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Ethical Dimensions and Filial Caregiving

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Abstract

Filial caregiving has significantly reduced nursing home admission for older relatives (LoSasso & Johnson, 2002). While much has been written about family caregiving stress, little has been written regarding ethical dimensions of filial (pertaining to a son or daughter) responsibility for older parents and their perception of moral demands. Therefore, this paper provides the following:

- An overview of the concept of family caregiving;
- A discussion of family characteristics; and
- An explication of ethical underpinnings and filial caregiver acceptance.

The ethical challenge for health care providers and researchers is to explore with adult children the reasons given for persuading themselves to provide care. Discussion expands the awareness of the interrelationship between the nature of the prior filial relationship, image of caregiving, and ethical views that underscore acceptance of filial obligation.

Keywords: Filial Caregiving; Ethics of Caregiving; Ethics and Decision-Making

INTRODUCTION

The elderly are growing rapidly today as life expectancy increases. One out of every 10 persons is now 60 years or older; by 2050, one out of five will be 60 years or older; and by 2150, one out of three will be 60 years or older (United Nations Division for Social Policy and Development, 2003). As the aging population increases, so does the need for family caregivers for elder frail relatives. In the United States, families assume a large share of caregiving responsibilities for elderly relatives (Amirkhanyan & Wolf, 2006; authors, 1994; Travis & Piercy, 2002; Walker, Pratt, & Eddy, 1995). The number of family and friends who provide some level of long-term care to elders in the community is now close to 30 million persons, and the value of their unpaid services is estimated to be worth between \$275 and \$300 billion annually (Arno, 2002).

Yet, while the number of elders is increasing, the pool of available family caregivers is shrinking. Family caregivers provide approximately 80% of the necessary care for the elderly. Usually, the caregiver is an adult daughter. Large numbers of woman continue to enter the workplace, including middle-aged women who are most often the caregivers of elderly relatives. It has been estimated that the average American woman will need to impart about 18 years of caregiving to elder relatives (Weber & Clark, 1997). Coupled with women's presence in the workplace are rising divorce rates, declining birth rates, aging Baby Boomers, and cutbacks in Medicare and Medicaid. All of these issues impact the growing phenomenon of family caregiving. Since relationships have been found to be central to women's definition of self (Gilligan, 1982; Lyons, 1983), their commitment to connectedness has influenced caregiving stress. Since relationships have been found to be central to women's self definition (Gilligan, 1982; Lyons, 1983), their commitment to connectedness has influenced caregiving stress. These

competing roles have often led to reduction in work hours or quitting jobs and depression. Life style disruptions have led to stress overload or caregiver burden (Brody, Kleban, Johnsen, Hoffman, and Schoonover, 1987; Pearlin et al., 1990; Yee & Schulz (2000); Pinquart & Sorensen, 2006.

Men too now constitute 44% of family caregivers (National Family Caregivers' Association, 2000). Male caregivers are providing caregiving tasks that range from the intimate to the instrumental in nature (Hourde, 2001). While caregiver stress literature has shown that women experience more caregiving health and financial costs than do men (Ingersoll-Dalton, Neal, Ha, & Hammer, 2003; Pinquart & Sorensen, 2004; Yee & Schulz, 2000), caregiving men could be drafted or volunteer as a sole caregiver, or the principal care manager, or part of a caregiver team. Men's presence among primary caregivers will become more significant as the aging population continues to explode (Kramer & Thompson, 2002).

Typically, men who become engaged in filial caregiving and who assume primary care provider roles are either without siblings, without sisters, or the only geographically available child (Campbell & Martin-Matthews, 2003,p.S350). While sons who assume the primary caregiver role are as extensively involved as daughters in the filial caregiving process (Horowitz, 1985), daughters are much more likely to provide assistance with personal care.

Over the past decade a substantial body of research has addressed the stress process and the consequences of providing care to elderly relatives (Brody, 1985; Pearlin 1989; Pearlin, Mullan, Semple, & Skaff, 1990; Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; McCarty, 1996; Raschick & Ingersoll-Dayton, 2004; United States Department of Health & Human Services, 2001). Despite this extensive literature on elder family caregiving, stress process, and health outcomes, little has been said regarding ethical dimensions of filial

responsibility for older family members and their perception of moral demands. Given that more and more adult children will be taking on parent caregiving for longer periods of time, how could they be helped in an anticipatory and proactive manner?

