%

*11 PD cases are missing either the LI or Zung SDS scores

depression. Lastly, the interaction of depression and grief was entered onto the fourth step to determine if this term has any additional influence on the health outcomes. Because of the use of the H&Y and UPDRS Table 19 shows the results for each dependent variable's full model.

Self-Esteem. Results show that depression as measured by the *Zung SDS* is negatively associated with self-esteem, even when controlling for disease stage and movement disability. Grief contributes an additional 11.2% of the variance in self-esteem scores after controlling for disease stage, movement disability, and depression. Within the full model, both depression (B = -.132, $p < .005$) and greater grief (B=-.083, $p < .001$) are negatively associated with self-esteem; the interaction was not significant.

Intrusive Thoughts and Avoidant Behavior (IES. Depression is positively associated with greater IES scores when controlling for the patient's disease stage and movement disability. Grief contributes an additional 17.5% of the variance in IES scores after controlling for depression and physical status. Within the full model, greater grief (B=.336, $p < .001$) is significantly associated with IES scores and depression (B = .314, $p < .05$) is marginally significant; the interaction was not significant.

State Anxiety. Depression is positively associated with greater state anxiety scores when controlling for the both disease stage and movement disability. Grief contributed an additional 27.0% of the variance in state anxiety scores after controlling for depression and physical status. Both greater grief (B = .379, $p < .001$) and depression (B = .321, $p < .01$) were positively associated with state anxiety within the full model, and the interaction was not significant.

General Health Questionnaire (GHQ). Similar to above, depression is associated with poor overall health when controlling for both disease stage and movement disability. Grief scores contribute an additional 14% of the variance in GHQ scores when disease stage, movement disability, and depression are controlled. Both greater grief (B = .134, p< .001) and depression (B=.262, *p*< .001) are significantly associated with poor overall health within the full model; their interaction was not significant.

Sleep Latency. When controlling for disease stage and movement disability only, depression is marginally associated with increased sleep latency (B= .467, *p*< .05). Grief, however, (B = .233, *p*<.05) was marginally associated with increased sleep latency beyond that of depression, disease stage and movement disability, contributing an additional 4.4% of the variance in sleep latency scores. Within the full model, only increased movement disability (B = .820, *p*< .01) was associated with increased sleep latency. The interaction term was not significant.

Sleep Efficiency. Depression marginally contributes additional variance (B= -.311, *p*< .05) to sleep efficiency scores after controlling for disease stage and physical disability. Grief significantly contributed 8.9% of the variance in sleep efficiency scores when disease stage, physical disability, and depression are controlled. Within the full model, those with greater grief scores have worse sleep efficiency (B = -.235, *p*< .005). However, depression and the interactive term were not associated with sleep efficiency within the full model.

Overall Sleep Quality. As expected, depression is associated with sleep impairment after controlling for disease stage and movement disability. Grief contributes 8.7% of the

variance in sleep quality scores even when depression, disease stage, and movement disability were controlled. Within the full model both depression (B = .085; $p \leq .01$) and movement disability (UPDRS, B = .095, $p < .05$) was marginally significant and are associated with poor sleep quality. Greater grief (B = .052, $p \leq .001$) is significantly associated with poor overall sleep quality; no significant interaction was seen.

Cumulative Illness Rating Scale (CIRS). Depression (B = .144; $p < .05$) is marginally associated with the number of medical illnesses after controlling for movement disability and disease stage. It contributed an additional 5.8% of the variance in CIRS scores. High grief scores did not contribute to CIRS scores above that of depression. Within the full model, neither grief, depression, nor their interaction was found significant.

Number of moderate to severe medical illnesses. Depression did not contribute to the number of moderate to severe medical illnesses when controlling for disease stage and movement disability. High grief scores did not contribute to total severe illnesses when also controlling for depression. Neither grief, depression, nor their interaction was associated with the number of moderate to severe illnesses. Movement disability and disease stage also did not predict the number of moderate to severe medical illnesses.

Activities of Daily Living Functioning. When controlling for movement disability and disease stage, depression was associated with ADL dysfunction (B = .199, $p \leq .001$) as measured by the UPDRS ADL component in which higher ADL scores indicate worse ADL functioning. Higher grief scores were not associated with ADL scores when also controlling for depression. Within the full model, movement disability (UPDRS, B =.224, $p < .01$) was significantly associated with ADL dysfunction, and disease stage (B = 2.23,

$p < .05$) and depression (B = .143, $p < .05$) were marginally significant. A trend toward marginal significance is seen with grief scores such that greater grief intensity is associated with greater ADL dysfunction (B = .057, $p = .06$). A marginally significant interaction term (B = -.005, $p < .05$) within the full model suggests that among those with very high depressive symptoms (90^{th} percentile), as grief symptoms worsen, ADL functioning slightly improves, however, among those with none to little depressive symptoms (10^{th} percentile), as grief worsens, so does ADL functioning. This interaction is represented graphically in Figure 4.

Summary. Overall, it appears that grief, as measured by the *Loss Inventory,* is associated with poor self-esteem, greater distress from traumatic events (IES total scale), greater state anxiety, poor overall general health, poor overall sleep quality, and marginally increased sleep latency even when controlling for depression, disease stage, and movement disability within this PD population. On the other hand, depressive symptoms were significantly associated with poor self-esteem, greater state anxiety, poor overall general health, and marginally associated with greater distress from traumatic events, poor overall sleep quality, and ADL dysfunction. Higher grief scores alone (and not depression) contributed to worse sleep efficiency within the full model. Neither depressive symptoms nor grief influenced the number of medical illnesses or number of moderate to severe illnesses. Lastly, a marginal significant interaction was seen between grief and depression only on ADL functioning. Increasing grief symptoms impact worse ADL functioning, but only for those with none to little depressive symptoms.

Table 19

Hierarchical Regressions: Influence of depression and grief on psychosocial outcomes, controlling for both disease stage (H&Y) and UPDRS physical/ movement disablity (PD patients only)

DV: Rosenberg's Self-Esteem

	B	SE	*B*	Sig.
Step 1				
*H & Y	-1.793	.852	-.235	.038
*UPDRS	-.149	.064	-.259	.023
**Adjusted R^2 = .165	Overall model fit: F(2,87) = 9.799, *p*=.000			
Step 2				
H & Y	-1.092	.683	-.139	.124
UPDRS	-.085	.057	-.148	.140
**Depression	-.218	.040	-.489	.000
**Change in R^2 = .208	Overall model fit: F(1,86) = 29.376, *p*=.000			
Step 3				
H & Y	-1.062	.683	-.139	.124
UPDRS	-.034	.053	-.060	.521
**Depression	-.130	.042	-.291	.003
**Grief	-.086	.020	-.413	.000
**Change in R^2 = .112	Overall model fit: F(1,85) = 19.142, *p*=.000			
Step 4				
H&Y	-1.054	.685	-.138	.128
UPDRS	-.027	.054	-.047	.619
**Depression	-.132	.042	-.296	.002
**Grief	-.083	.020	-.402	.000
Interaction	-.001	.001	-.050	.546
Change in R^2 = .002	Overall model fit: F(1,84) = .368, *p*=.546			

** $p<.01$ * $p\leq.05$

Table 19 (Continued)

DV: Impact of Event Scale

	B	SE	*B*	Sig.
Step 1				
H & Y	3.254	3.031	.123	.286
**UPDRS	.622	.214	.332	.005
**Adjusted R^2 = .143	Overall model fit: F(2,82) = 7.991, *p*=.000			
Step 2				
H & Y	.660	2.760	.025	.811
*UPDRS	.400	.197	.213	.046
**Depression	.665	.142	.462	.000
**Change in R^2 = .179	Overall model fit: F(1,81) = 22.012, *p*=.000			
Step 3				
H & Y	-.032	2.383	-.001	.989
UPDRS	.193	.174	.103	.270
*Depression	.300	.140	.208	.035
**Grief	.352	.065	.528	.000
**Change in R^2 = .175	Overall model fit: F(1,80) = 28.982, *p*=.000			
Step 4				
H&Y	-.246	2.368	-.009	.918
UPDRS	.136	.177	.073	.443
*Depression	.314	.139	.218	.027
**Grief	.336	.066	.505	.000
Interaction	.006	.004	.126	.131
Change in R^2 = .014	Overall model fit: F(1,79) = 2.324, *p*=.131			

** $p<.01$ * $p\leq.05$

Table 19 (Continued)

DV: State Anxiety

	B	SE	*B*	Sig.
Step 1				
H & Y	.752	2.671	.034	.779
UPDRS	.344	.202	.207	.091
Adjusted R^2 = .029	Overall model fit: F(2,87) = 2.347, p=.102			
Step 2				
H & Y	-1.565	2.316	-.071	.501
UPDRS	.131	.176	.079	.458
**Depression	.713	.124	.553	.000
*Change in R^2 = .265	Overall model fit: F(1,85) = 33.351, p=.000			
Step 3				
H & Y	-1.576	1.812	-.071	.387
UPDRS	-.113	.142	-.068	.425
**Depression	.313	.111	.242	.006
**Grief	.389	.052	.647	.000
**Change in R^2 = .270	Overall model fit: F(1,85) = 19.142, p=.000			
Step 4				
H&Y	-1.599	1.812	-.073	.380
UPDRS	-.146	.145	-.088	.318
**Depression	.321	.111	.249	.005
**Grief	.379	.053	.631	.000
Interaction	.003	.003	.076	.315
Change in R^2 = .005	Overall model fit: F(1,84) = 1.020, p=.315			

** p<.01 * $p\leq$.05

Table 19 (Continued)

DV: General Health Questionnaire

	B	SE	*B*	Sig.
Step 1				
H & Y	.525	1.267	.049	.680
*UPDRS	.244	.095	.303	.012
**Adjusted R^2 = .089	Overall model fit: F(2,86) = 5.293, p=.007			
Step 2				
H & Y	-.665	.994	-.062	.505
UPDRS	.107	.076	.133	.163
**Depression	.412	.054	.650	.000
**Change in R^2 = .362	Overall model fit: F(1,85) = 58.294, p=.000			
Step 3				
H & Y	-.768	.857	-.072	.372
UPDRS	.037	.067	.047	.576
**Depression	.260	.054	.411	.000
**Grief	.137	.025	.471	.000
**Change in R^2 = .140	Overall model fit: F(1,84) = 30.377, p=.000			
Step 4				
H&Y	-.785	.859	-.073	.364
UPDRS	.028	.068	.034	.686
**Depression	.262	.054	.413	.000
**Grief	.134	.025	.461	.000
Interaction	.001	.002	.053	.470
Change in R^2 = .002	Overall model fit: F(1,83) = .528, p=.470			

** p<.01 * $p\leq$.05

Table 19 (Continued)

DV: Sleep Latency

	B	SE	*B*	Sig.
Step 1				
H & Y	-5.804	3.883	-.172	.139
**UPDRS	1.254	.282	.512	.000
**Adjusted R^2 = .181 Overall model fit: F(2,82)=10.305, *p*=.000				
Step 2				
H & Y	-6.132	3.795	-.187	.100
**UPDRS	1.098	.284	.448	.000
*Depression	.467	.206	.230	.026
*Change in R^2 = .048 Overall model fit: F(1,81) = 5.139, *p*=.026				
Step 3				
H & Y	-6.311	3.706	-.187	.093
**UPDRS	.954	.285	.389	.001
Depression	.219	.230	.108	.345
*Grief	.233	.105	.258	.029
*Change in R^2 = .044 Overall model fit: F(1,80) =4.916, *p*=.029				
Step 4				
H&Y	-5.780	3.677	-.171	.120
**UPDRS	.820	.292	.334	.006
Depression	.290	.231	.143	.214
Grief	.204	.105	.226	.056
Interaction	.013	.007	.169	.093
Change in R^2 = .025 Overall model fit: F(1,79) = 2.885, *p*=.093				

** $p<.01$ * $p\leq.05$

Table 19 (Continued)

DV: Sleep Efficiency

	B	SE	*B*	Sig.
Step 1				
H & Y	-1.555	2.814	-.066	.582
**UPDRS	-.669	.215	-.370	.003
**Adjusted R^2 = .167 Overall model fit: F(2,82) =8.217, *p*=.001				
Step 2				
H & Y	-.656	2.790	-.028	.815
*UPDRS	-.568	.216	-.314	.010
*Depression	-.311	.148	-.224	.039
*Change in R^2 = .043 Overall model fit: F(1,81) = 4.425, *p*=.039				
Step 3				
H & Y	-.833	2.646	-.035	.754
UPDRS	-.402	.211	-.222	.060
Depression	-.048	.163	-.035	.766
**Grief	-.244	.077	-.378	.002
**Change in R^2 = .089 Overall model fit: F(1,80) = 10.097, *p*=.002				
Step 4				
H&Y	-.798	2.652	-.034	.764
UPDRS	-.363	.217	-.201	.099
Depression	-.055	.163	-.040	.737
**Grief	-.235	.078	-.363	.003
Interaction	-.004	.005	-.080	.431
Change in R^2 = .006 Overall model fit: F(1,79) = .628, *p*=.431				

