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## Existential mental health implications for kin-caregivers of Alzheimer's victims

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## Existential mental health implications for kin-caregivers of Alzheimer's victims

### Abstract

The purpose of this paper is to briefly outline assessment and progression of Alzheimer's disease (AD) in afflicted individuals (i.e., care recipients [CRs]) and review relevant research concerning the effects of AD progression on caregivers (CGs) as they care for loved ones. With this background, consideration will be made of how these findings suggest relevant tenets of Existential therapy. The author will also identify implications that could be meaningful to mental health professionals in their efforts to assist CGs as they attempt to cope with the emotional impact this disease has on them during caregiving and after the eventual death of the CR.

The premise of this paper is that Existential Therapy (ET) is particularly well suited for this area of psychotherapy because of the salient issues involved and because ET concepts can be utilized within many psychotherapeutic approaches (Yalom, 1980).

EXISTENTIAL MENTAL HEALTH IMPLICATIONS FOR KIN-CAREGIVERS OF  
ALZHEIMER'S VICTIMS

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A Research Paper

Presented to

The Department of Educational Leadership, Counseling,  
and Postsecondary Education  
University of Northern Iowa

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In Partial Fulfillment

of the Requirements for the Degree

Master of Arts

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by

Brock K. Knoll

May 2000

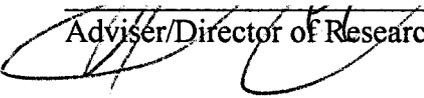
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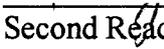
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Existential Mental Health Implications for Kin-Caregivers of Alzheimer's Victims

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The loss of a close kindred or spousal relationship as a result of death can lead to consideration of many of the tenets of Existential therapy (ET), such as meaning in life and relationships (Frankl, 1963, 1969), the power and responsibility in life choices (Yalom, 1980), and loneliness, isolation, and death (May, 1953, 1960; Yalom, 1980). In death, physical separation is immediate and final. The adjustment to this reality, usually termed bereavement or grief, is a process which is recognized as a significant, diagnosable psychological condition (American Psychiatric Association [APA], 1994; Lindemann, 1944; Murphy, Hanrahan, & Luchins, 1997). However, intimate, love relationships do not solely consist of knowing only the physical-self of another. It could be said that the physical manifestation of another person is the tangible representation of other intangible factors that, with the physical presence, constitute a relationship in toto. Although our love for another does not exclude other elements in life, all else exists in relationship to the one we love (Buber, 1958).

The purpose of this paper is to briefly outline assessment and progression of Alzheimer's disease (AD) in afflicted individuals (i.e., care recipients [CRs]) and review relevant research concerning the effects of AD progression on caregivers (CGs) as they care for loved ones. With this background, consideration will be made of how these findings suggest relevant tenets of Existential therapy. The author will also identify implications that could be meaningful to mental health professionals in their efforts to assist CGs as they attempt to cope with the

emotional impact this disease has on them during caregiving and after the eventual death of the CR.

The premise of this paper is that Existential Therapy (ET) is particularly well suited for this area of psychotherapy because of the salient issues involved and because ET concepts can be utilized within many psychotherapeutic approaches (Yalom, 1980). In a condition where the focus of concern is predominantly with the CR, ET can be used as a method of shifting attention to the here-and-now phenomenology of the CG. Beyond the implications of reducing psychological distress in CGs, it has been suggested that society at-large (Jorm, 1984; Mittelman, Ferris, Shulman, Steinberg, Ambinder, Mackell, & Cohen, 1995) and AD patients in particular (Talkington-Boyer & Snyder, 1994) will be better served by assisting CGs in their attempts to provide care for afflicted loved ones as this disease gradually and unrelentingly strips the mental and physical capabilities from their loved ones. The demographic outlook for the near future in our society indicates a large increase in the percentage of elderly, those most susceptible to AD (Jorm, 1984; Talkington-Boyer & Snyder, 1994). At present, the etiology of AD is unknown, and definite diagnosis can only be made postmortem. While research strides are being made in finding a cure for AD, at this time the best prospect for those diagnosed is to slow the progression somewhat through the use of medication. For these reasons, the need for mental health interventions for the CGs of Alzheimer's disease victims will likely continue to increase.

