Theoretical Perspectives Concerning Positive Aspects of Caring for Elderly Persons With Dementia: Stress/Adaptation and Existentialism

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Research concerning caregivers of persons with dementia has predominantly been guided by a stress/adaptation paradigm. This paradigm, however, does not fully address the issue of how caregivers manage to do so well under difficult circumstances. Existentialism offers an alternate theoretical view for exploring this issue. This article compares and contrasts these two paradigms — their key elements, strengths, and limitations, and areas of convergence and divergence. It identifies implications for future theory development, research, and clinical practice.

Key Words: Caregivers, Dementia, Existentialism, Stress/Adaptation

In our clinical practice and research of caregivers of persons with dementia, we remember specific caregivers who seem different from any others — their stories are poignant, they dramatically describe their experiences with caregiving, and we use their eloquent words to serve as examples for other caregivers. They present themselves in majestic serenity, calmness, and a sense of “being at peace” with what they are doing and experiencing. We look at them and wonder — What makes them different? How is it that as they experience the pain and sorrow of seeing a loved one succumb to dementia, they do so in such a poetic manner? These are the caregivers who have inspired us to look at the positive aspects of caring for persons with dementia and to understand this phenomenon clinically, empirically, and theoretically.

The majority of research concerning caregivers of persons with dementia has used a stress/adaptation paradigm. This perspective has primarily focused on negative stressors and outcomes associated with this experience (Kramer, 1997). More recent family caregiving literature has suggested that we broaden the current paradigm to include positive aspects concerning the caregiving process, resources, and outcomes (Deimling, 1994; Lawton, Moss, Kleban, Glickman, & Rovine, 1991; Pearlin, Mullan, Semple, & Skaff, 1990). Questions that emerge, however, include: What are these positive aspects of caregiving? Are they background variables, resources, appraisals and/or outcomes? How should they be measured? Can causal relationships be determined? and What types of research designs can help us answer these questions?

These questions can immobilize us on one hand, or they can encourage us to examine “new ways of looking at old problems.” New ways may involve taking an entirely different approach — a different epistemology, a fresh theoretical view, a new research design, or a humble admission that some questions will never entirely be answered. The purpose of this paper is to take a new look, to examine our current empirical stress/adaptation paradigm in light of a philosophical and almost intuitive paradigm, existentialism; to identify key elements, strengths, and limitations, to identify areas of convergence/divergence of each perspective; and to identify implications for future theory development, research, and clinical practice.

Stress/Adaptation: An Overview

Two somewhat similar but general stress/adaptation models have guided family caregiver research: 1) the Double ABCX model (McCubbin & Thompson, 1987), and 2) the cognitive phenomenological theory of psychological stress (Lazarus & Folkman, 1984). Two models, most commonly used and more specific to caregivers of persons with dementia, have primarily evolved out of Lazarus & Folkman’s general model (Lawton et al., 1991; Pearlin et al., 1990). Critiques of these models and comparisons of their similarities/dissimilarities have previously been published (Kramer & Vitaliano, 1994).

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Although there are variations in these conceptualizations (Kramer, 1997), recurring constructs describe the caregiving process, including background and contextual variables, stressors, resources, appraisals, and outcomes. Adaptation defines the entire process that occurs in response to the stress of caring for a person with dementia.

Two more recent but interrelated areas of progress have included a focus on the positive aspects of caregiving (Kramer, 1997) and the delineation of positive and negative outcomes (Lawton et al., 1991). Positive constructs that have been identified include satisfaction, uplifts, rewards, gratifications, growth and meaning, enjoyment, and benefits (see Kramer, 1996 for a review of existing studies). The focus on positive aspects of caregiving is not without its challenges, however. Notably, what are these positive aspects? Are they related to caregiver attitudinal variables, caregiver characteristics, resources, specific coping strategies, appraisals, or outcomes? What theory guides their development, and how can they be operationalized? (See Kramer, 1997 for a more complete discussion of these issues). The second area of progress lays the foundation for examining predictors of both the positive and negative outcomes associated with caregiving (Lawton et al., 1991).