** $p<.01$ * $p\leq.05$

Table 19 (Continued)

DV: Sleep Quality

	B	SE	*B*	Sig.
Step 1				
H & Y	.478	.613	.086	.438
**UPDRS	.182	.046	.433	.000
**Adjusted R^2 = .233	Overall model fit: F(2,86) =13.044, p=.000			
Step 2				
H & Y	.075	.555	.013	.892
**UPDRS	.137	.043	.324	.002
**Depression	.142	.030	.430	.000
**Change in R^2 = .160	Overall model fit: F(1,85) = 22.324, p=.000			
Step 3				
H & Y	.026	.518	.005	.960
**UPDRS	.107	.040	.255	.009
*Depression	.082	.032	.249	.013
**Grief	.056	.015	.367	.000
**Change in R^2 = .087	Overall model fit: F(1,84) = 13.962, p=.000			
Step 4				
H&Y	.004	.514	.001	.994
*UPDRS	.095	.041	.226	.022
*Depression	.085	.032	.257	.010
**Grief	.052	.015	.340	.001
Interaction	.001	.001	.128	.130
Change in R^2 = .014	Overall model fit: F(1,83) = 2.335, p=.130			

** p<.01 * $p\leq$.05

Table 19 (Continued)

DV: Number of Medical Illnesses/CIRS

	B	SE	*B*	Sig.
Step 1				
H & Y	1.532	1.194	.161	.203
UPDRS	.126	.093	.171	.178
*Adjusted R^2 = .059	Overall model fit: F(2,78) =3.523, *p*=.034			
Step 2				
H & Y	1.024	1.184	.108	.390
UPDRS	.090	.092	.122	.328
*Depression	.144	.063	.258	.024
*Change in R^2 = .059	Overall model fit: F(1,77) = 5.269, *p*=.024			
Step 3				
H & Y	1.073	1.184	.113	.368
UPDRS	.072	.093	.098	.439
Depression	.105	.073	.188	.154
Grief	.035	.034	.136	.297
Change in R^2 = .012	Overall model fit: F(1,76) = 1.103, *p*=.297			
Step 4				
H&Y	1.106	1.191	.116	.356
UPDRS	.081	.095	.109	.398
Depression	.102	.074	.182	.171
Grief	.039	.035	.148	.266
Interaction	-.001	.002	-.056	.616
Change in R^2 = .003	Overall model fit: F(1,75) = .253, *p*=.616			

** $p<.01$ * $p\leq.05$

Table 19 (Continued)

DV: Number of moderate to severe medical illnesses/CMI

	B	SE	*B*	Sig.
Step 1				
H & Y	.705	.461	190	.130
UPDRS	.050	.036	.173	.167
*Adjusted R^2 = .077	Overall model fit: F(2,78) = 4.318, *p*=.017			
Step 2				
H & Y	.580	.466	.157	.217
UPDRS	.041	.036	.143	.259
Depression	.036	.025	.163	.155
Change in R^2 = .024	Overall model fit: F(1,77) = 2.066, *p*=.155			
Step 3				
H & Y	.595	.468	.160	.208
UPDRS	.036	.037	.124	.334
Depression	.024	.029	.110	.827
Grief	.011	.013	.104	.429
Change in R^2 = .000	Overall model fit: F(1,75) = .003, *p*=.959			
Step 4				
H&Y	.593	.472	.160	.212
UPDRS	.035	.038	.123	.349
Depression	.024	.029	.110	.413
Grief	.010	.014	.103	.446
Interaction	.0004	.001	.006	.959
Change in R^2 = .000	Overall model fit: F(1,75) = .003, *p*=.959			

** $p<.01$ * $p\leq.05$

Table 19 (Continued)

DV: Activities of Daily Living

	B	SE	*B*	Sig.
Step 1				
*H & Y	2.844	1.109	.269	.012
**UPDRS	.266	.083	.336	.002
**Adjusted R^2 = .259	Overall model fit: F(2,88) =16.766, *p*=.000			
Step 2				
*H & Y	2.199	1.060	.208	.041
*UPDRS	.206	.080	.260	.012
**Depression	.199	.057	.323	.001
**Change in R^2 = .090	Overall model fit: F(1,87) = 12.367, *p*=.001			
Step 3				
*H & Y	2.184	1.054	.207	.041
*UPDRS	.181	.082	.229	.029
*Depression	.156	.064	.252	.018
Grief	.042	.030	.147	.165
Change in R^2 = .014	Overall model fit: F(1,86) = 1.965, *p*=.165			
Step 4				
*H&Y	2.230	1.024	.211	.032
**UPDRS	.224	.081	.282	.007
*Depression	.143	.063	.232	.025
Grief	.057	.030	.197	.062
*Interaction	-.005	.002	-.219	.015
*Change in R^2 = .042	Overall model fit: F(1,85) = 6.139, *p*=.015			

** $p<.01$ * $p<.05$

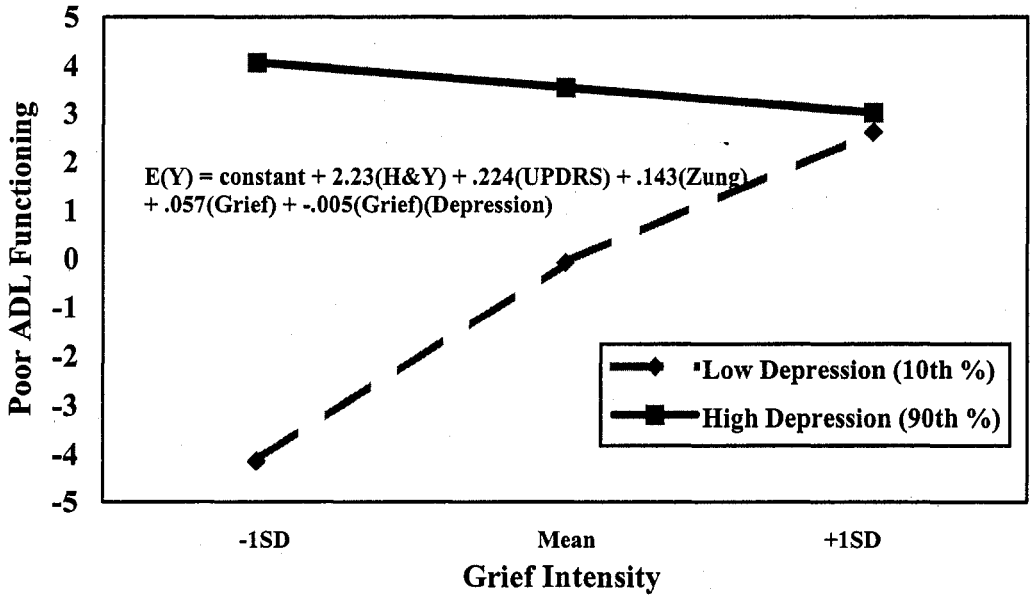

Figure 4 Interaction between grief and depression on ADL functioning at time 1

Grief and Depression as Risk Factors for Subsequent Mental Health and Physical Morbidity

These analyses examined the role of depression, grief, and their interaction on subsequent health outcomes (Time 2) after baseline (Time 1) scores, movement disability (UPDRS), and disease stage (H&Y) were controlled. Specifically, subsequent health outcomes included the following: self-esteem, distress from traumatic events, general overall health, state-anxiety, sleep quality, number of medical illnesses, number of moderate to severe medical illnesses, ADL functioning, grief, and depression. Again, analyses used only PD patients. Time 1 dependent variable scores, movement disability, disease stage, depression and grief, and their interaction were all simultaneously entered within step 1.

As expected, Time 1 dependent variables' scores significantly predicted Time 2 scores for all of the outcome variables (i.e. Time 1 self-esteem significantly predicted Time 2 self-esteem, etc.). Regarding the role of grief and depression on subsequent psychosocial outcomes, results showed that neither Time 1 depression, grief, nor their interaction significantly predicted any of the subsequent psychosocial health outcomes when controlling for initial disease stage, physical disability, and Time 1 health status. This result was seen even when excluding the grief by depression interaction variable from the model. However, when predicting subsequent depression scores, greater Time 1 grief scores ($B = .126$, $p < .05$) marginally predicted Time 2 depression scores even when baseline depression, disease stage, physical disability, and the interaction term were

controlled. Depression, however, did not significantly predict Time 2 grief within the full model. See Table 20 for more information.

Further exploratory analyses were conducted controlling for disease stage but not movement disability. This was done since disease stage and movement disability were significantly correlated with one another (r = .419, N = 97). Models also did not include the interaction term. Disease stage, Time 1 dependent variable scores, depression, and grief scores, were entered into the model simultaneously. Results showed that greater Time 1 grief marginally predicted poorer Time 2 self-esteem (B = -.054, p< .05) and worse ADL functioning (B= .060, p< .05). Only a trend toward marginal significance was seen for Time 1 grief scores predicting greater subsequent distress from traumatic events (B = .355, p= .052). Time 1 depression scores, however, did not significantly or marginally predict any of the health outcomes. When predicting subsequent depression scores, Time 1 depression (B = .680, p<.001) as expected was a significant predictor. Time 1 grief, however, trended toward marginal significance (B = .099, p=.059) when predicting subsequent depression scores. Further, only Time 1 grief scores (B = .637, p < .001) and *not* Time 1 depression scores significantly predicted Time 2 grief scores. See Table 21 for more information.

Overall, it appears that when taking into account both disease stage and movement disability along with Time 1 baseline scores neither depression, grief, nor their interaction contributed to Time 2 scores. Time 1 grief scores, however, only marginally predicted subsequent depression scores, but Time 1 depression scores did not predict subsequent grief scores. Analyses controlling only for disease stage, Time 1 baseline

scores, and depression found that Time 1 grief scores only marginally predicted subsequent self-esteem and activities of daily living. Depression, on the other hand, did not predict any subsequent health outcomes. Despite these findings, these results can be considered "chance" occurrences and therefore neither baseline grief nor depression can be considered significant predictors of 5-month post-baseline health outcomes within this population.

Table 20

Multiple regressions: Is grief or depression a predictor of future psychosocial outcomes?: controlling for both disease stage (H&Y) and UPDRS movement disability, and baseline DV variables (PD patients only)

DV: Rosenberg's Self-Esteem

	B	SE	*B*	Sig.
Step 1				
H&Y	-.416	1.030	-.042	.689
UPDRS	-.017	.081	-.022	.835
**T1 Self-Esteem	.756	.138	.692	.000
Depression	.031	.057	.066	.591
*Grief	-.052	.030	-.218	.093
Interaction	.002	.002	.094	.302
**Adjusted R^2 = .656. Overall model fit: F(6,42) =16.254, p=.000				

** p<.01 * $p\leq$.05

DV: Impact of Events Scale /IES

	B	SE	*B*	Sig.
Step 1				
H&Y	4.364	4.050	.142	.287
UPDRS	-.041	.320	-.018	.898
*T1 IES	.478	.216	.439	.032
Depression	.076	.203	.054	.710
Grief	.126	.147	.176	.395
Interaction	.005	.006	.089	.426
Adjusted R^2 = .464 Overall model fit: F(6,43) =8.067, p=.000				

** p<.01 * $p\leq$.05

DV: State Anxiety

	B	SE	*B*	Sig.
Step 1				
H&Y	-3.659	3.025	-.150	.233
UPDRS	-.070	.243	-.037	.774
**T1 State Anxiety	.603	.148	.631	.000
Depression	.207	.161	.184	.205
*Grief	.057	.100	.100	.571
Interaction	-.001	.004	-.012	.905
**Adjusted R^2 = .522 Overall model fit: F(6,43) =9.932, p=.000				

** p<.01 * $p\leq$.05

Table 20 (Continued)

DV: General Health Questionnaire

	B	SE	*B*	Sig.
Step 1				
H&Y	.259	1.447	.022	.859
UPDRS	-.087	.110	-.097	.435
**T1 General Health Questionnaire	.717	.152	.782	.000
Depression	-.035	.086	-.064	.687
Grief	.037	.043	.133	.400
Interaction	-.001	.002	-.055	.601
**Adjusted R^2 = .561 Overall model fit: F(6,41) =11.014, p=.000				

** p<.01 * $p\leq$.05

DV: Sleep Latency

	B	SE	*B*	Sig.
Step 1				
H&Y	-1.032	3.135	.036	.760
UPDRS	.108	.396	.036	.786
T1 Sleep Latency	.847	.172	.605	.000
Depression	-.400	.250	.196	.117
Grief	.020	.137	.020	.884
Interaction	-.003	.009	.041	.696
Adjusted R^2 = .501 Overall model fit: F(6,43) =9.197, p=.000				

** p<.01 * $p\leq$.05

DV: Sleep Efficiency

	B	SE	*B*	Sig.
Step 1				
H&Y	-2.193	3.654	-.103	.552
UPDRS	-.019	.286	-.012	.948
**T1 Sleep Efficiency	.397	.120	.562	.002
Depression	.335	.193	.334	.091
Grief	-.107	.104	-.216	.307
Interaction	.012	.006	.314	.043
**Adjusted R^2 = .221 Overall model fit: F(6,36) =2.981, p=.018				