## Assessment and Behavioral Changes of AD Patients

Formal assessment of evidence of existence or extent of the progression of AD can be obtained through neurological brain imagining techniques such as magnetic resonance imaging (MRI) or positron emission tomography (PET) which are used to determine the amount of physiological deterioration of brain tissue. Assessment can also be made through cognitive/behavioral measures such as Mini Mental State Exam, Clinical Dementia Rating (CDR), Wechsler Adult Intelligence Scale, and Clifton Assessment Procedures for the Elderly (Jorm, 1987). Neurological changes in brain structure detected through MRI or PET imagining aid in distinguishing AD from other forms of dementia (Jorm, 1987). Any diagnosis of AD is provisional because this disease can only be determined by direct examination of brain tissue through surgical means. However, the advantages of having a definite diagnosis are outweighed by the risks and limited benefits gained as a result of such an operation. Therefore, positive diagnosis is usually made post-mortem. Also according to Jorm (1987), a telling difference between AD and other forms of dementia is the rate at which cognitive and behavioral deterioration takes place, with AD being the more rapid of the two.

As a matter of practicality for CGs, disease progression marked by behavioral and cognitive changes is more useful than neurological measures because they define present or predict future implications of the nature of their relationship with the CR. For example, the CDR (see Appendix) delineates progression through five stages from healthy to severe dementia on dimensions of memory,

orientation, judgment and problem-solving, community affairs, home and hobby, and personal care.

With progression through the CDR stages, individual dimensions are redefined to reflect the deterioration of behavioral and cognitive capabilities typical for each stage. Educational interventions which prepare CGs for these eventualities have been shown to reduce self-perceived burden (Talkington-Boyer & Snyder, 1994). The CDR categories do not reflect, however, the emotional losses CGs experience as the CR loses functional abilities (Ponder & Pomeroy, 1996). Argyle, Jestice, and Brooks (cited in Jorm, 1987) reported the prevalence of problem behaviors in CR and the degree to which CGs were adversely affected. Analysis of these findings indicates that as CRs' behaviors become more unmanageable as a result of disease progression, CGs' ratings of inability to cope increases.

#### Impact on Caregivers

There tend to be two foci of study concerning the emotional effects on CGs throughout the course of disease progression from first suspicion of dementia to the end of the grieving after the CR's death. The first focus addresses CG reaction and adaptation to the caregiving role; the second focus, the effects of grief reaction through loss, both for progressive loss of capability while the CR is alive and bereavement after death. Several distinct emotions have been identified in CGs as they attempt to adapt to this role. These include depression (Bodnar & Kiecolt-Glaser, 1994; Kerson & Michelsen, 1995; Mittelman, Ferris, Shulman,

Steinberg, Ambinder, Mackell & Cohen, 1995; Mullan, 1992), burden (Kerson & Michelsen, 1995; Loos & Bowd, 1997; Mullan, 1992; Talkington-Boyer & Snyder, 1994; Walker & Pomeroy, 1996), anxiety (Bodnar & Kiecolt-Glaser, 1994; Kerson & Michelsen, 1995; Loos & Bowd, 1997), grief (Bass & Bowman, 1990; Ponder & Pomeroy, 1996; Walker et al. 1994b; Walker & Pomeroy, 1996), guilt (Loos & Bowd, 1997; Mullan, 1992), and anger (Kerson & Michelsen, 1995; Loos & Bowd, 1997). While some CG emotions predominate at various stages of dementia in the CR, others tend to surface and remain throughout the course of the disease. For example, grief is not confined to the end-stages of AD when the CR dies. The loss of unique personality characteristics of the CR are occasions to mourn (Ponder & Pomeroy, 1996). Because these repeated losses succeed one another, it is questionable whether grief for each loss is resolved before the next loss is encountered (Talkington-Boyer & Snyder, 1994).

While the predominate emotions of caregiving are usually associated with negative consequences, it should be noted that not all the identified emotions are deleterious. Based on CG perception, a sense of mastery and self-efficacy (Talkington-Boyer & Snyder, 1994) or personal meaningfulness (Farran, Miller, Kaufman, Donner, & Gogg, 1999) can be a positive outcome of the caregiving experience. This is a significant finding which clinicians can use to help CGs in therapy.