The major strength of the stress/adaptation theoretical perspective rests in its empirical philosophy of science. Namely, underlying assumptions of this philosophy, when applied to caregiver research, suggest that the parts can be operationalized; the whole can be represented by the corresponding parts; and stressors, resources, appraisals, and outcomes have a causal relationship.

A second strength that emanates out of this philosophy of science, rests on the vast improve in the operationalization of these general constructs in the past fifteen years, including: stressors; resource variables such as coping (Kramer & Vitaliano, 1994), personal control, self-efficacy, knowledge, and hardness; primary and secondary appraisal; and emotional and physical health outcomes (George & Gwyther, 1986; Schulz, Visintainer, & Williamson, 1990).

Four major limitations of the stress/adaptation paradigm and its relationship to positive aspects of caregiving can be identified. First, it has been noted that these positive aspects of caregiving are poorly defined and poorly operationalized (Kramer, 1997). Second, nearly half of the studies conducted to date had no theoretical base. Of those that did, a wide variation of theoretical perspectives were identified, including stress/adaptation, social exchange, work, motivation, job satisfaction, and existentialism (Kramer, 1997). Third, the majority of these studies were qualitative, and fourth, the stress/coping paradigm has identified far fewer predictors of positive than of negative outcomes (Lawton et al., 1991). Each of these limitations are discussed in greater detail in the following discussion.

It is no wonder that the positive aspects of caregiving are poorly defined — perhaps the terms stress and positive aspects are opposites that cannot be reconciled. Stress implies that something is wrong.
tion, while symptoms, caregiving duration, marital history, and perceived stress regarding IADLs predicted depression (Kramer, 1993a).

Where do we go from here? The stress/adaptation perspective has worked well to an extent. Are there existing theoretical paradigms that can contribute toward finding this missing link — that of understanding how it is that caregivers do so well under difficult circumstances? Are there theoretical perspectives that are less mechanistic, but at the same time contribute toward our understanding of the whole? Can these theoretical perspectives guide us with our research methods and design? Existentialism is posited as one alternative perspective that may assist us in answering some of these questions.

Existentialism: An Overview

Existentialism is a philosophical perspective that addresses such questions as “Who is man?” and “What does it mean to exist or to be human?” It makes certain assumptions about difficulties associated with being human, such as: each person experiences isolation at some point in an indifferent universe; each person suffers or despairs at some time in his/her life; and there are two things a person must do alone — to be born and to die. This perspective acknowledges the fact that humans have the potential to experience existential vacuum — times when one’s goals are not met, times when there are feelings of nothingness, meaninglessness, anxiety, and isolation. This perspective also identifies the tension between being free to make choices while at the same time assuming responsibility for what life sets before one, and the natural consequences of actions. Furthermore, it addresses the tremendous capacity that humans have to experience hope, to transcend and find meaning in the midst of difficult life experiences (Frankl, 1963, 1967, 1978; Nauman, 1971; Yalom, 1975, 1980).

Philosophers, theologians, psychologists, clinical practitioners, novelists, and poets have based their work on existentialism. Viktor E. Frankl, a Viennese psychiatrist, is one of the major proponents of an existential paradigm. He based his clinical practice on logotherapy — helping people find meaning in the midst of both mundane and critical life experiences. He further expanded this perspective under more extreme personal experiences in German concentration camps during World War II. His easy-to-read, lay rendition of this perspective, Man's Search for Meaning, became well known in the 1960's (1963). Another well known lay presentation of an existential perspective is Kushner's When Bad things Happen to Good People (1981).

Levine et al. (1984) appear to be one of the first groups who took some of the basic themes of existentialism and applied them to the process of caring for persons with dementia. They suggested that spouses of persons with dementia “live in a prison, struggle on a battlefield, and languish in a concentration camp” (p. 222). Furthermore, they suggested that existential freedom may confront caregivers with “terrifying new choices” and may be reflected in “a fear of unwelcome possibility” (p. 220) — that is, caregivers face the freedom to choose not to become caregivers, but may become so frightened in considering this possibility that they may act out of fear instead of “true choice” (p. 220).

