ABSTRACT. Despite a considerable literature on family care of the elderly, comparatively little attention has been devoted to the ethical dimensions of caring for frail and dependent older family members. Nor is there an extensive literature available to guide family therapists or others in the helping professions who work with families experiencing ethical dilemmas and issues associated with caring for elderly loved ones. The purpose of this paper is to highlight some of the ethical dilemmas families face in caring for an elderly loved one, and to identify several ethical principles that can be used to address these dilemmas. There is an explicit focus on families caring for aged parents afflicted with a dementia such as Alzheimer’s disease. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <getinfo@haworthpressinc.com> Website: <http://www.HaworthPress.com> © 2001 by The Haworth Press, Inc. All rights reserved.]

KEYWORDS. Ethical issues, ethical principles, family caregiving, filial obligation, family therapists, dementia, Alzheimer’s disease

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INTRODUCTION

More than 4 million adults age 65 or older receive some form of personal assistance from informal caregivers, the majority of whom are family members (e.g., adult children, spouses, siblings). The number of older persons requiring assistance from families is expected to climb as the nation’s elderly population moves toward a projected figure of 80 million by the year 2050 (Hobbs & Damon, 1996).

The impact of these trends in the everyday lives of families has spawned an extensive literature on caregiving, much of which has been dedicated to exploring factors affecting the well-being of caregivers and care recipients, particularly in cases where the recipient suffers from a dementia such as Alzheimer’s Disease (Dura, Stukenberg, & Kiecolt-Glaser, 1991). Largely absent from this body of research, however, is a discussion of the ethical dimensions involved in caring for frail and dependent older family members. A few notable exceptions are found in the work of Hasselkus (1991), Kapp (1995), Pratt, Schmall, and Wright (1987), Turnbull (1994), and Selig, Tomlinson, and Hickey (1991). Nor is there an extensive literature to guide family therapists, counselors or other human service professionals as they help caregiving families grapple with ethical dilemmas associated with caregiving (Hasselkus, 1991). As far as we can determine, Hanna, Hargrave, and Miller (1997) may be the only authors who have directly addressed ethical issues for family therapists in treating the elderly, but they devote less than one page of guidelines to this topic.

The purpose of this article is to highlight some of the ethical dilemmas families face in caring for an elderly loved one, with a particular focus on filial caregivers and elderly parents suffering from a dementing illness such as Alzheimer’s disease. The article also identifies ethical principles that can be used in addressing these dilemmas, and outlines some guidelines that may be of benefit to family therapists working with caregiving families.

**Contextual Family Therapy**

It is recognized that family therapists are not the only helping professionals who might benefit from the information in this article. For example, counselors who facilitate caregiver support groups may also find this information useful, as will counseling psychologists, family practice physicians, occupational therapists, and other professionals dedicated to helping older adults and their families cope with the experience
of caregiving. Nevertheless, this article has been written with the objective of providing guidelines for family therapists. Our rationale for this emphasis is that family therapy—and particularly Contextual Family Therapy—entertains a focus on systemic issues rather than individual causes and illness, as is often the case with medical models of intervention (Hanna & Hargrave, 1997). Hargrave and Anderson (1997) observe that the Contextual Family Therapy approach is especially effective in working with aging families since it "emphasizes the healing of relationships through growth in familial commitment and trust be developing loyalty, fairness, and reciprocity" (p. 62). Further, the Contextual Family Therapy approach fits with current trends in family therapy to be resource-focused rather than illness- or problem-focused. Hanna and Hargrave (1997) provide a contemporary view of the role of the family therapist in working with aging families when they state:

(s)tepping between generations, the practitioner meets older families at the final crossroads where their behavior may affect generations to come. As family therapists move toward an integration with aging issues, the challenge brings with it an opportunity for personal growth and practice refinement. (pp. 32-33)

**The Role of Family in Caring for the Frail and Dependent Elderly**

Families have always been and continue to be the primary source of help to frail and disabled elders (Barber, 1989). It is estimated nationally that family and friends are the sole source of assistance for nearly three-quarters of impaired older adults in the community (Doty, 1986). They are also the preferred source of help for most elders (Cantor & Johnson, 1978; Comptroller General of the U.S., 1977; Eggert et al., 1977; McAuley & Arling, 1984; Shanas et al., 1968; Stone, Cafferata, & Sangl, 1987; U.S. DHEW, 1978).

In 1996, the National Alliance for Caregiving and AARP conducted a nationwide survey to identify and profile the experiences of caregiving (National Alliance for Caregiving and American Association for Retired Persons, 1997). This survey provides the most recent national data on a random sample of households in the U.S. The sampling strategies ensured the inclusion of minorities and enabled the identification of caregivers for persons age 50 and over with a variety of disabling conditions. Based on results of this survey, nearly one in four U.S. households contains at least one caregiver (defined as currently or previously providing care within the last 12 months to a relative or friend at
least 50 years old). This translates into 22.4 million caregiving households nationwide during the 12-month period of study.