## Relevant Existential Therapy Issues

Yalom (1980) identified four areas of existential conflict: death, freedom, existential isolation, and meaninglessness. According to Yalom, we experience anxiety when confronted with these areas of ultimate concern. If anxiety becomes overwhelming, it can lead to psychopathology. It is this author's contention that the CG of a loved one who has been diagnosed with AD is confronted with these areas of conflict in ways that are perhaps more acutely realized than by those who do not have this experience. In contrast to the immediacy and finality of physical death, those who love and care for victims of AD experience a series of incremental losses (Walker, Pomeroy, McNeil, & Franklin, 1994b), deaths, as it were, of the cognitive, behavioral, and emotional aspects of the relationship before they experience the inevitable physical death. As Jorm (1986) stated, it is as though a loved one has died even though he or she is still physically alive, or, as Kapust stated (as cited in Walker, Pomeroy, McNeil, & Franklin, 1994a), it is an on-going funeral as CGs witness the gradual mental and physical deterioration of the Alzheimer's patient that precedes death. For CGs, these emotional experiences often come in addition to the loss of freedom and feelings of loss of control (i.e., power) they experience in their efforts to provide for an afflicted loved one's physical and emotional needs throughout the course of this disease.

## Freedom and Power

Yalom (1980) stated that with freedom comes the responsibility to become the authors of our lives; that we bear the responsibility to choose the way we conduct our lives. Therefore, freedom might be the first existential condition counselors face with CGs, or more specifically, the loss of freedom and sense of lack of choice that CGs experience when faced with the increased demands of caregiving. For example, in their case study of an Alzheimer's disease CG, Loos and Bowd (1997) reported that the respondent considered caregiving a mandate; that there was, in essence, no choice (i.e., no freedom) to decline this role. This attitude was attributed to societal advice given in an effort to help the CG cope with this new circumstance.

These demands are usually expressed as *burden*, which was defined by Lefley (cited in Walker & Pomeroy, 1996) as "...the subjective distress felt in response to demands of caregiving" (p. 247). While there is some abatement in the demands of CG time and physical effort when the CR is placed in a nursing facility, the burden of the caregiving role does not end (Loos & Bowd, 1997). This self-perception will likely continue to some degree throughout the caregiving role, that is to say, until the death of the CR. However, Kerson and Michelsen (1995) found that as burden decreased, CGs had time to focus on the impact that this experience had on them. Nursing home placement might, therefore, be a time to offer counseling services as many of the distressing conditions of caregiving will still exist while the CG is released from the physical demands.

The existential concept of freedom involves the idea that we have choices in how we conduct our lives. Farran et al. (1999) found that individuals who realized that the caregiving role was a matter of choice experienced a feeling of emotional strength in their efforts to cope. Wilson (cited in Loos & Bowd, 1997) reported that there are choices CGs can make, even if the choices are from undesirable alternatives. Simos (cited in Loos & Bowd, 1997) stated that it is important to recognize the control CGs have in their choices to offset, to some degree, the magnitude of loss of control they experience. Those CGs who are able to reflect on their choice to adopt this role can then consider what personal meaning this experience has in their lives. Talkington-Boyer and Snyder (1994) found that, given individual differences in situational response, some CGs experienced an increased sense of self-efficacy (i.e., power) with an increased sense of burden. While caregiving limited activities outside the home, their study found that CGs felt they were able to affect change within this limited setting.

In 1963, James Bugental, then president of the American Association of Humanistic Psychology, stated that one of the truths about human beings is that "...man (*sic*) is not a bystander to his existence" (p. 19, cited in Yalom, 1980). The idea that CGs have the power to make choices about their roles has been shown to have positive mental health effects. Bass and Bowman (1990) found that character traits, such as sense of mastery, higher self-esteem, and a positive attitude toward change mitigated the emotional effects of the caregiving role. Similarly, Farran et al. (1999) found that a sense of powerlessness led to the

potential for despair in CGs. Research findings indicated that a successful way of increasing a sense of mastery is through interventions that educate CGs in managing CR behaviors (Mittelman et al., 1995; Mullan, 1992). Out of the realization of the freedom to choose this role and act within it can come a sense of freedom (Talkington-Boyer & Snyder, 1994). Although CGs might have less *physical freedom*, they can come to a sense of *emotional freedom* to choose the direction of their lives which, according to ET, is associated with mental health.