Few caregiver studies have specifically identified an existential perspective. Our own experience with open-ended, qualitative caregiver responses led us to consider this paradigm along with the construct of finding meaning through caregiving (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991). Initial attempts to interpret these qualitative data through the lens of a stress/adaptation perspective left some of the story untold, namely, how to account for the positive aspects of caregiving reported by 90% of the caregivers (N = 94). Our further exploration of theories of loss/grief helped us to “explain” the feelings of loss and powerlessness, experienced by 84 and 82 percent of the caregivers, respectively; cognitive-behavioral perspectives helped us to interpret the personal choices caregivers reported making with respect to their experiences, but no one perspective seemed to pull it all together.

A somewhat serendipitous re-reading of Frankl's, Man's Search for Meaning, and an introduction to his professional writings (1967, 1978) suggested that "this was it." Namely, that difficult experiences provide caregivers the opportunity to find provisional and ultimate meaning; that the process of finding meaning or seeing the positive is a choice caregivers can make; that their pre-existing values provide a basis for meaning; and that caregivers have responsibility for right action and conduct (Farran et al., 1991; Frankl, 1967, 1978).

Two subsequent studies enabled us to develop and test the Finding Meaning through Caregiving measure derived from these qualitative data. The measure was validated with general loss/grief, finding meaning, and religiosity measures (N = 46); the measure was further validated with a larger sample of Black and White caregivers using caregiver-specific measures (N = 208; Farran, Miller, Kaufman, Donner, & Fogg, 1996). A third study examined finding meaning as a resource variable in the prediction of caregiver depression and global role strain in this same sample of Black and White caregivers (N = 208). Mean differences between Black and White caregivers were found for each of the three finding Meaning subscales, namely: Blacks reported lower levels of loss/powerlessness and higher levels of provisional and ultimate meaning than White caregivers. Multivariate analyses suggested that finding meaning had direct effects in the prediction of two negative caregiver outcomes (Global role strain and depression) but was not moderated by race (Farran, Miller, Kaufman, & Davis, in press).

Several caregiver studies, using a stress/adaption perspective, have identified constructs similar to finding meaning. Pearl et al., (1990) identified personal meaning as a positive caregiver resource. Lawton et al., (1992) identified traditional caregiver ideology as a potential predictor of positive caregiver outcomes.
Early attempts to operationalize existential constructs, such as finding meaning, were done by Crumbaugh and Maholick in their development of the Purpose in Life measure (1969) and the Seeking of Noetic Goals test (Crumbaugh, 1977). A more recent and the most comprehensive theoretical and empirical work, using a life-span approach, has focused on development of the Life Attitude Provide-Revised (LAP-R), Sources of Meaning Profile (SOMP), and Ladder of Life Index (LOLI; Reker, 1992; Reker, Peacock & Wong, 1987). The LAP-R, SOMP, and LOLI were used to validate the Finding Meaning through Caregiving measure (Farran et al., 1996b), and show that empirical validation of these constructs is possible.

Along this same line, Ryff and colleagues have used a social-psychological approach, including developmental psychology, clinical psychology, and mental health, to affirm the importance of psychological well-being. Six dimensions of well-being have been verified using factor analyses. They include: personal growth, purpose in life, autonomy, environmental mastery, positive relations with others and self-acceptance (Ryff, 1989a, 1989b; Ryff & Keyes, 1995; Ryff, Lee, & Na, 1993; Ryff, Lee, Essex, & Schmutte, 1994). These six factors have many similarities to what has been identified as provisional meaning from an existential perspective (Farran et al., 1991, 1996).