** p<.01 * $p\leq$.05

Table 20 (Continued)

DV: Sleep Quality

	B	SE	*B*	Sig.
Step 1				
H&Y	-.688	1.000	-.083	.495
UPDRS	.059	.078	.093	.454
**T1 Sleep Quality	.771	.175	.642	.000
Depression	-.017	.054	-.045	.756
Grief	.051	.029	.263	.081
Interaction	-.003	.001	-.220	.047
**Adjusted R^2 = .566 Overall model fit: F(6,41) = 11.198, p=.000				

** p<.01 * $p\leq$.05

DV: Number of Illnesses/CIRS

	B	SE	*B*	Sig.
Step 1				
H&Y	.874	.967	.119	.372
UPDRS	-.082	.075	-.141	.276
**T1 Number of Illness/CIRS	.508	.079	.742	.000
Depression	.026	.049	.074	.603
Grief	.005	.027	.028	.857
Interaction	.001	.001	.099	.360
**Adjusted R^2 = .579 Overall model fit: F(6,36) = 10.614, p=.000				

** p<.01 * $p\leq$.05

DV: Co-morbidity/Severity of Illness/CMI

	B	SE	*B*	Sig.
Step 1				
H&Y	.384	.458	.131	.407
UPDRS	-.018	.035	-.075	.620
**T1 Co-morbidity/CMI	.355	.088	.516	.000
Depression	.022	.023	.156	.350
Grief	.010	.012	.149	.404
Interaction	.000	.001	.041	.743
**Adjusted R^2 = .413 Overall model fit: F(6,36) =5.928, p=.000				

** p<.01 * $p\leq$.05

Table 20 (Continued)

DV: Activities of Daily Living

	B	SE	*B*	Sig.
Step 1				
H&Y	1.563	1.224	.120	.209
UPDRS	.174	.095	.173	.074
**T1 Activities of Daily Living	.734	.100	.737	.000
Depression	-.049	.058	-.082	.405
Grief	.008	.034	.026	.819
Interaction	.001	.002	.060	.450
**Adjusted R^2 =.752 Overall model fit: F(6,43) =25.799, *p*=.000				

** $p<.01$ * $p\leq.05$

DV: Grief

	B	SE	*B*	Sig.
Step 1				
H & Y	8.114	4.693	.216	.091
UPDRS	.044	.362	.015	.904
T1 Depression	.006	.236	.004	.978
** T1 Grief	.549	.129	.606	.000
Interaction	-.002	.007	-.035	.738
Adjusted R^2 = .509 Overall model fit: F(5,44) = 11.175, p=.000				

** $p<.01$ * $p\leq.05$

DV: Depression

	B	SE	*B*	Sig.
Step 1				
H & Y	3.998	2.222	.180	.079
UPDRS	-.126	.172	-.074	.469
**T1 Depression	.610	.111	.596	.000
* T1 Grief	.126	.061	.242	.044
Interaction	-.006	.003	-.160	.064
Adjusted R^2 = .682 Overall model fit: F(5,45) = 22.424, p=.000				

** $p<.01$ * $p\leq.05$

Table 21

Multiple regressions: Is grief or depression a predictor of future psychosocial outcomes?: controlling for disease stage (H & Y) and Baseline DV variables (PD patients only)

DV: Time 2 Rosenberg's Self-Esteem

	B	SE	*B*	Sig.
Step 1				
H&Y	-.091	.601	-.012	.880
**T1 Self-Esteem	.776	.124	.714	.000
Depression	.028	.048	.061	.565
*Grief	-.054	.023	-.233	.025
**Adjusted R^2 = .685. Overall model fit: F(4,50) =30.365, p=.000				

** p<.01 * $p\leq$.05

DV: Time 2 Impact of Events Scale/IES

	B	SE	*B*	Sig.
Step 1				
H&Y	5.616	2.764	.218	.047
**T1 IES	.355	.180	.325	.055
Depression	.014	.177	.010	.936
*Grief	.228	.115	.323	.052
**Adjusted R^2 = .487. Overall model fit: F(4,50) =13.792, p=.000				

** p<.01 * $p\leq$.05

Table 21 (Continued)

DV: Time 2 Activities of Daily Living

	B	SE	*B*	Sig.
Step 1				
H&Y	1.546	.807	.153	.061
**T1 Activities of Daily Living	.730	.094	.716	.000
Depression	-.068	.051	-.114	.190
*Grief	.060	.028	.194	.037
**Adjusted R^2 = .740. Overall model fit: F(4,51) =40.112, p=.000				

** p<.01 * $p\leq$.05

DV: Time 2 Depression

	B	SE	*B*	Sig.
Step 1				
H&Y	1.967	1.476	.112	.188
T1 Grief	.099	.051	.187	.059
**Depression	.680	.101	.653	.000
**Adjusted R^2 = .650. Overall model fit: F(3,53) =35.60, p=.000				

** p<.01 * $p\leq$.05

Discussion

The primary goal of this study was to determine if symptoms conceptualized as dimensions of intrapersonal grief could be identified and distinguished from symptoms of depression within Parkinson's disease and Essential Tremor rehabilitation patients. There is considerable evidence in support of the distinction between complicated grief symptoms and major depression symptoms among those who are bereaved or who have lost a loved one (Lichtenthal, Cruess, & Prigerson, 2004; Prigerson & Maciewjewski, 2005; Zhang et al., 2006). Although it is intuitive to think that grief-related symptoms, instead of or in addition to depression symptoms, can occur during medical illness and functional loss, no study has investigated whether grief-related symptoms occur or if they are distinct from depression within the context of medical illness.

In order to examine this primary goal, the study first needed to evaluate the reliability and validity of the newly developed *Loss Inventory* (Niemeier et al., 2004) as a measure of intrapersonal grief. Second, the study examined the prevalence of intrapersonal grief and depression among a Parkinson's disease population. Third, analyses were completed assessing how the symptoms of grief were associated with various psychosocial health outcomes at baseline and 5-6 months later beyond the variance accounted for by disease stage, movement disability, and depression.

Reliability and Validity of the Loss Inventory

Since grief intensity in this study is based on scores from the newly developed *Loss Inventory*, it was first necessary to examine its reliability and validity in this population. The *Loss Inventory* was very reliable, with similar internal consistency (Cronbach's alpha: Time 1 = .975; Time 2 = .976) and split-half reliabilities (.952) as found in Niemeier et al.,'s (2004) study of a diverse rehabilitation population. Test-retest reliability over a 5 to 6 month time span was modestly high as well (r = .728), suggesting that grief scores can be generalized over time among PD and ET patients. Exploratory analyses were completed to determine if change in physical functioning (as measured by ADL scores) over time (Time 1 to Time 2) would predict Time 2 LI scores. Although examining objective movement disability data would have been optimal, the study did not collect Time 2 UPDRS movement disability scores. Results showed that changes in ADL functioning did not predict Time 2 LI scores. The LI was not sensitive physical functioning change over a 5-6 month time span within this population. However, this may be due to the small amount of physical change that occurred over this time period, which is as expected given the nature and chroniciity of Parkinson's disease.

Validity was demonstrated in several ways. First, the *Loss Inventory* showed a strong positive association with distress from traumatic events, and a negative association with self-esteem, as expected. The *Loss Inventory* was also significantly associated with state anxiety (STAI-state), poor general overall health and well-being (GHQ), and poor sleep quality (PSQI). These findings were expected and are similar to what the literature has reported when examining the degree of grief or interpersonal loss in a bereaved

population. Physical and medical characteristics were also associated with the *Loss Inventory* as expected. Greater number of illnesses, more moderate to severe medical illnesses, greater ADL dysfunction, and greater movement disability were positively associated with grief intensity as measured by the *Loss Inventory*. Demographic variables of age and education were also related to the *Loss Inventory*. Younger patients reported more intense grief than older patients. Illness may be a bigger adjustment for younger patients. This finding has been seen in past research examining age differences in coping with medical stressors and emotional adjustment (cancer; Williamson & Schulz, 1994; amputation; Dunn, 1997; Liveneh, Antonak, & Gerhardt, 1999; heart transplant; Rybarczyk, Grady, Naftel, Kirklin, White-Williams, & Kobashigawa; 2007). It may be possible that aging benefits include greater coping skills due to life experiences and some expectancy of having medical illness and disability in later life (Neugarten, 1969; Williamson, Schulz, Bridges, & Behan, 1994). Those with less education report more grief than those with more education. This may be a function of socioeconomic status; those with more education may have higher paying jobs, which may result in the financial resources to pay for ADL equipment, healthcare, medicine, etc. making their losses more manageable. Individuals with more education may also be more aware of potential supportive community resources to buffer them from intense grief reactions. This association between education and grief intensity is consistent with a recent finding from the Yale Bereavement Study (Maciewjewski, Zhang, Block, & Prigerson, 2007), which also found that less education (high school or less) was associated with greater

disbelief, depression symptoms, and less acceptance of the death 12 to 24 months post-loss (Maciewjewski et al., 2007).

Contrary to the study's hypotheses, no correlation between grief intensity and number of years of diagnosis was found. It was hypothesized that those with a long-standing diagnosis would experience greater functional losses and grief if they are at later disease stages. Results, however, support the variability of the grief reaction throughout the disease process. Those with a relatively new diagnosis may experience greater grief compared to those with a long-standing diagnosis or vice versa. This finding is consistent with this study's finding of no significant correlation between disease stage (*Hoeyn & Yahr Disease Staging*) and *Loss Inventory* scores, although the relationship is positively associated. Variability in grief reactions (i.e. severity and length of mourning) is also seen among spousally-bereaved (Wortman & Silver, 2001). A few studies have even identified different categories of bereavement response courses (i.e. common, resilient, recurrent, chronic) prospectively after a death (Bonanno, Wortman, Lehman, Tweed, Haring, Sonnega et al., 2002; Levy, Martinkowski, & Derby, 1994; Ott, Lueger, Kelber, & Prigerson, 2007).

Lastly, the study hypothesized that greater expectedness of the illness would be associated with less grief intensity. This was hypothesized since within the spousal bereaved literature, those bereaved by traumatic or unexpected deaths versus natural deaths had greater difficulty in making sense of the loss and in accepting the loss (Currier, Holland, & Neimeyer, 2006). Other research has indicated that preparation for the loss or death or a degree of expectedness of the loss is associated with better

psychological adjustment to the loss (Barry et al., 2001). Despite this, no relationship was found within this study; expectedness of the diagnosis was not associated with current grief intensity. Results, however, may be dependent on a lack of varied responses of expectedness of the diagnosis or are dependent on the length of time of having the diagnosis. Further examination of the study data showed that the study population did vary in their expectedness responses (i.e. no variable skewness was seen; M = 2.25, SD = 1.27; Range=1 to 5). Additionally, when controlling for length of diagnosis, again no relationship between expectedness and grief intensity was seen (r = -.01, p=.904, N=147). Unlike a spousal bereaved population, a surprise diagnosis of the illness is not associated with higher grief intensity, at least among this medical population.

The study showed divergent validity in that the *Loss Inventory* was not correlated with cognitive impairment (MMSE) or self-reported marriage satisfaction and happiness. Contrary to hypothesis, a moderate correlation (r = .58) between the *Loss Inventory* and the *Zung SDS* was found among the PD population. This moderate correlation supports the idea that intrapersonal grief and depression are likely to co-occur and are moderately associated with one another. Using the *Loss Inventory*, a similar correlation with Niemeier et al.,'s (2004) mixed acute rehabilitation population was also seen (r = .59, p<.05, N=103). Yet another study found a significant correlation (r =.37, p<.001, N=181) between grief symptoms and depression on the *Beck Depression Inventory-II* among medical patients with motor neuron disease or cancer (Clarke, Kissane, Trauer, & Smith, 2005). Among a bereaved population (children and adults), similar moderate correlation between depression and grief is also seen (McDemott et al., 1997; Milhem, Moritz,

Walker, Shear, & Brent, 2007; Prigerson, Frank et al., 1995). After all, it would be of greater concern if the two scales proved to be totally unrelated to one another. The two constructs focus on negative mood and both questionnaires have similar test-taking procedures. Despite the degree of association, at least 67% of the variance of the sample's LI grief scores is unexplained by depression. Taking questionnaire error into account, at least 40% of the variance of grief scores is unexplained by depression scores. Thus, one could interpret that grief and depression are associated empirically and are co-morbid, similar to depression and anxiety. A patient may experience depression or grief separately, but the majority of PD patients experience both together.