### Isolation and Death

While Yalom (1980) considered these concepts separately, many of the experiences of CGs are relevant when considered together. While physical death is the inevitable outcome of AD, there are sequential losses that precede physical death from the time a CG begins noticing cognitive and behavioral changes in his or her loved one (Walker et al., 1994a). These events can serve to remind CGs of their own mortality (Walker et al., 1994b) and progressively isolate the CG from the CR.

The ideas of isolation and death then begin to take similar meanings when considering the gradual nature of CGs' losses. Because of the characteristic progression of AD as noted above, the concepts of death, loss, and grief are muddled. While these definitions work well enough when considering a death that occurs under normal circumstances, it is as if the death of an AD patient takes place in slow motion (Walker et al., 1994b).

While a clinical definition of bereavement is the emotional and behavioral reactions to physical death (see APA, 1994), the ideas of grief, loss, and bereavement are often used in conjunction with the behavioral, emotional, and personality changes CGs perceive that precede the physical death of CRs. Although Lindemann (1944), in his seminal paper on grief, was referring to physical death when he defined bereavement as "...the sudden cessation of social interaction..." (p. 141), it seems consistent to conceptualize the gradual losses of personality through AD as events to be grieved. There are, therefore, feelings of grief for each loss a CG experiences over the course of caregiving (Given, Collins, & Given as cited in Walker et al., 1994a).

While changes that result from the progression of AD remind CGs of the loss of control in their own lives (Loos & Bowd, 1997), the incremental losses can also serve as a means for preparing the CG for the CR's death (Mullan, 1992). In this way, it is possible that CGs can experience less distress at and following the time of death than if they had not experienced incremental loss (Mittelman et al., 1995). The end stages of AD in which the CR is unresponsive may, in effect, become the end of the relationship which precedes actual death (Walker et al., 1994b). This might be a time when psychotherapists could encourage CGs to say good-byes and attempt to resolve unfinished business.

Feelings of depression (Kerson & Michelsen, 1995) and depression coupled with anxiety (Bodnar & Kiecolt-Glaser, 1994) have been reported in research findings, although a link between these conditions and existential factors was not

proposed in these studies. It can be noted that depression in this sense seems to be more similar to an Adjustment Disorder than Major Depression (APA, 1994). While the focus of treatment for grief is on the CG's/client's losses, interventions for depression often address the client's distorted thinking about life events. Counselors should be aware that CGs need emotional support rather than information when experiencing loss (Walker & Pomeroy, 1996).

Because of the nature of AD and its effects on the CG, the idea of *anticipatory grief* is often cited (e.g., Ponder & Pomeroy, 1996; Walker et al., 1994b). This concept, first proposed by Lindemann (1944), postulates that a person who is facing the threat of losing a loved one to death can go through a premature adjustment to the death in anticipation of what might transpire. Coupled with the experiences in losses of personality as AD progresses, it is not surprising that reactions that fit the definition of anticipatory grief exists among CGs, as Ponder and Pomeroy found in their research. Walker et al. (1994b) suggested that this condition exists slightly before and after the diagnosis of AD, confirming CGs' suspicions and the reality of death to come.

#### Clinical Services for Caregivers

The point at which, if at all, CGs might seek personal, psychotherapeutic assistance is difficult to determine. Emotional trauma may have begun at the time that CGs initially attempted to adjust to changes they observed in the CR, well before a formal diagnosis of Alzheimer's disease in the CR. Decisions about the types of interventions and services that CGs could benefit from might be

predicated by, among other factors, the stage of dementia of the CR, the type and amount of direct care the CG is currently providing, and the impact that the demands of caregiving have had on the CG (e.g., financial, familial, emotional). For these reasons, therapists should consider interventions or referrals based on the unique needs of individual CGs.

### Initial Services

Initial services provided to CGs are often social services centered on educating CGs in practical methods of providing for the CR; referral to organizations which could provide respite or other forms of care; and, when appropriate, local governmental entities which could provide financial assistance (Kerson & Michelsen, 1995). Although pragmatic in nature, this form of assistance can facilitate positive psychological change in the CG by reducing the sense of overwhelming burden and empowering CGs with knowledge of the effects AD. These forms of assistance are, however, focused on the CR, and only secondarily addressing the needs of the CG.