FAMILY CAREGIVING

Families have been the cornerstone of care giving in the United States for the past quarter of a century; 80 % of the every day assistance for elder relatives is provided by their families (U.S. General Accounting Office, 1977). Family care has involved assisting elder family members with physical care, emotional support, managing crises, maintaining connections with others, and helping them with decision – making (Eliopoulos, 2005, p. 542). Family care is considered to be informal, is usually unpaid, and often delays placing the elder relative in long – term care (Pandya & Coleman, 2000; Shirey & Summer, 2000).

Yet, each family draws on its own "family history" as it approaches the stage of caring for an elder member/s. Contextual features cannot be ignored (Satow, 2005; Family Caregiver Alliance National Center on Caregiving, 2005. These features include the following:

- 1. Allocation of family roles and responsibilities;
- 2. Perception of parent identify and prior filial relationship impacting negotiation styles;
- 3. Family members' expectations of care (adult child and parent);
- 4. Images of care giving (care of others and self);
- 5. Communication and negotiation styles; and
- 6. Coping pattern and social support history.

It is essential to elucidate these features in order to understand the reasons by which an adult child convinces oneself to assume this care. How can one begin to address filial caregiving issues and concerns without exploring the context of family roles and relationships; prior perception of the filial relationship; parent identity; family negotiation styles and coping patterns; rules; and expectations that would affect the caregiving process?

Given the context of family roles and relationships, bonds of affection, mutuality, and reciprocity take root in past relationships, older parents and adult children bring a specific history of interactions to the caregiving process (Given, Kozachik, Collins, DeVoss, & Given, 2001, p. 682; Sebern, 2005). In addition, family interactions are based on the family structure that includes a system of rules that govern the family organization, power, position, and roles (decision – maker, scapegoat, placatory) (Satir, 1967). The family's system of mutual expectations of family members-patterns, rules, and roles- need introduction in order to understand how specific family functioning affects the filial caregiving process (Minuchin, 1974).

Each family member carries an evolving "dossier" of impressions and evaluations of each other. The personal identity of the elder parent was partially defined as the mental image that the adult child has had of the elderly parent. It is derived from the past associations, present observations, and reconciliation of the past with the present. According to Goffman (1962), as persons interacted over time, ach developed a consistently evolving "dossier" about the other that contained a history of events, impressions, normative role expectations, and evaluations that uniquely identified one person to the other. The image of personal identity impacts on the ways in which the filial caregiver views the elder's behaviors and ways in which the adult child will enact the caregiving role (Phillips & Rempusheski, 1986).

The image of the caregiving situation has been partially defined as the degree to which the caregiver's personal imperatives, standards, and values were realized by the caregiving situation. The concept associated with this construct has been the reconciliation of proscription with the perceived reality of caregiving, which has been defined as the degree to which the caregiver's observations and perceptions of the situation have diverged from the caregiver's beliefs about propriety. Caregivers often have come to the caregiving situation with an implicit set of standards for their behavior, the behavior of the elder parent, and life in general. These standards have constituted an ideal against which observations and perceptions of reality have been judged (Phillips & Rempusheski, 1986; author, 1993).

Standards of behavior are challenged in the filial caregiving relationship with a parent. A pronounced reconciliation of past and present perceived identify of the parent occurs- whether it involved loss of independence due to physical disability and /or cognitive impairment. What if the filial caregiver views the present caregiving situation through a lens from the past? Could the perceived identify of the parent be frozen? Could also the believed standards related to the caregiving situation, the behavior of self and that of the parent be "frozen" (author, 1993; author, 1996)?

The adult child's perceived responsibility to the parent is defined by the adult child's values, especially those related to control and existential beliefs. Beliefs of control may relate to the ability or the inability of the child to reconcile the parent's past identity. Existential beliefs may relate to the ability, or the lack thereof, for the child to create meaning and hope in an ever changing image of caregiving (author, 1993).

Families approach elder caregiving with a previously developed repertoire of communication and negotiation styles; they have embossed these communication axioms over time. These

imprints hold marked caregiving implications. Entering the caregiving process may alter or impact on the communication axioms that have transpired over the years between parent and child. Has there been a symmetrical pattern of communication? What happens if the adult child now takes the lead in the communication process? Does communication be come unilateral? ... paternalistic? May the parent become passive in response...or may it create a power struggle? Communication patterns may affect the negotiation style of caregiving.

Caregiving expectations are interwoven with the construction of the filial caregiver and that of parent, care- recipient. Both have preconceptions about what their roles entail (Edwards & Noller, 1998). Caregiving expectations and preferences, as well as appraisals of caregiving, may not overlap between parent, other family members, and the primary filial caregiver (Lyons, Zarit, Sayer, & Whitlatch, 2002). These expectations and preferences hold marked implications for communication patterns and caregiving negotiation styles – as well as family coping, gender associated roles, impact of culture, and the perception and meaning of social support. While it is recognized that the phenomenon of filial caregiving is multi-factorial, discussion of this myriad of factors is beyond the scope of this paper. Rather, the focus is filial caregiving contextual characteristics as they relate to the adult child's ethical values and moral perspectives foundation.