The major strengths of an existential perspective rest on its philosophy of science. Existential perspectives are deeply intuitive, and assume an interpretive or phenomenological perspective (Reker & Wong, 1988; Yalom, 1980). This perspective suggests that the whole can only be understood in context and from the perspective of the persons involved — the impaired family member, the family caregiver, and other family members (Levine et al., 1984). It assumes that humans are capable of symbolization and suggests that they “more than” respond to their environment, that they have the power to potentially “transcend” the boundaries of their past, present and future, and to both “discover” and “create” meaning. Clinical and theoretical work suggests that existentialism is relevant to caregivers of persons with dementia (Frankl, 1967, 1973; Levine et al., 1984), and empirical work further supports the operationalization of these constructs (Farran & Keane-Hagerty, 1991; Farran et al., 1996; Lawton et al., 1989; Pearlin et al., 1990; Reker & Wong, 1988; Ryff et al., 1993, 1994, 1995).

A number of limitations concerning existentialism can be noted. An existential perspective is not empirical in the typical sense. Its components cannot be readily identified within a model, and relationships among constructs are not necessarily assumed to be linear, as with a stress/adaptation perspective. Empirical validation of existential constructs has also lagged behind its basic tenets.

### Stress/Adaptation and Existentialism:
**Complementary Paradigms?**

There are areas where the stress/adaptation and existential paradigms have direct similarities, other areas where the stress/adaptation perspective makes major contributions, and still other areas where an existential paradigm appears to extend the stress/adaptation paradigm.

#### Model Similarities

**Stressors/Suffering.** — Stress/adaptation and existential paradigms use similar terms in reference to difficult life experiences. A stress/adaptation paradigm uses more discrete and specifically operationalized terms that refer to care-receiver and caregiver stressors. Care-receiver characteristics and potential stressors include the impaired family member’s illness severity, cognitive status, problematic behaviors, and functional status. Caregiver indicators most commonly associated with stress include depression, psychotropic drug use and alterations in physical health (Kramer, 1997; Lawton et al., 1989; Pearlín et al., 1990).

An existential perspective uses the broader term, “suffering,” and suggests that when individuals experience difficult life events they suffer on physical, psychological, social, and spiritual levels (Missene, 1984; Soelle, 1975). Both of these perspectives identify the multidimensional aspect of stress and/or suffering. The stress/adaptation perspective has succeeded in identifying and operationalizing discrete stressors, while an existential paradigm speaks to overall effect of the caregiving experience — that of potentially suffering.

**Negative and Positive Components/Dialectical Relationships.** — A second major area where direct similarities exist between these two models concerns their interpretations about positive and negative model components. Earliest caregiver research, using a stress/coping paradigm, primarily reflected negative aspects of caring for a person with dementia (Lawton et al., 1991). More recent caregiver research has identified potentially positive aspects (uplifts; Kinney & Stephens, 1989), positive mediating or resource variables such as managing meaning (Pearlin et al., 1990), traditional caregiving ideology (Lawton et al., 1989), and positive outcomes such as caregiver satisfaction (Lawton et al., 1989).

An existential paradigm assumes that positive and negative experiences and feelings have a dialectical relationship — one cannot experience a full range of health without at some point experiencing non-health or illness; one cannot be hopeful without having experienced hopelessness, nor can one experience meaning without having experienced meaninglessness (Farran, Herth, & Popovich, 1995; Frankl, 1963, 1967, 1978). This dialectical relationship between potentially positive or negative constructs further supports the simultaneous existence of hassles and uplifts (Kanner, Coyne, Schaefer, & Lazarus, 1981; Kinney & Stephens, 1989), caregiver distress and well-being or satisfaction (George & Gwyther, 1986; Lawton et al., 1991), depressive symptoms, and finding meaning (Farran et al., 1996a; Lawton et al., 1992). The coexistence of these potentially positive and negative (or dialectical) constructs provides fur-
ther support for a recursive model of caregiving (Lawton et al., 1991).

Model Differences

There are two areas where major differences are noted between these two paradigms — one, in terms of interpretation, and two, in terms of operationalization. A stress/adaptation is very cognitive, rational, and linear in its interpretation. This perspective suggests that caregivers identify their stressors and their level of distress, they draw upon their resources and may subsequently reappraise their situation. When they cope with these issues, problem-focused or cognitively oriented strategies have been most effective in dealing with stress-related outcomes (Haley, Levine, Brown, & Bartolucci, 1987). What may be missing is the broader context and fluid perspective offered by existentialism.