### Support Groups

Support groups consisting of other CGs have been shown to be helpful because they normalize the emotions CG experience when beginning to assist the CR (Mittelman et al., 1993). Support groups can also provide a social outlet that is often sacrificed when the demand of caregiving begins.

### Interventions and Dementia Stages

Interventions which counselors might find most effective may vary according to the dementia stage of the CR which can, in turn, affect the presenting issues of the CG. The CDR (see Appendix) is a tool therapists could use to identify stages that might explicate the experience of the CG when first confronted with increasingly substantive changes in the personalities of CRs and throughout the course of caregiving. Ponder and Pomeroy (1996) found that, with each change in level of CR behavior, came an increase in CG sense of grief. Walker et al. (1994a) found CR stages correlated to increases in CG sense of mourning.

Changes in the functioning of the CR might also be generalized to specific categories of existential distress in the CG. For example, deteriorating conditions in the CR might trigger ET issues of powerlessness and freedom in the CG during initial stages. Middle stages of AD (“Mild” through “Moderate” CDR) in the CR might bring issues of isolation and meaningfulness of relationships. End stages (“Severe” CDR through death) and post-death might give rise to the CG confronting non-being and isolation. From information gained through experience and research, therapists can work proactively to prepare CGs for the distress typically associated with progressive increase in dementia in their loved one. While many mental health interventions work to reduce the emotional upheavals of the past, CGs face a certain, defined future with the CR.

This is not to say that any one issue or cluster of issues might predominate or resurface during various stages in the CG’s course of therapy. While there might

be a greater likelihood of specific issues associated with specific dementia stages, therapists should be alert to unresolved distress from previous stages or distress experienced in anticipation of the future.

During the middle stages of AD, CGs may be confronting the most difficult portion of this disease. The CR will lose significant cognitive abilities, thus increasing the demands on the CG. This might be the point at which CGs are increasingly unable to manage CR behaviors, evoking a sense of powerlessness in the face of CGs' efforts. If CGs are still providing all or most of the direct care for the CR, the demands on their time and patience will be great. At this juncture, the CG might consider full-time professional care for the CR, such as nursing home placement. Loos and Bowd (1997) found that CGs experienced a sense of grief when this decision came.

### Effects of Therapy

The CR is often the initial focus of concern for social service providers, while rapport with the CG is established through on-going contact. In such a relationship, emotional support of the CG might be ancillary to providing social services for the CR. For this reason, it is important that there are services that specifically address the mental health needs of CGs. The problem then becomes the method in which contact will be made between CG and mental health provider.

Subjects in Kerson and Michelsen's (1995) study expressed that it was all they could do to maintain a semblance personal life apart from caregiving duties let

alone find time for personal counseling. Often CGs have family and employment obligations in addition to the demands that becoming a CG brings. This case study exemplifies the feelings of depression and loss which can exacerbate other areas of the CG's life. Caregiving entails demands of time and physical effort from people who might have been straining these resources before becoming a CG. For these reasons, the CG might not initiate contact with a mental health professional during the beginning stages of caregiving. Additionally, CGs might use the demands of caregiving as a reason to avoid focusing on the emotional upheaval they are experiencing. This avoidance will not necessarily end when the CR is placed in institutional care or when he or she dies. Given these possibilities, helping CGs become aware of psychotherapeutic services through nursing home staff, social service agencies, and support services specifically targeted to CGs (e.g., local Alzheimer's organizations) might be the most effective method of initiating contact, much as Murphy et al. (1997) suggested for hospice services. Counselors might consider nontraditional methods of offering their services to CGs. Research indicated that having on-going contact through cards and phone calls was beneficial to CGs emotional well-being (Mittelman et al., 1993).

The psychological needs of CGs, as evidenced by research, is significant and pervasive. Unfortunately, the demands of this role increase the likelihood that CGs will not seek mental health counseling of their own volition. The account of AD care from Kerson and Michelsen's (1995) case study adds the element of

societal expectation to the demands of CGs. Time demands of caring for a loved one with AD warrant excluding many of the activities in life that are not directly involved with caregiving. These include CGs' care of self, physically and emotionally. The accounts of CGs suggest that although they perceived personal needs, this, as well as all else, becomes secondary to their caregiving role.