In a further effort to show divergent validity between the *Loss Inventory* and the *Zung SDS,* items from both questionnaires were entered into a principal component analysis. It was hypothesized that items from the *Loss Inventory* would cluster together and separately from the items of the *Zung SDS.* This method has been used previously in research differentiating symptoms of depression, anxiety, and complicated grief among the bereaved (Boelen, van den Bout & de Keijser, 2003; Chen et al., 1999; Horowitz et al., 1997; Ogrodniczuk et al., 2003; Prigerson, Bierhals et al., 1996; Prigerson, Frank et al., 1995; Prigerson, Maciewjewski et al., 1995; Prigerson, Shear et al., 1996). Recent research among medical patients with metastatic cancer and motor neuron disease also found that similar grief items (i.e. thoughts of the loss, pangs, memories/intrusive thoughts of the loss, and yearning for the loss) clustered together and separately from items arbitrarily defined as "demoralization" and "anhedonia" in a PCA analysis (Clarke et al., 2005; Clarke, Smith, Dowe, & McKenzie, 2003). As expected, in this study the LI

items clustered together, and the *Zung SDS* items clustered together. There were, however, a few exceptions. Most notably, the *Zung SDS* item, "I feel down-hearted and blue" loaded onto both the "grief" and "depression" components, but loaded more strongly onto the "grief" component. Additionally, four *Zung SDS* items loaded onto the "grief" component ("I have crying spells or feel like it", "I eat as much as I used to", "I notice that I am losing weight", and "I find it easy to do the things I used to do."), but ultimately had higher loadings on the "depression" components. These cross-loadings provide some evidence that feelings of sadness, appetite, and daily routine disturbances are associated with both grief and depression, and may partially explain the moderate correlation between grief and depression. Nevertheless, separate component loadings for the grief and depression items suggest a distinction between grief and depressive symptoms within this medical context. Overall, these patterns of results largely confirmed hypothesized relationships from the literature review, hence supporting the convergent and divergent validity of the *Loss Inventory* within this rehabilitation population.

Prevalence of Grief and Depression in Parkinson's disease

The study population reported varying levels of grief intensity related to Parkinson's disease. However, contrary to initial hypotheses, a majority of participants did not report "high" levels of grief (above the median) while at the same time reporting no depression to minimal levels of depression. Only 8.7% of the sample could be categorized into this category, while 41% endorsed symptoms of mild to severe depression *and* "high" levels of grief. This pattern is consistent with the moderate

correlation found between grief and depression within this population. However, the number of persons within each category may be characteristic of this specific population only. For example, the "high grief" category was based on this sample's median *Loss Inventory* score, which may potentially be very different in another medical sample. Additionally, although there is still some controversy about the exact nature of depression in Parkinson's disease, some believe that depressive symptoms are caused by the morbidity of the disease and some believe that depression may be an early manifestation of future diagnosis (Ishihara & Brayne, 2006). This unique nature of depression in Parkinson's disease may have inflated those categorized with depressive symptoms, thus lowering the potential prevalence of those with "high grief" without depression. Additionallly, categorizing patients with depressive symptoms versus depressive disorder may also impact the prevalence of finding those with "high" grief symptoms alone (i.e. no depression). Thus, the prevalence of "high grief" only will vary depending on the population, the medical context, and the operalization of grief and depression. Future research should continue to examine the prevalence of grief and depressive symptoms among other medical or rehabilitative populations. Further, research should begin to determine how to operationalize high intrapersonal grief by examining variation in grief intensity among differing disease severities and among healthy populations.

Influence of Depression and Intrapersonal Grief on Concurrent Psychosocial and Health Outcomes

Although grief was moderately correlated with depression, study results also provided evidence for the clinical utility of the *Loss Inventory* and for its distinction from

depression within a Parkinson's population. Specifically, greater grief scores independently contributed to poor self-esteem, greater distress from traumatic events or the illness, greater state anxiety, worse general health and well-being, and poor overall sleep quality above and beyond the influence of disease stage, movement disability, and depression. Interestingly, greater grief scores independently contributed to sleep efficiency and marginally contributed to sleep latency scores, while depression scores did not. Because the majority of grief symptoms as measured by the *Loss Inventory* are related to thoughts of the loss, this may have influenced the role of grief on sleep latency and sleep efficiency if difficulty falling asleep is related to increased cognitive arousal and worry (Harvey, 2002). Additionally a marginally significant interaction between grief and depressive symptoms was seen such that as grief symptoms increased, ADL functioning worsened, but only for those with none to little depressive symptoms. Regarding the number and severity of medical illnesses, neither grief nor depression was influential beyong the influence of disease stage and movement disability. This is interesting because prior research has shown a link between depressive symptoms and number and severity of medical illness (Berkman, Berkman, Kasl, & Freeman, 1986; Fortin, Braveo, Hudon, & Lapointe et al., 2006; Palinkas, Wingard, & Barrett-Connor, 1990; Williamson & Schultz, 1992), and between grief and future medical illness among the bereaved (Prigerson et al., 1997; Ott, 2003; Silverman et al., 2000). Further examination, however, after excluding disease stage movement disability, and the grief and depression interaction term (each of these variables did not predict number of illnesses or number of severe illnesses within the full linear regression model) showed

that higher depression (B = .171, p<.005) and marginally significant grief (B = .054, p<.05) scores were associated with the number of medical illnesses. On the other hand, only depression significantly predicted the number of moderate to severe medical illnesses, while grief scores did not. Overall, these results indicate that depression is associated both with the number of medical illnesses and with the number of more severe illnesses, (which is consistent within the literature), while grief intensity is associated only with number of illnesses within this population. While this differential association between grief intensity and depression may provide further evidence for distinguishing grief from depression, future studies should replicate this finding before definitive conclusions can be drawn.

Overall, these findings provide evidence that intrapersonal grief has incremental validity and predicts unique variance in the aforementioned health outcomes. Most importantly, this data also lends support to the meaningfulness of the construct of intrapersonal grief during medical illness and to distinction from depression. These results are consistent with a very recent study examining the unique contribution of complicated grief (CG) symptoms on measures of overall global functioning (interviewer ratings, friend ratings, self-report, and autonomic arousal) among spousally-bereaved individuals. While controlling for both depression and Post-Traumatic Stress Disorder, CG symptoms , among this population, emerged as a unique predictor of functioning, both cross-sectionally and prospectively (Bonanno, Yuval, Mancini, Coifman, & Litz, 2007).

Intrapersonal Grief and Depression as Risk Factors for Subsequent Psychosocial Outcomes

The predictive nature of baseline (Time 1) grief and depression on subsequent mental and physical health outcomes was also examined, and the study's hypotheses were not supported. Neither grief nor depression nor the interaction between the two predicted subsequent health outcomes when controlling for the baseline health variables, disease stage, or movement disability. Within these models, the best predictor of subsequent health outcomes was the baseline level of the dependent variable. However, because disease stage and movement disability were moderately correlated ($r = .419$, N = 97), further exploratory analyses examined disease stage, baseline depression and grief, and baseline health variable scores only on the subsequent psychosocial health outcomes. After controlling for Type 1 Error, results showed that greater grief scores marginally predicted subsequent worse self-esteem and worse ADL functioning five to six months after baseline. Depression scores, on the other hand, only predicted subsequent depression scores and did not predict any subsequent health outcomes, including subsequent grief scores. However, these results should be noted cautiously since they are marginally significant when adjusting the *p*-values for Type 1 error. Despite this, these results are partially consistent with findings among a spousal bereaved population (Prigerson, Frank et al., 1995). Baseline bereavement-related complicated grief scores (taken six months post-death) were significantly associated with impairments in global functioning (*Global Assessment Scale*), depressive mood (one item from the *Hamilton Depression* scale), sleep (PSQI total scale), and self-esteem (*Interpersonal Support*

Evaluation List subscale), even when controlling for depression and months since the death of the spouse (Prigerson, Frank et al., 1995). Overall, by showing that intrapersonal grief is associated with short-term functional impairment, the study provided additional preliminary evidence that the concept of intrapersonal grief has predictive validity and practical utility among this medical population. However, given the marginal findings, these particular results should be replicated in similar sample populations.

Intrapersonal Grief within Parkinson's disease and Essential Tremor Patients

In light of limited knowledge of intrapersonal grief indicators among a medical population, a factor analysis of the *Loss Inventory* items gave insight as to how bereavement-related symptoms can be categorized. If symptoms related to intrapersonal grief are similar to bereavement-related grief, then symptoms would cluster together similarly. Results from the LI factor analysis yielded a three-factor solution primarily reflecting 1) thoughts of the loss and life before the diagnosis, 2) symptoms of depressed mood and distress, and 3) feelings of unfairness, anger, and bitterness. However, examination of the high intercorrelations among the three factors, the scree plot, and the greater than 5% variance rule, suggested a one-factor unidimensional parsimonious model. No individual item from the *Loss Inventory* was excluded due to low (< .6) factor item loadings and, as mentioned earlier, internal consistency for the *Loss Inventory* was very high at both time points. The one-factor solution explained more than one-half of the total variance (59.1%).

Using the well-known reliable and valid *Inventory of Complicated Grief*, Prigerson and colleagues have suggested that bereavement-related complicated grief

symptoms also cluster together and form one underlying construct, and this finding has been replicated in numerous studies (Boelen et al., 2003; Dyregrov, Nordanger, Dyregrov, 2003; Forstmeier & Maercker, 2007; Melhem et al., 2004; Melhem et al., 2007; Ogrodniczuk, Piper, Joyce, Weideman et al., 2003; Prigerson, Frank et al., 1995; Prigerson, Maciejewski et al., 1995, Prigerson, Bierhals et al., 1996; Prigerson, Shear et al., 1999; Prigerson & Jacobs, 2001; Ritsher & Neugebauer, 2002).

From the current study's *Loss Inventory*, items with the highest item-average were the following: "I am longing to have what I have lost again." M = 3.05 "I think about what I have lost." M=2.85, and "I can't help thinking about the "good old days" before my loss" M=2.80. This suggests that these items are endorsed the most frequently. Interestingly, Niemeier et al.,'s (2004) study with an acute rehabilitation population also found that "longing to have what I lost again" or "longing for the time before the loss" was the most frequently endorsed. This was seen for both men and women separately. Yearning has also been found to be the the most frequently endorsed among a bereaved population in both normal and complicated bereavement-related grieving (Forstmeier & Maercker, 2007; Maciewjewski, Zhang, Block, & Prigerson, 2007; Zhang et al., 2006). For example, from Prigerson, Maciewjewski et al., (2005)'s *Inventory of Complicated Grief* (ICG), the most frequently endorsed item, was also "longing for the person who died", followed by "feeling that life is empty without the person who died." This latter item was not assessed in the *Loss Inventory.* In addition, only one study thus far has examined the relative magnitude and patterns of change over time post-loss of five grief indicators (acceptance, yearning, depression, anger, and disbelief) (Maciewjewski et al.,

2007). Using a community sample of 233 widows or widowers, the study also found that yearning or longing for the loss/spouse was the most highly endorsed negative indicator and that it remained the most elevated symptom of grief two months and two years post-loss (Maciewjewski et al., 2007).

From the current study's Loss Inventory item loadings, items with the highest loadings and the highest item-total correlations were the following: "I get upset when I remember having what I lost." (.877), "I am upset by reminders of my loss." (.863), "I feel I cannot accept my loss." (.840), "Thoughts of what I lost come to me when I don't expect them." (.839). This suggests that the elements of anger, feelings of non-acceptance, and intrusive thoughts of the loss are the best items to differentiate those with low versus high grief intense reactions to medical illness. These results are consistent with the literature that has found that greater acceptance and less anger are predictive of better well-being in several rehabilitative and medical populations (Dan et al., 2007; Johnstone, Glass, & Oliver, 2007; Wollaars, Post, van Asbeck, & Brand, 2007). Interestingly, factor analysis from the ICG (Prigerson, Maciewjewski et al., 1995); also show that "bitterness over death" and "being preoccupied with thoughts of the deceased to the point of distraction" were the best items to differentiate between persons with uncomplicated versus complicated grief. Different from medical population, another key indicator for complicated grief among spousally bereave was "being stunned or dazed by the loss." (Prigerson, Maciewjewski et al., 1995). Overall, intrapersonal grief as measured by the LI, may be considered an extension of grief as defined among the spousal bereaved and the two appear to be more similar than not.

Limitations and Future Recommendations

In considering these results, a few limitations must be kept in mind. First, limitations should be noted regarding the items of the Loss Inventory. Only 29 out of 30 Loss Inventory items were administered in this study. One central item "*I feel disbelief about what had happened.*") was inadvertently not used due to a clerical error, making it potentially difficult to compared this study's data to other LI results. The missing item, however, was given to participants who completed Time 2 questionnaires (N=100). Reliability analyses show that this particular item had an item-total scale correlation of .7309, which was comparable to other item-total scale correlations. The 30-item scale's Cronbach alpha was 0.9755, and with the item in question deleted it was .9748. Therefore, the lack of this item did not substantially alter the total scale's internal reliability, total scale score, or factor structure. Despite the item's relevance to other items of the Loss Inventory, opportunity to reduce the number of LI items is recommended given the questionnaire's high internal consistency. This would be beneficial when administering the LI in a medical setting or in a medical population, whom may easily fatigue while answering questions. Additional studies should complete confirmatory factor analysis to further examine the scale's reliability and construct validity in various medical populations as well as over time. Future studies examining the factorial validity of the LI should include a minimum of 300 persons for optimum results. Although the Bartlett's test of sphericity and the Kaiser-Meyer-Olkin test results were favorable, the current study used only 197 total subjects, thus potentially limiting it is overall interpretation of its factor structure.