An existential paradigm, on the other hand, espouses values, freedom of choice, responsibility, and consequences of actions (Nauman, 1971; Yalom, 1980). Frankl (1963) suggests that values play a major role in determining how persons deal with difficult life circumstances. Values may be expressed as caregivers creatively deal with their situation. They may be expressed experientially through relationships or feelings that persons have toward others. They may also be expressed through attitudes or life beliefs. An existential paradigm also maintains that persons have freedom of choice, but this freedom is imbedded in moral responsibility (Callahan, 1988; Klein, 1989) and a willingness to assume the consequences for their actions.

More recent caregiver research has explored the relationship between such attitudinal variables and stress, including: feelings of obligation (Albert, 1992), reciprocity, continuing a family tradition, mutual concern (Lawton et al., 1992), marital closeness and gratification (Montenko, 1989), and inner strength, social captivity, intimacy, love, and social distance (Braithwaite, 1996). Largely unexplored within caregiver research, however, are those values which motivate persons to become caregivers and the values that assist persons in dealing with difficulties associated with caregiving on an ongoing basis. Also unexplored are caregivers' feelings of choice. Do caregivers make a free choice to provide care to a family member, or is this choice made out of fear (Levine et al., 1984)? And finally, as clinicians and researchers, we are concerned about the negative consequences of caregiving. Are these natural consequences of a difficult life experience, or can we intervene to promote more positive consequences? It would appear that an existential paradigm may assist us in asking some of these more difficult questions and a stress/adaptation perspective may assist us in operationalizing such constructs as suffering, values, choices, responsibilities, consequences of actions, transcendence, and meaning.

Extension of the Model

There are two areas where an existential perspective not only builds upon, but could extend the stress/adaptation paradigm. These include the area of coping/transcendence and transformation, and management/discovery or creation of meaning.

Coping/Transcendence and Transformation. — The stress/coping paradigm has placed considerable emphasis on coping — affective or emotion-focused, and cognitive or problem-focused (Lazarus and Folkman, 1984). An existential perspective, while not referring to coping per se, acknowledges the affective (suffering, hope/hopelessness, meaning/meaninglessness) and cognitive aspects (freedom of choice) of dealing with difficult life situations, but adds one important dimension — transcendence or transformation of the experience or situation — that is, the ability to “make sense of” or “rise above” one's external situation.

While the stress/adaptation perspective refers to the notion that caregivers may “reinterpret” and/ or “accept” their situation, an existential perspective refers to transcendence and transformation of mind and affect (Reker, 1991). This transformation may occur as caregivers reappraise the situation, but in this case, caregivers go one step further to “transform” the situation to something new (Cartwright et al., 1994). Caregivers may identify making cognitive and/or motivational changes, but they also identify such things as having grown through the experience of caregiving and becoming a stronger, better person because of this experience (Farran et al., 1991).

Frankl (1963, 1967, 1978) generally refers to this ability to rise above one’s immediate situation as “will to meaning” or finding meaning through suffering. He suggests that persons “create” meaning by making choices. In a situation of caregiving, for instance, these choices may include, but not be limited to, making a choice as to whether to become a caregiver at all, or making choices about one's attitude toward the caregiving situation such as appreciating the positive, finding paradox in the situation, taking one day at a time, and/or using a sense of humor (Farran et al., 1991). While many of these approaches are similar to cognitive coping strategies, a person's philosophical or life belief values distinguish how caregivers with particular value systems may be “different from” or do “more than” just making cognitive changes.

Management of Meaning/Discovery or Creation of Meaning. — The major area where an existential paradigm extends a stress/coping paradigm is with respect to meaning. A stress/coping paradigm most commonly asks, “What does it mean to provide care to an impaired family member in terms of caregiving tasks (stress appraisal), what resources are available to caregivers, and what effect does this experience have on caregivers (outcomes)?” An existential paradigm, on the other hand, asks, “How can I discover or create meaning?”