Finding emotional relief through areas of social support is an excellent example of the type of personal sacrifice CGs make. At a time when social support could be beneficial to CGs' well-being, they believe that they cannot find the time to avail themselves of social opportunities. It seems, therefore, that there is little likelihood that CGs will seek counseling during active caregiving. For this reason, outreach on the part of mental health professionals, such as those listed above, might be an effective method of initiating contact. Therapists might also consider providing services that meet the time and physical demands of the CG. Therapy might be best for the CG, although not ideal from a clinical sense, in nontraditional settings such as with the CG as he or she spends time with the CR.

The importance of effective therapy throughout AD progression has positive effects post-death as well. Bass and Bowman (1990) found that CGs who sought assistance prior to the death of the CR were at a greater likelihood of experiencing greater distress at the time of bereavement. Consequently, reducing CG strain before death can lead to less troubled bereavement.

## Conclusion

Existential therapy might seem, on first consideration, an inappropriate therapeutic approach for CGs of AD patients. The psychological needs of CGs, as evidenced by cited research, are such that more directive, educational approaches would usually be considered to be of greater benefit to this population. It should be remembered that ET is not based on technique, but rather provides a philosophical foundation which therapists can use as an approach or basis for understanding the inner experience of the client.

While information about caregiving and AD aids in improving CG emotional well-being, these types of interventions achieve primary effects through secondary gain; if the CR responds in a positive way to new approaches and methods of interaction with the CG, a reduction of psychological distress might be achieved. Addressing CGs' psychological distress through ET themes, on the other hand, is intended to provide an underlying sense of self and relationship for the CG from which they can find greater emotional strength to fulfill this role.

For those who love and care for victims of Alzheimer's disease, the concepts of freedom, isolation, meaninglessness, and death seem to manifest in a unique way as the life of their loved one is slowly, inexorably lost. Through mental health interventions utilizing Existential therapy, it is possible that clients will find new meaning and understanding in their lives while finding better methods of coping with this ultimate loss.

## References

American Psychiatric Association. (1994). Diagnostic and statistical manual of mental disorders (4<sup>th</sup> ed.). Washington DC: Author.

Bass, D. M., & Bowman, K. (1990). The transition from caregiving to bereavement: The relationship of care-related strain and adjustment to death. The Gerontologist, 30, 35-42.

Bodnar, J. C., & Kiecolt-Glaser, J. K. (1994). Caregiver depression after bereavement: Chronic stress isn't over when it's over. Psychology and Aging, 9, 372-380.

Buber, M. (1958). I and thou (2<sup>nd</sup> ed.). (R. G. Smith, Trans.). New York: Charles Scribner's Sons.

Farran, C. J., Miller, B. H., Kaufman, J. E., Donner, E., & Gogg, L. (1999). Finding meaning through caregiving: Development of an instrument of family caregivers of persons with Alzheimer's disease. Journal of Clinical Psychology, 55, 1107-1125.

Frankl, V. E. (1963). Man's search for meaning: An introduction to logotherapy. New York: Washington Square.

Frankl, V. E. (1969). The will to meaning: Foundations and applications of logotherapy. New York: World Publishing.

Jorm, A. F. (1987). A guide to the understanding of Alzheimer's disease and related disorders. New York: Washington Square.

Kerson, T. S., & Michelsen, R. W. (1995). Counseling homebound clients and their families. Journal of Gerontological Social Work, 24, 159-190.

Lindemann, E. (1944). Symptomatology and management of acute grief. The American Journal of Psychiatry, 101, 141-148.

Loos, C., & Bowd, A. (1997). Caregivers of persons with Alzheimer's disease: Some neglected implications of the experience of personal loss and grief. Death Studies, 21, 501-514.

May, R. (1953). Man's search for himself. New York: Dell.

May, R. (Ed.). (1960). Existential psychology (2<sup>nd</sup> ed.). New York: Random House.