A second limitation is related to the use of the Loss Inventory and the Zung SDS questionnaires. First, the Loss Inventory is limited in that its items concern symptoms known to be related to bereavement-related grief. The one-factor solution from the LI explained more than half of the variance (59.1%); however, in principle, other symptom indicators may account for additional variance in intrapersonal grief. This may include feeling distant from loved ones, avoiding social contact, and feelings of loneliness. Second, instructions from the Zung SDS asked participants to rate how they have been feeling "during the past several days". These instructions were not given explicitly for the Loss Inventory. Instead participants were asked to think of their losses related to Parkinson's disease. Thus, the relationship between grief and depression, as measured by these questionnaires, is potentially limited by the differential instructions. Participants' grief scores may be related to their experiences with their illness in total, while participant's depression scores are related specifically to feelings of the "past several days".

Another limitation involves the recruitment strategy (i.e. mailing out questionnaires) for the study, which may have influenced the type of subjects obtained. Individuals with incorrect addresses in the patient databases were not able to receive questionnaires. Further, potential participants may have easily forgotten about the research study, if they had not been to the hospital clinic during the time study data was collected. Additionally, patients with severe medical illness, functional impairment (i.e. writing, memory difficulties), or prior psychopathology may not have been able to participate, and are likely to be the most vulnerable to intrapersonal grief reactions. In

this way, study group selection biases may have resulted in the underestimation of intrapersonal grief reactions and reduced power to detect significant effects of grief on the follow-up measures of functioning. Data from the study did show that those who responded to both sets of questionnaires (Time 1 and Time 2) presented with less movement disability and distress and endorsed lower grief scores at Time 1 compared to those who only responded to Time 1 questionnaires only. Therefore, those who did not respond to the second set of questionnaires were more impaired physically than those who completed questionnaires at both timepoints. Opportunity for research staff to complete home visits and assist participants in answering questionnaires may mitigate any potential sample differences between those who do and do not mail-in questionnaires.

It should also be noted that the study may not generalize to all medical illnesses. While research findings may have important implications for understanding grief and depression within Parkinson's disease and Essential Tremor, the data may not generalize to individuals dealing with other medical illness. For example, intrapersonal grief due to a medical chronic illness like amputation may be different than grief due to a neurodegenerative disease like PD or multiple sclerosis. Differences in these types of illnesses may be related to differences in the etiology of the disease and psychological distress for those illnesses with episodic exacerbation of symptoms. Interestingly, despite potential group differences between medical illnesses, when comparing the current study sample's total all-male average LI scores with unpublished raw data from Niemeier et al., (2004)'s all-male, mixed acute (i.e. stroke, TBI, amputee, etc.) rehabilitation study, the

two study groups scored similarly on the LI: (PD and ET: M = 64.41, SD = 26.50, N=185; Mixed acute rehab: M = 67.92, SD = 22.14, N=109; also without question #9). This suggests that grief intensity may be similar between acute and chronic rehabilitative groups. However, it may be difficult to operationalize the losses faced by PD and ET patients as solely chronic, since during the course of PD or ET, a new and acute loss may be experienced every couple of months or more frequently. Regarding depressive symptoms, in the case of Parkinson's disease, accurately measuring depression symptoms was difficult given that many symptoms of Parkinson's disease overlap with symptoms of depression. As mentioned earlier, some research suggests that depression is a symptom of PD and not a consequence of the disease. This, in turn, could make the association between grief and depression inflated in the PD population compared to its relationship within other medical illnesses. Thus, the unique role of depression on Parkinson's disease potentially limits the study's generalizability. Additionally, examining demographic group differences (i.e. race, gender) could not be done in this study given the use of a mostly male, Caucasian, veteran population. Group differences in intrapersonal grief may exist, as suggested by Niemeier et al., (2004), who found that minorities and women endorsed significantly greater grief reactions compared to males and Caucasians.

Lastly, the use of self-report data only, and not objective clinical ratings, is another limitation. Self-report data are subjective and potentially biased. Some participants may be reluctant to endorse symptoms of anxiety, depression, or intrapersonal grief, while others seeking attention from medical providers may overreport symptoms. Given this population, some participants may have needed assistance from

their caregiver (usually their wife) and therefore may have responded in a manner that they perceived to be desirable to their wives.

Despite these limitation, the present study is unique in that it provided preliminary data for the usefulness of the *Loss Inventory* on physical and mental health outcomes concurrently (at least within PD), and future studies should attempt to replicate these findings. Continuing to examine the potential discriminant validity of intrapersonal grief from depression among various medical populations is recommended to guide the assessment and potential treatment or care of varied reactions to medical illnesses. Similar to results in the bereavement literature, biological and/or psychological correlates may differentiate between intrapersonal grief and depression. For example, from the current study, although preliminary, less education, was associated with greater grief scores, while depression was not associated with amount of education. Similarly, greater depression scores were associated with less marital satisfaction and later disease stage (H&Y), while grief was not. There may be additional differential associations with biological markers (McDermott et al., 1997; Schucter et al., 1986), demographics (Fitzpatrick & Van Tran, 2002; Goldsmith et al., 2006; Wijngaards-de Meij et al., 2005), or personality and interpersonal styles (Carr et al., 2000; Cleiren et al., 1994; van Doorn et al., 1998). Within the context of intrapersonal grief and medical illness, behavioral and cognitive coping styles, quality of life, use of anti-depressant medication and health care, social and family functioning, or the symptom course may differentially be associated with either intrapersonal grief or depression. Furthermore, future research should examine the influence of intrapersonal grief on health-care behaviors like smoking,

adherence to medications, and physical activity. This is particularly important since these behaviors have the potential to impact the care of many chronic and disabling medical illnesses (i.e. lung disease, diabetes, etc.). After all, complicated grief scores among the spousally bereaved have been found to predict these health behaviors (Prigerson et al., 1997; Silverman et al., 2000). As partially examined by Neimeier et al (2004), research should also examine potential moderators (i.e. gender, race) of grief on these same health outcomes (i.e. number of illnesses, health care utilization, health behaviors).

Examining the course of intrapersonal grief from initial diagnosis onward is recommended as well. This would potentially answers questions such as, "Does a person adjust to their illness over time?", and "Does the highest amount of distress occur at diagnosis?" It would also allow empirical examination of the grief stages (i.e. disbelief, yearning, anger, depression, and acceptance) within a medical population. As mentioned earlier, only one empirical study has done this within the spousal bereaved literature (Maciejewski et al., 2007). Interestingly, this study found that negative indicators of grief (disbelief, yearning, etc.) all peaked within 1 to 6 months of the spousal deaths. Yearning was the dominant negative grief indicator throughout the 24 months postloss observation period and acceptance scores gradually increased as time from loss increased. On average, depressive symptoms peaked at 6 months post-loss and also declined over time. Similar to this study, repeated assessments of grief indicators and depression may show differing resolution or exacerbation of these constructs, thus adding to the discriminant validity of intrapersonal grief from depression. The course of grief and depression may also vary depending on the illness. It may be possible that grief or loss continuously

fluctuates or worsens without improvement over time for a patient with a chronic degenerative illness, whereas grief may subside or improve over time for those with an acute illness and among those with a chance to return to full independence (Choi & Bohman, 2007; Koenig, Johnson, & Peterson, 2006; Leentjens, 2004; Lyness, Niculescu, Tu, Reynolds, & Caine, 2006; Simon, Von Korff, & Lin, 2005).

Clinical Implications and Conclusions

The current study has implications for mental and medical health practitioners working with Parkinson's disease and Essential Tremor patients specifically, but has potential to influence other medically ill patients as well. First, the study provides some additional promising psychometric properties for a measure of grief due to functional losses within a medical population. *The Loss Inventory* gives clinicians the opportunity to potentially identify a subset of patients who may require treatment that specifically targets symptoms of grief related to illness to improve their functioning. It also allows opportunity to examine the course of these symptoms over time.

Second, the study provides initial evidence of the existence and clinical significance of intrapersonal grief within the medical context. Grief symptoms, as measured by the *Loss Inventory*, appear to be a unique predictor of concurrent physical and mental health outcomes and marginally predict future self-esteem and ADL functioning, even when controlling for disease related variables and depression. Altogether, study results provide preliminary support for the discriminant, construct, and incremental validity of the concept of grief from functional losses. There may be many

dimensions of negative affect besides depression after and during medical illness, and intrapersonal grief is a meaningful syndrome of distress within this population.

Finally, the study also showed preliminary evidence to suggest that those with medical illness endorse similar symptom items with similar intensity to those recently bereaved. If bereavement-related grief and intrapersonal grief from illness are similar, then this has potential implications clinically and for the DSM.

Currently, criteria for a Major Depressive Episode use an exclusion criterion to prevent a false-positive diagnosis; the symptoms cannot be better explained by bereavement. However, this criterion ignores many other kinds of serious losses that can also lead to intense symptoms of normal sadness or complicated reactions. Findings from this study raise the question of whether the DSM is justified in singling out bereavement as the only type of loss that produces intense sadness or a reaction that is not considered depression. If loss experienced from illness is similar to loss experienced from bereavement, then the reactionary intense sadness symptoms should not automatically be considered symptoms of a depressive disorder without considering the existence of a grief-related condition (separate from depression) from the loss. If current DSM criteria label bereavement reactions as non-disorders or not depression, then episodes that occur after or during other losses (like medical illness) may plausibly also be non-disordered, and are distinct from depression, especially if reactions from bereavement and medical illness are similar. Additionally, similar to the bereavement literature, the grief-like reaction from medical illness could also potentially be classified as complicated versus

uncomplicated, with higher intrapersonal grief intensity more likely to be associated with poor well-being as seen in this study.

A recent study by Wakefield, Schmitz, First, and Horwitz (2007), using data from the National Comorbidty Survey (N=8098), compared uncomplicated bereavement and uncomplicated reactions to other losses on a variety of disorder indicators and symptoms and found similar symptom profiles between the two loss categories. If future research confirms these findings with nonbereavement-related losses, then the bereavement exclusion criteria for major depression should also be considered for nonbereavement triggers of intense sadness.

In sum, the present findings lend support for the meaningfulness of intrapersonal grief as a construct separate from depression. Those with Parkinson's disease or Essential tremor were able to identify and endorse symptoms known to bereavement-related grief. Loss from medical illness may in some ways be similar to bereavement-related reactions. The present findings also demonstrate intrapersonal grief's relevance to adjustment to illness. Specific symptoms of distress may be appropriate additional targets fro clinical intervention similar to that seen within the bereavement literature (Shear et al., 2005).

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Appendix A

Initial Letter to Participant

Dear PADRECC Patient,

February 2006

I am writing to inform you about a new study that the Parkinson's Disease Research Clinical and Education Center is undertaking here at the Richmond VAMC. It is also part of my dissertation research and I hope that you will be able to participate. You are welcomed to participate in this study on *"Emotional well-Being in Parkinson's Disease patients"*

The purpose of this study is to examine how our PADRECC patients are coping with their illness. We would like to examine your physical and personal responses to having been diagnosed with Parkinson's Disease.

Within the next week, you should receive a questionnaire packet through the mail. To participate in this study, you will need to complete your packet of questionnaires and PROMPTLY return it to the VA Hospital in the pre-stamped envelope. Answering the questionnaires should take no more than 1 hour. Also you will be asked to answer the same questionnaire packet 5 months in the future. More specific information and instructions about the questionnaires and the study will be provided in your packet of questionnaires.

If you have any questions please contact us at (XXX) XXX-XXXX. Thank you; we look forward to working with you.

Sincerely,

Rashelle Brown,MS
&
PADRECC STAFF

Appendix B

Recruitment Flier

RESEARCH OPPORTUNITY

Parkinson's Disease Research Education and Clinical Center
PADRECC
Richmond McGuire VAMC

"Emotional Well-Being in Parkinson's Disease patients"

- PADRECC patients are welcomed to participate
- You will receive and complete a packet of questionnaires regarding your health concerns and feelings.
- You will complete the same packet of questionnaires 5 months in the future after having returned the first packet.
- Questionnaires should take no longer than 1 hour to complete.
- Feel free to mail the questionnaires promptly in your pre-stamped envelope or stop by the clinic to return your completed questionnaires.

REQUIREMENTS

- Participation in this study takes up to 1 hour and involves completing a packet of questionnaires at two time periods: Time 1 and Time 2 (5 months in the future)
- Packets will be mailed and you will be able to complete the packet of questionnaires at home.
- Patients must have been diagnosed with idiopathic Parkinson's Disease or Essential Tremor.