ETHICS AND FILIAL CAREGIVING

A review of the literature has identified thee major philosophical views related to the basis for filial duties. They are as follow:

- Ethical tradition commands lifelong parental reverence;
- Parents are owed a debt of gratitude for care that they provided to children; and

 Care for parents is the expression of friendship and love (Selig, Tomlinson, & Hickey, 1991, p.625)

"Honor thy mother and father" (Ephesians 6:2-3). McKenzie (1999) stated that those who wish to be faithful to the biblical witness note that duties to parents and the elderly area target with concentric circles. The immediate family occupies the "bulls- eye" and hence our highest priority, with others occupying more distant rings of the target – receiving less attention (Tim.5: 1-5). Heeding such an absolute commandment, persons who hold this view of their filial obligations may find it difficult to qualify them in any way. Having no reasoned basis for assuming such an obligation, they will have no reasoned basis for modifying it (Selig, Tomlinson, & Hickey, 1991, p.625).

FILIAL CAREGIVING: TRADITION COMMANDING PARENTAL REVERENCE

If an adult child assumes the filial caregiver role based on the absolute belief that "tradition commands life long parental reverence," may the adult child be considered high risk for burden as the caregiving circumstances progress and intensify over time? If role expectations of self, as revering child, are held constant throughout the changing circumstances, how might the adult child's self - efficacy as filial caregiver be impacted over time? Has a promise been made to the parent regarding care? Have other family members' expectations regarding allocation of caregiving role and responsibility furthered the primary caregiver's expectations of self? Or may the filial caregiver perceive self as fulfilling one's designated family role and opportunity to care for a parent – regardless of intensifying caregiving circumstances? If it is the later, the filial caregiver may have chosen to assume this role in an earnest "expression of friendship and love."

The injunction to "honor one's parents" has not been treated as an absolute duty that took precedence over other family duties (spouse and children) (Selig, Tomlinson, & Hickey, 1991; although it does not today as well. It is noted that today's parent caregiving trajectory continues for many more years with parents living into very advanced age and with multiple chronic conditions. If the filial caregiver takes ethical cues from "what people have always done for parents," historical facts may be liberating or may pose more dilemmas. The filial caregiver's dilemma may center on pondering availability of community resources and options for long — term placement.

FILIAL CAREGIVING: PARENTS ARE OWED A DEBT OF GRATITUDE

Although family caregivers are those people who have "volunteered" for this role, voluntariness in this caregiving context may be very complex from a psychological perspective (Kapp, 2003- 2004). Adult children may also subscribe to the belief that they are indebted to parents for what their parents did for them (Selig, Tomlinson, & Hickey, 1991). Or the adult child may respond to persuasion from other family members, from the parent, from health professionals, or from his / her own beliefs ("only child" or "designated caregiver").

Selig, Tomlinson, & Hickey (1991) also reviewed the concept of reciprocity; they posited that when parents go "beyond the call of duty," it is with love and not as a part of a contract with the child, who has not freely entered into such an agreement. Therefore, to appeal to past parental sacrifices beyond the call of duty does not support absolute filial obligation. Rather, an obligation may consider the extent and the nature of those sacrifices and the child's moral responsibility in accepting those gifts. This relativity may be helpful in terms of exploring, clarifying, and /or validating with the adult child reasonable moral limits on obligations. Selig,

Tomilson, & Hickey (1991) noted that by reflection on those parental sacrifices and the benefits that the adult child willingly accepted, such awareness may facilitate setting limits on caregiving.

Author (1993; 1996) noted that the adult child who expressed a sense of debt and obligation drew on more neutral and the "darker side" of prior parental identity and memory of filial relationship. Often, the adult child did not reflect upon a reservoir of mutuality and reciprocity in relationship and comforting memories; filial caregiving was often assumed by default. Further, the caregiving negotiation style presented in rather a unilateral and dominant style of communication.

This lack of mutual and reciprocal negotiation style was noted to intensify with filial caregivers who drew on ambivalent parent identity and conflictual relationships (Phillips & Rempusheski, 1986; author, 1993; author, 1996; Donorfio & Sheehan, 2001). Conflictual relationships are characterized by emotional disturbance and incompatibity problems, and power struggles. Filial caregivers, who draw on such a repertoire, were most vulnerable as they often assumed the caregiving role from obligation motive and / or "one last chance" to be regarded as a "favored child" (Brody, 1990). Such a filial caregiver was often "frozen" in past prior parent identity and image of caregiving; this adult child was a most vulnerable caregiver. Such a filial caregiver may view the parent through a prior lens while expressing the belief that the parent may retain prior capabilities and manipulative deliberation. Caregiver situations could hold potential for elder neglect and abuse (Phillips & Rempusheski, 1986; author, 1993; author, 1996).