Mittelman, M. S., Ferris, S. H., Shulman, E., Steinberg, G., Ambinder, A., Mackell, J. A., & Cohen, J. (1995). A comprehensive support program: Effect on depression in spouse-caregivers of AD Patients. The Gerontologist, 35, 792-802.

Mittelman, M. S., Ferris, S. H., Steinberg, G., Shulman, E., Mackell, J. A., Ambinder, A., & Cohen, J. (1993). An intervention that delays institutionalization of Alzheimer's disease patients: Treatment of spouse-caregivers. The Gerontologist, 33, 730-740.

Mullan, J. T. (1992). The bereaved caregiver: A prospective study of changes in well-being. The Gerontologist, 32, 673-683.

Murphy, K., Hanrahan, P., & Luchins, D. (1997). A survey of grief and bereavement in nursing homes: The importance of hospice grief and bereavement for the end-stage Alzheimer's disease patient and family. Journal of the American Geriatrics Society, *45*, 1104-1107.

Ponder, R. J., & Pomeroy, E. C. (1996). The grief of caregivers: How pervasive is it? Journal of Gerontological Social Work, *27*, 3-21.

Talkington-Boyer, S., & Snyder, D. K. (1994). Assessing impact on family caregivers to Alzheimer's disease patients. The American Journal of Family Therapy, *22*, 57-66.

Walker, R. J., Pomeroy, E. C., McNeil, J. S., & Franklin, C. (1994a). A psychoeducational model for caregivers of patients with Alzheimer's disease. Journal of Gerontological Social Work, *22*, 75-91.

Walker, R. J., Pomeroy, E. C., McNeil, J. S., & Franklin, C. (1994b). Anticipatory grief and Alzheimer's disease: Strategies for intervention. Journal of Gerontological Social Work, *22*, 21-39.

Walker, R. J., & Pomeroy, E. C. (1996). Depression or grief?: The experience of caregivers of people with dementia. Health & Social Work, *21*, 247-254.

Yalom, I. D. (1980). Existential psychotherapy. New York: Basic Books.

## Appendix

### Clinical Dementia Rating (CDR)

#### Healthy CDR

Memory: No memory loss or slight inconstant forgetfulness.

Orientation: Fully oriented.

Judgment and problem solving: Solves everyday problems well; judgment good in relation to past performance.

Community affairs: Independent function at usual level in job, shopping, business and financial affairs, volunteer and social groups.

Home and hobbies: Life at home, hobbies and intellectual interests maintained.

Personal care: Fully capable of self-care.

#### Questionable Dementia CDR

Memory: Mild consistent forgetfulness; partial recollection of events; 'benign' forgetfulness.

Orientation: Fully oriented.

Judgment and problem solving: Only doubtful impairment in solving problems, similarity, and differences.

Community affairs: Only doubtful or mild impairment, if any, in these activities.

Home and hobbies: Life at home, hobbies, and intellectual interests well maintained or only slightly impaired.

Personal care: Fully capable of self-care.

### Mild Dementia CDR

Memory: Moderate memory loss, more marked for recent events; defect interferes with everyday activities.

Orientation: Some difficulty with time relationships; oriented for place and person at examination but may have geographic disorientation.

Judgment and problem solving: Moderate difficulty in handling complex problems; social judgment usually maintained.

Community affairs: Unable to function independently at these activities though may still be engaged in some; may still appear normal to casual inspection.

Home and hobbies: Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interests abandoned.

Personal care: Needs occasional prompting.

### Moderate Dementia CDR

Memory: Severe memory loss; only highly learned material retained; new material rapidly lost.

Orientation: Usually disoriented in time, often to place.

Judgment and problem solving: Severely impaired in handling problems, similarities, differences; social judgment usually impaired.

Community affairs: No pretense of independent function outside home.

Home and hobbies: Only simple chores preserved; very restricted interests, poorly sustained.

Personal care: Requires assistance in dressing, hygiene, keeping of personal effects.

### Severe Dementia CDR

Memory: Severe memory loss; only fragments remain.

Orientation: Orientation to person only.

Judgment and problem solving: Unable to make judgments or solve problems.

Community affairs: No pretense of independent function outside home.

Home and hobbies: No significant function in home outside of own room.

Personal care: Requires much help with persona; care; often incontinent.

Hughes et al., 1982 (cited in Jorm, 1987).