Appendix C

Follow-up letter to participants

March 2006

Dear PADRECC Patient,

A couple of weeks ago the PADRECC clinic here at the Richmond McGuire VA Hospital mailed out a questionnaire packet regarding "Emotional Well-Being in Parkinson's Disease patients" We are hoping that you will be able to participate. If you would like to participate please complete your questionnaire packet and return back to the VA Hospital via the pre-addressed and stamped envelope or return to the PADRECC clinic at the VA Hospital at your earliest convenience.

Thank you again for your participation!

Sincerely,

Rashelle Brown, MS
&
PADRECC STAFF

Appendix D

Participant Questionnaire

Emotional Well-Being Project

Baseline Questionnaire

TIME 1

Thank you for agreeing to participate in this important study. We realize that this may be a difficult time for you so we encourage you to take your time as you answer the questions in this survey. We hope that you will be able to answer all of the questions so that we can learn the most about your experiences and feelings. If you should grow tired as you are completing this questionnaire, feel free to take a break and then return to it.

Please mail in the questionnaire in the packet provided or hand deliver the completed questionnaire to the PADRECC, McGuire Veterans Administration Hospital, Richmond Va. as soon as possible in the envelope provided. Please do not distribute your questionnaire packet to anyone else. You should only complete the questionnaire mailed to you as each questionnaire packet has an identifying ID number. Thank you for your help.

PADRECC
McGuire Veteran Affairs Hospital
Richmond, VA.

PLEASE BEGIN ON PAGE 2

Preliminary Information (Completed by Investigator)
Respondent Number: _____
Date Questionnaire Delivered: _____
Date Questionnaire Returned: _____

Patient Questionnaire: TIME 1 **ID:**_____

Date: _____

BACKGROUND INFORMATION

1. What is your age? _____

2. Male _____ Female _____

3. What is your race?
___ (1) White _____(2) Black/African American

___ (3) Hispanic _____(4) Asian

___ (5) Native American _____(6) Other (please specify) _____

4. Check the answer below which best describes your level of education.

___ (1) Did not graduate from high school
___ (2) High school graduate
___ (3) Attended some college or trade school
___ (4) College graduate
___ (5) Have done some additional graduate work

5. Are you currently employed? (Check one answer and then write in your occupation.)

___ (0) No (last occupation) _____
___ (1) Part-time . . . What do you do? _____
___ (2) Full-time . . . What do you do? _____

6. What are your present living arrangements?
___ (1) Live alone
___ (2) Live with child or children
___ (3) Live with relative . . . who? _____
___ (4) Live with friend
___ (5) Other . . . describe _____

7. Are you currently ____ Married

____ Divorced

____ Widow/Widower

____ Separated

____ Never Married

8. If married currently, how long have you been married? _____

9. According to the scale below how happy would you say your marriage/significant relationship is?
(Circle a number on the scale)

1--------2--------3--------4--------5--------6--------7
Very Unhappy — Perfectly Happy

10. Has someone very close to you like a family member died in the past two years or so?

YES_____ NO_____

HEALTH QUESTIONS

1. How would you describe your overall general health since your initial diagnosis of Parkinson's Disease according to the scale below? (Circle a number from 1-7 on the scale that describes your health.)

1--------2--------3--------4--------5--------6--------7
Poor Health — Excellent Health

2. What was the month and year that you were told you have Parkinson's Disease?

Month _____ Year _____

3. How would you describe the expectedness of hearing you have Parkinson's Disease from the scale below? (Circle a number from 1-5 that describes your expectedness).

1----------2----------3----------4----------5
Unexpected Expected

4. Have you had Deep Brain Stimulation Surgery?

YES _____ NO _____

5. Are you ***currently*** taking antidepressant medication?

YES_____ NO_____

6. Have you been diagnosed by a mental health professional with Major Depressive Disorder ***Before*** the onset of the Parkinson's Disease?

YES_____ NO _____

7. Have you taken antidepressant medication in the ***past***?

YES_____ NO_____

8. Please indicate below if you have sought professional assistance related to your emotional feelings regarding your diagnosis of Parkinson's Disease and if so, how often:

		Not at all	Once or twice	Almost weekly	More than once a week
a.	Health Care Provider (i.e. medical doctor, psychiatrist)	0	1	2	3
b.	Clergy	0	1	2	3
c.	Mental Health Professional (i.e. psychologist, social worker, therapist, etc.)	0	1	2	3
d.	Grief Support Program	0	1	2	3
e.	Other:	0	1	2	3

The Loss Inventory© VCU

INSTRUCTIONS: Please answer all the questions as best you can. All of your responses will be kept confidential

What losses do you think you have experienced because of your illness of Parkinson's Disease?

Please check the boxes below to describe your feelings about these losses over the PAST TWO WEEKS.

	Never	Rarely	Sometimes	Often	Always
1. I feel like crying when I think about my loss.					
2. I think about what I have lost.					
3. I think about my loss so much it is hard for me to do things I normally do.					
4. Memories of how I was before my loss upset me.					
5. I feel I cannot accept my loss.					
6. I think it is unfair that I have this loss.					
7. I am angry about my loss.					
8. I am longing to have what I lost again.					
10. I feel envious of others who have not had a loss like this.					
11. I don't feel like a whole person since my loss.					
12. I feel stunned and dazed over what has happened.					
13. I feel myself longing for the time before my loss.					

	Never	Rarely	Sometimes	Often	Always
14. I feel bitter about having this loss.					
15. I feel anxious.					
16. I have had dreams about what I lost.					
17. I feel the urge to cry when I think about my loss.					
18. I feel the need to talk about my loss.					
19. Thoughts of what I lost come to be when I don't expect.					
20. I get upset when I remember having what I lost.					
21. I feel panic.					
22. I feel guilty about having this loss.					
23. It is hard for me to believe that what I lost is gone.					
24. I have trouble sleeping because of thoughts about what I lost.					
25. I can't help thinking about the "good old days" before my loss.					
26. My situation seems unreal to me.					
27. I am upset by reminders of my loss.					
28. I have dreams that I still have what I lost.					
29. I feel sad about my loss					
30. I feel numb since my loss.					

Rosenberg's Self-Esteem

INSTRUCTIONS: Below is a list of statements dealing with your general feelings about yourself. Please place a checkmark ( ) if you STRONGLY AGREE, AGREE, DISAGREE, or STRONGLY DISAGREE with each statement.

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. On the whole, I am satisfied with myself.				
2. At times, I think I am no good at all.				
3. I feel that I have a number of good qualities.				
4. I am able to do things as well as most other people.				
5. I feel I do not have much to be proud of.				
6. I certainly feel useless at times.				
7. I feel that I'm a person of worth, at least on an equal plane with others.				
8. I wish I could have more respect for myself.				
9. All in all, I am inclined to feel that I am a failure.				
10. I take a positive attitude toward myself.				

Zung SDS

INSTRUCTIONS: Please read each statement and decide how much of the time the statement describes how you have been feeling during the past several days. Make a checkmark ( ) in the appropriate column.

	A little of the time	Some of the time	Good part of the time	Most of the time
1. I feel down-hearted and blue.				
2. Morning is when I feel the best.				
3. I have crying spells or feel like it.				
4. I have trouble sleeping at night.				
5. I eat as much as I used to.				
6. I still enjoy sex.				
7. I notice that I am losing weight.				
8. I have trouble with constipation.				
9. My heart beats faster than usual.				
10. I get tired for no reason.				
11. My mind is as clear as it used to be.				
12. I find it easy to do the things I used to do.				
13. I am restless and can't keep still.				

	A little of the time	Some of the time	Good part of the time	Most of the time
14. I feel hopeful about the future.				
15. I am more irritable than usual.				
16. I find it easy to make decisions				
17. I feel that I am useful and needed.				
18. My life is pretty full.				
19. I feel that others would be better off if I were dead.				
20. I still enjoy the things I used to do.				

Impact of Events

INSTRUCTIONS: Below is a list of comments made by people after stressful life events. Using the following scale, please indicate with a ( ) how frequently each of these comments were true for you DURING THE PAST 7 DAYS.

	Not at all	Rarely	Sometimes	Often
1. I thought about it when I didn't mean to.	0	1	3	5
2. I avoided letting myself get upset when I thought about it or was reminded of it.	0	1	3	5
3. I tried to remove it from memory.	0	1	3	5
4. I had trouble falling asleep or staying asleep because of pictures or thoughts about it that came into my mind.	0	1	3	5
5. I had waves of strong feelings about it.	0	1	3	5
6. I had dreams about it.	0	1	3	5

	Not at all	Rarely	Sometimes	Often
7. I stayed away from reminders of it.	0	1	3	5
8. I felt as if it hadn't happened or wasn't real.	0	1	3	5
9. I tried not to talk about it.	0	1	3	5
10. Pictures about it popped into my mind.	0	1	3	5
11. Other things kept making me think about it.	0	1	3	5
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.	0	1	3	5
13. I tried not to think about it.	0	1	3	5
14. Any reminder brought back feelings about it.	0	1	3	5
15. My feelings about it were kind of numb.	0	1	3	5

STAI- State

INSTRUCTIONS: A number of statements which people have had used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you feel right now, that is, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	Not at all	Somewhat	Moderately So	Very Much So
1. I feel calm	1	2	3	4
2. I feel secure.	1	2	3	4

	Not at all	Somewhat	Moderately So	Very Much So
3. I am tense.	1	2	3	4
4. I feel strained.	1	2	3	4
5. I feel at ease	1	2	3	4
6. I feel upset	1	2	3	4
7. I am presently worrying over possible misfortunes	1	2	3	4
8. I feel satisfied.	1	2	3	4
9. I feel frightened.	1	2	3	4
10. I feel comfortable.	1	2	3	4
11. I feel self-confident.	1	2	3	4
12. I feel nervous.	1	2	3	4
13. I am jittery.	1	2	3	4
14. I feel indecisive	1	2	3	4
15. I am relaxed .	1	2	3	4
16. I feel content	1	2	3	4
17. I am worried.	1	2	3	4
18. I feel confused.	1	2	3	4
19. I feel steady.	1	2	3	4
20. I feel pleasant.	1	2	3	4

GHQ-12

INSTRUCTIONS: The following questions ask about your overall general health recently. Please circle the most appropriate answer for each statement.

Have you recently?

1. Been able to concentrate on what you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
2. Lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
3. Felt you were playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
4. Felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
5. Felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
6. Felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
7. Been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
8. Been able to face up to your problems?	More so than usual	Same as usual	Less so than usual	Much less able
9. Been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
10. Been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
11. Been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
12. Been feeling reasonably happy, all things considered	More so than usual	About same as usual	Less so than usual	Much less than usual;

PSQI

Instructions: The following questions relate to your usual sleep habits during the *past month only*. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. Please answer all questions.

During the past month,

1. When have you usually gone to bed? _____.

2. How long (in minutes) has it taken you to fall asleep each night? _____.

3. When have you usually gotten up in the morning? _____.

4. How many hours of actual sleep did you get that night? (This may be different than the number of hours you spend in bed) _____.

5. *During the past month, how often have you had trouble sleeping because you…*	**Not during the past month**	**Less than once a week**	**Once or twice a week**	**Three or more times a week**
a. Cannot get to sleep within 30 minutes				
b. Wake up in the middle of the night or early morning				
c. Have to get up to use the bathroom				
d. Cannot breathe comfortably				
e. Cough or snore loudly				
f. Feel too cold				
g. Feel too hot				
h. Have bad dreams				

5. *During the past month, how often have you had trouble sleeping because you...*	Not during the past month	Less than once a week	Once or twice a week	Three or more times a week
i. Have pain				
j. Other reason(s), please describe, including how often you have had trouble sleeping because of this reason(s):				
	Not during the past month	Less than once a week	Once or twice a week	Three or more times a week
6. During the past month, how often have you taken medicine (prescribed or "over the counter") to help you sleep?				
7. During the past month, How often have you had trouble staying awake while driving, eating meals, or engaging in social activity?				
8. During the past month, how much of a problem has it been for you to keep up enthusiasm to get things done?				
	Very Good	Fairly Good	Fairly Bad	Very Bad
9. During the past month, how would you rate your sleep quality overall?				

CIRS/CMI

INSTRUCTIONS: The following questions ask about what you perceive your health to be for each of the following organ/systems. Please estimate to the best of your ability based on the following descriptions.

0= NONE: No impairment to that organ/system.