FILIAL CAREGIVING: EXPRESSION OF FRIENDSHIP AND LOVE

Caregiver burden has been noted to decrease with a sense of reciprocity or balance of exchange within the caregiving dyad (Reid, Moss, & Hyman, 2005; author, 1996; Donorfio & Sheehan, 2001). Some filial caregivers in their "expression of friendship and love" may seem to go "beyond the call of duty." Furthermore, what may appear as "going beyond the call of duty" to others may not be perceived as stress by the filial caregiver, especially if the cognitive view of caring is one of contentment. Possibly this filial caregiver may have the ability to find gratification in the relationship with the impaired person and meaning in the caregiving situation... and the caregiver's ability to perceive the impaired person as reciprocating by virtue of his/her existence (Hirshfield, 1983, p. 26). Hirshfield (1983) defined this "ability to find gratification" as mutuality; such levels of mutuality enabled caregivers to continue caregiving despite objectively difficult situations. Archbold, Steward, Greenlick, & Havaath, (1990) also addressed mutuality as a predictor of caregiver role strain. Hierarchical multiple regression was used to determine whether mutuality and preparedness (how well prepared the caregiver believed he or she was for the tasks and stress of the caregiving role) were related to lower levels of caregiver strain. Mutuality may be considered a component of the filial caregiver's perception of parent identifies, and preparedness may be considered a component of the perception of the caregiving image.

Further, filial caregivers often reminisced about positive parental identity, reciprocal relationships, and engagement in meaningful filial relationships. Such caregivers drew on these beliefs and perceptions, and transactions as they entered the filial caregiving role. They expressed a sense of "choice" and "opportunity" in assuming this role (author, 1993; author, 1996; Donorfio & Sheehan, 2001).

PRACTICE IMPLICATIONS

Discussion with the adult child engaged in filial caregiving must go beyond filial piety and obligation- expressions of "feeling responsible to the parent" or "feeling guilty." Use of ethical measurement tools within the filial caregiving assessment process would ground contextual intervention approaches in accord with ethical underpinnings and moral perspectives. While respecting choice and self – determination, assessment data can be collected both subjectively (interview technique) and objectively by the following ethical measurement tools:

- Caregiver Reciprocity Scale (Carruth, 1996);
- Defining Issues Test (Rest, Narvaez, Bebeau, & Thomas, 1998);
- Caregiver Appraisal (Gesino & Haas, 2000); and
- Survey of Ethical Attitudes (Hogan & Dickstein, 1972).

Therapeutic interventions are interwoven within the ethical decision associated with assuming the filial caregiver role. The filial caregiver's ethical lens needs to be evidence – based with ethical measurement tool findings and interview techniques. Exploration, validation, clarification, reframing, and facilitation of the filial caregiver's boundary and limit setting must proceed from objective and subjective evidence.

Deontological theory drives rules and standards from the duties human beings owe one another by virtue of commitments that are made and roles that are assumed. Within this theoretical perspective, priority is given to the dignity of human beings and respect for fulfilling one's obligations to human beings (Guido, 2001, p. 54). This theoretical perspective led to a more reciprocal/ mutual filial caregiving communication and negotiation style (author, 1993; author, 1996).

Another ethical theoretical perspective is the teleological approach. Here conduct standards or conduct norms are driven from the consequences of the actions. Often, this theory is also called utilitarianism, which states that an action is deemed right or wrong based on its utility for the "greatest good for the greatest number" (Guido, 2001). This perspective may be considered if the filial caregiver is operating from an absolute parental reverence perspective. Eogism would be considered the opposite perspective as it proposes that an acceptable decision is based on one that benefits oneself (Eliopoulos, 2005). This perspective may need consideration if the filial caregiver is proceeding from an "obligation" perspective and presenting with a unilateral communication style and / or caught in a "frozen" conflictual relationship and negotiation style with the elder parent (author, 1993; 1996).

Discussion needs to uncover reasons and beliefs that the adult child has regarding her / his norms of filial obligation, perception and meaning associated with parent identity, and image of caregiving. Otherwise, well intentioned professional interventions could proceed along a prescriptive pathway - rather than one based on family context and preference, as well as on "goodness of fit" ethical and moral perspective.

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