Pearlin and colleagues, in their stress/coping caregiver model, suggested that management of meaning could serve as a caregiver resource variable (1990). An existential paradigm suggests that mean-
outcome variable. That is, positive approaches such as finding meaning may "predict" more positive emotional and/or physical health outcomes, but higher levels of health might also "predict" higher levels of finding meaning, suggesting a potential reciprocal relationship over time (Reker, 1994). An existential perspective suggests that the process of finding meaning through difficult life experiences is based upon the values one embraces and the choices one makes, as well as one's willingness to assume responsibility for right action and conduct. Frankl (1963) also suggests that provisional and ultimate meaning exist. Provisional meaning refers to more short-term or transitory experiences that provide life with meaning, while ultimate meaning refers to a person's exploration of deeper meanings in life often associated with one's spiritual nature (Missine & Willeke-Kay, 1985). In a qualitative study, caregivers reported finding provisional meaning when they saw their care recipient's positive response to care, felt confident that they were providing good care, and through their own feelings that they were growing or changing as a result of caring for their relative (Farran et al., 1991).

Reker, in using an existential framework, suggests that meaning can be both "discovered" and "created" (1991). For example, a caregiver with a religious/spiritual value system may provide care for a family member because it is "God's will" and thereby discover or attribute meaning to a difficult situation that otherwise might be meaningless. On the other hand, a caregiver might also seek to "create" meaning in this situation. This "creation" of meaning rests upon the "transformative" process described earlier.

The major area of difference between an existential and stress/adaptation perspective is that in the former, it is assumed that meaning can be discovered or created — that is, one's situation can be changed or transformed. This process has been likened to the alchemists who desired to turn mundane elements into gold (Cartwright et al., 1994).

Summary and Recommendations

The stress/coping paradigm, as applied to caregiving, is based upon a strong empirical history, but current trends have suggested that this model should be broadened. This article has proposed that an existential paradigm serves as one alternative method for extending this existing model. The article has identified areas where stress/coping and existential models overlap, where they have distinct differences, and where an existential paradigm extends the stress/coping paradigm, namely, with respect to its attention to values, moral decisions, and the ability of humans to both discover and create meaning through transcendence and transformation of difficult life experiences.

Combining what we know from a stress/coping paradigm and what we might learn by incorporating existential perspectives suggests that we may be able to use more extensive research designs and methods to more fully answer the following questions. Prospective studies of caregiving could assist us to answer such questions as "What abilities do persons bring with them prior to assuming caregiving responsibilities, and how do these characteristics influence the caregiving process and outcomes?" and "How do prior values influence the decision to provide care to an impaired family member, and the process and outcomes associated with this experience?"

Studies that combine qualitative and quantitative methods (Pearlin, 1992) would help us to address such questions as "Can we assume that if we measure physical, mental, social, and spiritual aspects of suffering, that we have captured the essence of suffering?" "Can we ever assume that we can capture the full impact of what families experience in terms of their suffering over the 5, 10 or 20 years during which time they may care for a family member with a chronic illness?" "How is it that family caregivers "make sense" of these experiences and do so well under difficult circumstances?" "Might there be caregiver resources that have not yet been identified and operationalized?" "What abilities do caregivers develop while they are in the process of caregiving?" "How is it that people find or create meaning?"

Longitudinal studies might answer such questions as, "Can the transformative process of creating meaning be articulated by caregivers, and might it change over time?" and "How does the experience of caring for a family member affect the caregiver after the death of the impaired family member?" "Is meaning only discovered or created during the caregiving experiences, or does this process continue after caregiving responsibilities have been relinquished?" Intervention studies might focus on such questions as, "Can finding meaning be taught and if so, how?" and "What influence might the ability to find meaning through difficult experiences have on caregiver outcomes?" (Farran & Keane-Hagerty, 1991).

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