1= MILD: Impairment does not interfere with normal activity; treatment may not be required; prognosis is excellent (examples: skin lesions, hernias, hemorrhoids)

2= MODERATE: Impairment interferes with normal activity; treatment is needed; prognosis is good (examples: gallstones, diabetes, fractures)

3= SEVERE: Impairment is disabling; treatment is urgently needed; prognosis is guarded (examples: respectable carcinoma, pulmonary emphysema, congestive heart failure)

4= EXTREMELY SEVERE: Impairment is life threatening; treatment is urgent or of no avail; prognosis is grave (examples: myocardial infarction, cerebrovascular accident, gastrointestinal bleeding, embolus)

a. Cardiac (heart only) _____

b. Hypertension (**rating** is based on severity; affected systems are rated) _____

c. Vascular (blood, blood vessels and cells, marrow, spleen, lymphatics) _____

d. Respiratory (lungs, bronchi, trachea below the larynx) _____

e. EENT (eye, ear, nose, throat, larynx) _____

f. Upper GI (esophagus, stomach, pancreas; do no include diabetes). _____

g. Lower GI (intestines, hernias) _____

h. Hepatic (liver only) _____

i. Renal (kidneys only) _____

j. Other GU (ureters, bladder, urethra, prostate, genitals) _____

k. Musculo-skeletal-integumentary (muscles, bone, skin) _____

l. Neurological (brain, spinal cord, nerves; do not include dementia) _____

m. Endocrine-Metabolic (includes diabetes, infections,) _____

n. Psychiatric/Behavioral (includes depression, anxiety, psychosis, not dementia) _____.

Activities of Daily Living

INSTRUCTIONS: The following questions pertain to how well you are able to care for yourself in everyday activities. For each category, choose and circle the best statement that describes your level of functioning currently.

1) **SPEECH**
0 = normal
1 = mildly affected, no difficulty being understood
2 = moderately affected. Sometimes asked to repeat.
3 = severely affected. Frequently asked to repeat.
4 = unintelligible most of the time

2) Salivation
0 = normal
1 = slight but definite excess of saliva; may have nighttime drooling
2 = moderately excess saliva, may have minimal drooling
3 = marked excess saliva with some drooling
4 = marked drooling, requires constant tissue

3) Swallowing
0 = Normal
1 = rare choking
2 = occasional choking
3 = requires soft food
4 = requires NG tube or gastrostomy

4) Handwriting
0 = normal
1 = slightly slow or small
2 = moderately slow or small; all words are legible
3 = severely affected; not all words legible
4 = the majority of words are not legible

5) Cutting Foods/Handling Utensils
0 = normal
1 = somewhat slow and clumsy, no help needed
2 = can cut most food; some help needed
3 = food must be cut but can feed self
4 = needs to be fed

6) Dressing
0 = normal
1 = slow but needs no help
2 = occasional assistance needed with buttons, getting arms in sleeve
3 = considerable assistance needed with button, getting arms in sleeve.
4 = helpless

7) Turning in Bed/Adjusting Bedclothes
0 = normal
1 = somewhat slow but needs no help
2 = can turn alone or adjust sheets but with difficulty
3 = can initiate but not turn or adjust sheets alone
4 = helpless

8) Falling (Unrelated to Freezing)
0 = normal
1 = rare falling
2 = occasional falls, less than once per day
3 = falls an average of one per day
4 = falls more than once per day.

9) Freezing when Walking
0 = normal
1 = rare freezing when walking may have start hesitation
2 = occasional freezing when walking
3 = frequent freezing, occasional falls from freezing
4 = frequent falls from freezing

10) Walking
0 = normal
1 = mild difficulty, may not swing arms or may tend to drag leg
2 = moderate difficulty, but requires little or no assistance
3 – severe disturbance of walking, requiring assistance
4 = cannot walk at all, even with assistance

11) Tremor
0 = normal
1 = slight and infrequently present
2 = moderate; bothersome to patient
3 = severe; interferes with many activities
4 = marked; interferes with most activities

12) Sensory Complaints Related to Parkinson's Disease
0 = normal
1 = occasionally has numbness, tingling, or mild aching
2 = frequently has numbness, tingling, or aching, not distressing
3 = frequent painful sensations
4 = excruciating pain

Thank you for taking the time to complete this questionnaire.
Please return it in the self-addressed, stamped envelope provided.

Appendix E

Additional Descriptive Results

Zung SDS and Loss Inventory

The average raw score mean for the *Zung Self-Rating Depression Scale* among Parkinson's patients was 44.67 (Range = 23 to 79) and for Essential Tremor patients was 42.52 (Range = 22 to 64). No significant differences between these diagnostic groups were found, $t(27.70) = .800$, $p=.431$. After converting this raw score into an equivalent scaled score ((total score/80)*100), the questionnaire's norms suggest that on average the study population experienced mild levels of depression (*Zung SDS Index score* = 55.49). Specifically, among the PD patients, 33.3% reported none to few symptoms of depression as assessed by the *Zung SDS* (index scores $\leq$50). Mild symptoms (Index scores of 51 and 60) were endorsed by 39.7% , 16.7% endorsed moderate symptoms (Index scores between 61 and 70), and 10.3% endorsed severe symptoms of depression (Index scores between 71and 80). Table 21 shows differences in various psychosocial and medical outcomes among these depression categories.

The study population's total raw average score from 29 items of the *Loss Inventory* (LI) was 65.22. Variability in total responses was seen (See Figure 3) among all participants. The total average score for the *Loss Inventory* for Parkinson's disease patients was 66.29 and for Essential Tremor patients was 58.23. Despite lower loss scores among the ET patients, the differences were not significant, $t(195) = 1.442$, $p=.151$. Compared to a recently completed study by Niemeier et al., (2004), a younger

aged mixed acute rehabilitative, all male population (*Loss Inventory* score: M= 65.65; N=109, also without question #9), the current study population scored with similar *Loss Inventory* scores, indicating similar grief intensity. This suggests that the grief intensity regarding losses of functionality is similar after acute and chronic illnesses and across age at least among males.

General Health Questionnaire and Rosenberg's Self-Esteem

The study population's average score on the *General Health Questionnaire* was 14.49 (SD = 7.7, range 0 to 36); a score of greater than 15 indicates distress and greater than 20 indicates severe difficulties and psychological distress. As expected those who reported currently taking antidepressant medication reported significantly greater levels of distress compared to those who did not (Using Antidepressants: M=17.75, SD = 8.22; No antidepressants: M=12.833, SD = 6.93, $t(190) = 4.291$, $p<.001$). Similar significant differences were found between those who endorsed a prior MDD diagnosis and those who did not (MDD: M=21.66, SD = 8.39; no MDD: M=13.36, SD = 7.04, $t(194) = 5.54$, $p<.001$. Additionally, Parkinson's disease patients scored with significantly more distress compared to Essential Tremor patients $t(197) = 2.81$, $p\leq.005$. *Rosenberg self-esteem* scores show moderate amounts of self-esteem (M=28.07, SD = 5.97) for the total population, but significant differences between the MDD and no MDD groups, $t(195) = -4.38$, $p<.001$, and the use of anti-depressant medication or no anti-depressant medication groups $t(193) = -3.25$, $p<.002$ were found. Tables 2 through 4 have more information.

Impact of Events Scale and STAI state anxiety

The overall study population reported moderate amounts of overall subjective distress (i.e. intrusive thoughts and avoidance) related to coping with their chronic illness (M=24.24, SD = 17.67). A score above 26 indicates a moderate or severe impact. A trend toward significance was found between the Parkinson's and Essential Tremor group, $t(189) = 1.72, p<.09$, such that Parkinson patients express more intrusive thought and avoidant behavior related to their chronic illness. Likewise, those who endorsed a history of MDD or who currently use anti-depressant medication also reported greater distress (MDD: $t(186) = 5.06, p<.001$; anti-depressant: $t(181) = 3.418, p<.001$). Results on the *STAI-state inventory* suggest normal amounts of state anxiety for the total population (M=38.68, SD = 14.44). Again, a trend toward significance was found between the Parkinson's and Essential Tremor groups, $t(154) = -1.77, p<.08$, such that those with PD reported more state anxiety. Those who endorsed a history of MDD or currently use anti-depressant medication reported greater amounts of state anxiety (MDD: $t(200) = 5.13$, $p<.001$; anti-depressant: $t(98.68) = 3.76, p<.001$). Tables 2 through 4 have more information.

Pittsburgh Sleep Quality Index

The total sample had a global sleep quality index of 5.76 (SD=4.01, range = 0 to 19) indicating poor sleep overall. Significant differences were found between Parkinson's and Essential Tremor patients such that ET patients scored with worse overall sleep quality (PD: M = 5.42, SD = 3.86; ET: M=8.20, SD = 4.33, $t(200) = -3.26, p<.002$. The majority of the total sample was able to fall asleep within 15 minutes of going to bed

(57%), 22.1% had a sleep latency of 16 to 30 minutes, and 21.1% had a sleep latency of greater than 30 minutes. The average sleep efficiency (total number of house asleep/total number of hours in bed) for the total sample was 80.67 (SD = 16.69). No differences were found between PD and ET patients in sleep efficiency, $t(186) = 1.202$, $p=.231$. As expected those who endorsed a prior MDD history had worse global sleep scores, $t(196) = 5.25$, $p<.001$, longer sleep latencies, $t(26.00) = -2.52$, $p<.02$, and lower sleep efficiency, $t(26.59) = -2.52$, $p<.02$. Those currently using anti-depressant medication also reported worse global sleep scores, $t(192) = 4.405$, $p<.002$, longer sleep latencies, $t(70.83) = 2.54$, $p<.02$, and lower sleep efficiency, $t(88.45) = -2.46$, $p<.02$. Tables 2 through 4 have more information.

Differences among Depression Categories on Psychosocial Outcomes

When using the total sample, depression category differences (i.e. mild versus moderate versus severe depression) were found for age, ($F(3, 190) = 3.419$, $p<.02$) such that the group endorsing severe amounts of depression was significantly younger than both the mild ($p<.01$) or no depression ($p<.06$) groups, but did not differ in age from the moderate depression group ($p=.192$). No group differences were found for the number of years of disease ($F(3, 164) = 1.174$, $p=.321$). Group differences were found on the *Rosenberg Self-Esteem* measure ($F(3, 191) = 30.151$, $p<.001$) such that each group differed significantly from all others and increasing self-esteem was related to fewer depressive symptoms. Those with moderate or severe depression scored significantly different and worse than those with no or mild symptoms of depression on the *Impact of Events Distress Scale* ($F(3, 182) = 27.513$, $p<.001$). Similarly, those with no depressive

symptoms reported the least *STAI-state anxiety* symptoms compared to all other depression groups and each group differed significantly from one another ($F(3, 192) = 35.044$, $p<.001$, No Depression: M = 33.66, SD = 11.07). Group differences were also found on the *General Health Questionnaire* such that each depressive group differed significantly from the other ($F(3, 188) = 51.19$, $p<.001$) and those with greater depression endorsed worse GHQ total scores (Severe depression: M = 26.13, SD = 7.09). Total sleep quality global scores also differed among depressive groups ($F(3, 189) = 20.168$, $p<.001$) such that the severe depression group had significantly worse sleep quality and differed from the other depression categories. The moderate and mild depression groups did not differ in sleep quality ($p= .233$) and the no depression and mild groups did not differ ($p=.292$). Regarding physical health, only the severe depression group differed from all of the other groups in the total number of medical illnesses ($F(3, 170) = 7.01$, $p<.001$, 2Severe Depression: M = 15.78, SD =7.31) and number of moderate to severe illnesses ($F(3, 170) = 6.06$, $p<.002$, Severe Depression: M = 4.56, SD = 2.99. Likewise, the no depression group endorsed fewer ADL limitations among all depressive groups ($F(3, 192) = 10.752$, $p<.001$; No Depression : M = 12.79, SD =7.59). Similarly, the severe depression group endorsed the greatest movement disability on the UPDRS ($F(3, 147) = 5.304$, $p<.005$, Severe Depression: M = 28.79, SD =10.38). All of the other depression groups did not significantly differ from one another on both the *UPDRS ADL subscale* and *UPDRS movement disability subscale*. The initial clinic visit's *Hoehn and Yahr Disease Staging* and MMSE total scores did not differ among the depressive groups. See Table 21 for means, standard deviations, and one-way ANOVA results.

Table 22

Means, standard deviation, and one-way ANOVA results for participants categorized as No Depressed, Mild, Moderate, and Severe Depression

Variable	Group	N	Mean	SD	Df	F	Sig
Age	Not Depressed	66	71.30	10.38	3,190	3.419	.018
	Mild	73	72.79	9.06			
	Moderate	33	70.61	9.83			
	Severe	22	65.23	10.12			
Length of diagnosis	Not Depressed	58	8.0	6.05	3,162	1.164	.325
	Mild	64	9.53	7.75			
	Moderate	24	8.04	5.36			
	Severe	20	6.65	5.96			
LI Score	Not Depressed	52	42.13	11.03	3,188	161.24	.000
	Mild	51	47.58	11.28			
	Moderate	13	76.46	10.06			
	Severe	76	91.37	18.25			
Self-Esteem	Not Depressed	68	31.84	5.04	3,191	30.15	.000
	Mild	72	28.03	4.47			
	Moderate	32	24.97	5.16			
	Severe	23	21.57	6.01			
Zung Index	Not Depressed	69	43.06	7.19	3,195	301.6	.000
	Mild	74	55.86	2.71			
	Moderate	33	65.79	3.12			
	Severe	23	76.84	6.58			
IES Score (Impact of Events Scale)	Not Depressed	64	14.78	12.17	3,182	27.51	.000
	Mild	70	21.85	14.18			
	Moderate	30	37.23	20.08			
	Severe	22	42.18	15.98			
STAI Anxiety (State-Trait Anxiety Inventory)	Not Depressed	69	33.66	11.07	3,192	35.04	.000
	Mild	72	42.63	9.38			
	Moderate	33	49.48	16.24			
	Severe	22	61.63	14.52			
General Health	Not Depressed	68	9.61	3.97	3,188	51.19	.000
	Mild	73	13.80	6.08			
	Moderate	29	18.96	7.56			

Table 22 (Continued)

Variable	Group	N	Mean	SD	Df	F	Sig
General Health	Severe	22	26.13	7.08			Severe
Sleep	Not Depressed	69	4.28	3.06	3,189	20.168	.000
	Mild	73	5.34	3.39			
	Moderate	30	6.80	4.38			
	Severe	21	10.95	4.17			
CIRS # illnesses	Not Depressed	66	7.41	8.06	3,170	7.01	.000
	Mild	62	9.29	5.91			
	Moderate	28	11.54	8.03			
	Severe	18	15.78	7.31			
Co-morbidity CMI	Not Depressed	66	2.00	2.85	3,170	6.0	.001
	Mild	62	2.11	2.12			
	Moderate	28	3.61	3.38			
	Severe	18	4.56	2.99			
ADL (Activities of Daily Living)	Not Depressed	68	12.79	7.59	3,192	10.752	.000
	Mild	73	17.80	6.49			
	Moderate	33	17.45	7.12			
	Severe	22	21.59	8.00			
Initial H&Y (Hoehn & Yahr)	Not Depressed	35	2.57	0.73	3,99	1.164	.327
	Mild	36	2.50	0.81			
	Moderate	21	2.83	0.61			
	Severe	11	2.86	1.14			
S&E ADL (Schwab & England)	Not Depressed	49	82.24	10.06	3,142	1.08	.359
	Mild	50	79.60	11.60			
	Moderate	28	77.86	12.28			
	Severe	19	77.89	16.52			
Initial UPDRS3 (Unified Parkinson's Disease Rating Scale)	Not Depressed	52	18.71	9.72	3,147	5.535	.001
	Mild	54	22.72	8.60			
	Moderate	27	24.22	7.58			
	Severe	18	28.00	10.38			
MMSE (Mini-Mental Status Exam)	Not Depressed	46	28.46	2.91	3,131	1.334	.266
	Mild	47	28.32	2.86			
	Moderate	26	27.12	3.55			
	Severe	16	27.69	2.52			

Description of Losses reported by Parkinson's disease and Essential Tremor Patients

Patients were able to record their specific losses experienced related to their respective chronic illness. Of the total sample about 45% (N=95) recorded their answers. Losses identified from both PD and ET patients were similar. Nearly half of this sample (50.5%) reported losses related to movement, balance, tremor, and agility. Approximately 21% reported losses related to activities of daily living difficulty (i.e. not able to bathe, eat, "not able to take care of myself"). Losses related to a special interest (i.e. "woodworking, fixing up my garden, playing basketball") were identified by 17.9% and the loss of a job was identified by 16.8%. Nearly 16% of the population reported memory complaints ("I can't concentrate like I used to", "cannot think") and 10.5% reported a loss in confidence. Losses in speech volume were identified in 9.5% ("cannot communicate", "talk like before", "speech"). Patients identified losses related to friends/social activities (8.4%), family/ wife/ girlfriend/ children (6.3%), and driving (8.4%). Other losses identified were the loss of energy (2.1%), hearing (1.1%), weight (1%), reading (1.1%), and one person wrote "loss of long life". Losses identified at both time points were similar; no new losses were mentioned at Time 2.

Differences between those who completed a Time 2 questionnaire and those who did not

100 out of 160 Parkinson's disease participants completed and returned their questionnaire at Time 2. Those who completed a Time 2 questionnaire were more likely to be older (M=73.1, SD = 8.9) compared to those who did not (M=69.0, SD = 10.7, $t(155) = 2.013$, $p<.05$). All other demographics between the two groups were similar (i.e. % married, employed, length of marriage, etc.). Medically, there were no differences in

the patient's disease staging (*Hoehn & Yahr*), $t(103) = -.445$, $p=.658$, but there were differences in the patient's initial clinic visit *S&E ADL score*, $t(129) = 2.392$, $p<.03$, and UPDRS movement disability subscale score, $t(139) = -2.632$, $p<.02$. Those who returned questionnaires had better ADL and movement ability scores. Similarly, those who returned questionnaires scored lower on the number of illness scale (CIRS), $t(138) = -2.241$, $p<.03$ and lower on the self-perceived ADL functioning, $t(158) = -2.649$, $p<.01$. Scores on the impact of events scale, state-anxiety, self-esteem measure, and sleep measures were not different between the two groups. Additionally, scores on the *Zung SDS* depression scale did not differ, $t(153) = -1.41$, $p=.163$. There were significant differences in the group's total *Loss inventory* score (completed Time 2: M = 63.39, SD = 26.57; Time 1 only: M = 73.41, SD = 25.93, $t(151) = -2.313$, $p<.03$) as well as general health and well-being (GHQ), $t(154) = -2.303$, $p<.03$. Those who completed a Time 2 questionnaire reported less intrapersonal grief and better overall well-being compared to those did not complete a second questionnaire.

Changes in Psychosocial Outcomes between Time 1 and Time 2

Paired t-tests showed no significant changes in questionnaire scores from Time 1 to Time 2 for the *Loss Inventory, Zung SDS depression, Rosenberg self-esteem*, GHQ-12, IES, *STAI-state anxiety*, CIRS number of medical illnesses, number of moderate to severe illnesses (CMI), and UPDRS ADL functioning. Given this and as expected, changes in a person's ADL functioning or number and severity of medical illnesses did not predict subsequent LI scores. However, significant differences were seen in the overall sleep quality index only (PSQI), such that participants reported worse overall sleep quality at

Time 2. (PSQI Time 1: M = 5.15, SD = 4.09; PSQI Time 2: M = 7.83, SD = 4.99; $t(88) = -7.163$, $p<.001$. Further examination revealed that specific scale item differences were related to the average patient's report of worse subjective sleep quality, $t(93) = -8.534$, $p<.001$, increased frequency in the use of sleep medications $t(94) = -3.431$, $p<.002$, increased daytime sleepiness and lack of energy, $t(92) = -6.098$, $p<.001$, and increased number of nighttime awakenings, $t(93) = -9.333$, $p<.001$ all at Time 2.

Predictors of Intrapersonal Grief as measured by the Loss Inventory

To determine predictors of grief/loss as it related to Parkinson's disease and Essential Tremor patients, a series of multiple regression analyses were completed. Variables were divided into distinct groups (demographics, medical history (clinical exam), medical history (questionnaires), and psychosocial variables). A final prediction model used only those significant variables from each of the other previous stepwise models. See Table 23 for more information.

Demographic Factors and the Loss Inventory. The total *Loss Inventory* score was regressed on age, education, race (dichotomized as white vs. non-white) marital status (dichotomized as married or coupled vs. not) and number of years of diagnosis. Age and education were the only variables to significantly enter the model [$F(5, 156) = 3.36$, $p<.008$] such that younger age (B = -.233) and less education (B = -.191) was associated with greater grief. The total model accounted for 6.8% of the variance.

Medical Questionnaires and the Loss Inventory and Depression. The total *Loss Inventory* score was regressed on the CIRS (number of medical illnesses in addition to PD), CMI (co-morbidity of illnesses) and the patient's self-perceived *ADL functioning scales*. The overall model was significant [$F(3,170) = 16.82$, $p<.001$] but only greater ADL dysfunction (B = .395) was associated with greater grief. The total model accounted for 21.5% of the variance.

Clinical Exam and the Loss Inventory and Depression. When using the initial clinic visit *Hoehn & Yahr Disease Staging* scores, the S&E ADL scores, and the UPDRS movement disability scores, only the UPDRS movement disability scale significantly contributed to scores on the *Loss Inventory* [$F(3, 91) = 4.35$, $p<.008$] such that greater movement disability (B = .324) was associated with greater grief. The total model accounted for 9.7% of the variance.

Psychosocial Variables and the Loss Inventory and Depression. The following psychosocial variables were regressed on the *Loss Inventory* total score: state-anxiety, distress from the *Impact of Events scale (IES)*, self-esteem, sleep quality, general overall health, history of self-reported depression or not, current use of anti-depressant medication or not, and past history of seeking emotional support from their medical doctor or not. From these variables, general overall health, distress from the IES, state anxiety, current use of anti-depressant medication, and past history of seeking emotional support from their doctor were associated with the *Loss Inventory* [$F(9, 155) = 38.64$, $p<.001$]. Specifically, worse general overall health (B = 1.044), greater intrusive/avoidance stress (B = .465), greater state anxiety (B = .377), current use of anti-

depressant medication (B = 9.95), and seeking emotional support from their medical doctor (B = 6.05) were all associated with greater grief. The total model accounted for 67.4% of the variance.

Final Prediction Model for the Loss Inventory. The final overall prediction model for the *Loss Inventory* included the following: age, education, ADL functioning, CIRS/burden of illnesses, UPDRS movement disability, general overall health, state anxiety, scores from the IES/intrusive/avoidance, the dichotomous variable of current use of anti-depressant medication and the dichotomous variable of seeking emotional support from their doctor. From these variables, only state anxiety, distress from the IES scale, ADL functioning, and current use of anti-depressant medication significantly predicted scores from the *Loss Inventory* when all of these variables were entered in the model [$F(9, 118) = 37.99, p=.000$]. Specifically, greater state anxiety (B = .556), greater distress from the IES (B = .418), a positive use of anti-depressant medication currently (B =11.69), and greater ADL difficulties (B = .632) were all significantly associated with greater grief. This total model accounted for 72.4% of the variance.

Table 23

Multiple regression analyses: Predictors of time 1 intrapersonal grief

Demographics

Grief	B	SE	*B*	*p*	95%CI
Step 1					
**Age	-.604	.201	-.233	.003	-1.0 - -0.206
*Education	-4.05	1.65	-.191	.015	-7.31- -0.797
Race (Caucasian or not)	-5.47	6.27	-.070	.385	-17.86 – 6.93
Marriage (married or not)	1.09	4.67	.018	.817	-8.142 – 10.31
Length of diagnosis	.159	.264	.047	.548	-.362 - .679

* Adjusted R^2=.068 F(5,156) = 3.36, p<.008

Medical Questionnaires

Grief	B	SE	*B*	*p*	95%CI
Step 1					
CIRS	.568	.544	.167	.298	-.506–1.641
CMI	.207	1.433	.144	.885	-2.62– 3.04
**ADL	1.409	.252	.395	.000	.913 – 1.91

** Adjusted R^2 = .215 F(3, 170) = 16.82, p<.001

Initial Clinic Exam

Grief	B	SE	*B*	*p*	95%CI
Step 1					
Hoehn & Yahr Disease Staging	-2.292	4.281	-.065	.594	-10.80 – 6.21
S&E ADL	-.260	.282	-.108	.360	.820 - .301
**UPDRS movement	.912	.335	.324	.008	.247 – 1.577

** Adjusted R^2=.097 F(3, 91) = 4.35, p<.008

Table 23 (Continued)

Psychosocial Variables

Grief	B	SE	*B*	*p*	95%CI
Step 1					
*STAI anxiety	.377	.157	.202	.017	.068 - .686
**IES Distress	.465	.089	.309	.000	.290 - .641
Self-esteem	-.360	.297	-.079	.227	-.946 - .227
Sleep quality	-.290	.374	-.045	.439	-1.028 - .448
**General overall health	1.044	.282	.311	.000	.487 – 1.601
Hx of self-reported depression	-7.909	4.180	-.103	.060	-16.167 - 348
**Current use of anti-dep meds	9.948	3.083	.175	.002	3.859 – 16.04
*Sought emotional support from MD	6.053	2.887	.107	.038	.350 – 11.757
Zung SDS Total Score	.047	.156	.022	.763	-.260 - .354

** Adjusted R^2 = .674 F(9,155) = 38.638, p<.001

Final Prediction Model

Grief	B	SE	*B*	p	95%CI
Step 1					
age	-.099	.133	-.037	.459	.362 - .164
education	-.473	.982	-.024	.630	-2.417 – 1.470
**ADL	.632	.218	.175	.005	.200 – 1.065
General overall health	.317	.293	.097	.281	-.262 - .896
**STAI anxiety	.556	.162	.309	.001	.235 - .876
**IES Distress	.418	.092	.284	.000	.236 - .599
UPDRS	.025	.162	.009	.879	-.297 - .346
**Current use of anti-dep meds	11.69	3.14	.210	.000	5.46 – 17.91
Sought emotional support from MD	3.144	2.871	.057	.276	-2.542 – 8.829

** Adjusted R^2 = .724 F(9, 118) = 37.985, p<.001

Vita

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