Consistently reported across all studies of caregiving—including the NAC/AARP survey—is the finding that spouses are the first source of caregiving assistance. Likely related to the nature of the marital relationship, spouses are also often the sole caregiver (Stone et al., 1987; Tennstedt, McKinlay, & Sullivan, 1989) and provide the most extensive and comprehensive care, particularly in the care of individuals with dementia or functional disabilities (Cantor, 1983; Horowitz, 1985; Johnson, 1983; Shanas 1979a, 1979b; Stone et al., 1987). Adult children are usually the next source of informal care, with daughters and daughters-in-law more likely than sons or sons-in-law to be in this role. Note that this article is oriented for filial caregivers more so than for spousal caregivers. Hence, the term caregiver will throughout this article generally refer to an adult child, and the term care recipient will refer to an elderly parent.

In addition to the increased demand for caregiving, the family caregiver role itself has become more stressful. Despite a persistent myth that adult children do not care for their aged parents as much as was the case historically, the irony of the myth is that “nowadays adult children provide more care and more difficult care to more parents over much longer periods of time than they did in the good old days” (Brody, 1985, p. 21). Caregiving today often exceeds the capacity of family members to deal with it in the context of other demands on their lives and forces caregivers to confront difficult choices among competing demands and obligations. As women (especially adult daughters) have returned in large numbers to the labor force, parent care has become an additional demanding task that can lead to tremendous stress. Further, an increase in the divorce rate among middle-aged women also makes them less likely to be financially or emotionally capable of providing care to the increasing number of disabled parents (Pilisuk & Parks, 1988; Pratt & Kethley, 1988). Among the documented stresses of caregiving are role fatigue (Houlihan, 1987), depression (George & Gwyther, 1986), and the diminishing quality of the relationship between the caregiver and the care receiver (Scharlach, 1987).

To summarize, we have tried to make the following introductory points: (a) one of the consequences of an aging population is the increased demand for caregivers, (b) the family is the primary source of informal support for frail elders living in the community, (c) the responsibilities involved in caring for older family members often create conflicts with other obligations, (d) the ethical dilemmas faced by caregivers
have received comparatively little attention in the caregiving literature, and (e) there is little information available that will guide family therapists and other helping professionals as they help family caregivers grapple with the ethical issues involved in caregiving. The remainder of this article is devoted to identifying ethical issues, principles and dilemmas faced by caregivers (particularly filial caregivers), and some guidelines to help families who are caring for elderly loved ones.

ETHICAL DIMENSIONS OF CAREGIVING

Ethical Decision Making and Family Therapy

Zygmond and Boorhem (1989) have applied Kitchener’s model of ethical decision-making to family therapy practice (Kitchener, 1984, 1985, 1986). Kitchener (as summarized by Zygmond & Boorhem) describes two levels of ethical decision-making: the intuitive level and the critical-evaluative level. The intuitive level involves basic moral sense, or basic values. However, there are times when this intuitive level is insufficient, and the critical-evaluative level is needed in order to make a decision. The first consideration at the critical-evaluative level involves the use of ethical rules, such as those embodied in the Code of Ethics of the American Association for Marriage and Family Therapy (AAMFT). If the AAMFT Code of Ethics (1998) does not address the issue, then the next level of critical evaluation must be utilized: ethical principles, several of which are discussed in this article. It is important to note that the AAMFT Code of Ethics (1998) does not address specific clinical issues, and is very general in its description of clinical work. Relevant parts of the Code for working with aging families include: “Section 1.4: Marriage and family therapists respect the right of clients to make decisions and help them to understand the consequences of these decisions,” and “Section 3.6: Marriage and family therapists do not diagnose, treat, or advise on problems outside the recognized boundaries of their competence” (American Association for Marriage and Family Therapy, 1998). Section 1.4 relates to the ethical principle of autonomy (discussed below), while Section 3.6 of the AAMFT Code of Ethics requires that therapists do not practice outside of their scope of training and competence. Beyond these general guidelines, therapist must utilize ethical principles in their decision-making processes in working with aging families.
Ethical Dilemmas in Caregiving

Ethical dilemmas occur in problem situations for which there are no clear "right" or "wrong" answers, and generally involved a conflict between two or more ethical principles. Families (particularly adult children) face a number of ethical dilemmas related to the dependent care of an elderly loved one. Six of these dilemmas are common to most caregiving experiences (Gatz, 1995; Hasselkus, 1991).

1. *Determining the extent of filial responsibility.* While filial responsibility motivates adult children to care for aging parents, an ethical quandary arises when caregivers must decide to what extent they should provide care. How much sacrifice should be made?

2. *Family equity.* A common assumption among many families is that caregiving duties should be shared among family members. But what happens when one family member provides (willingly or unwillingly) more than her or his share of the responsibility?

3. *Competing commitments.* How do caregivers balance obligations they have to other family members and to outside commitments (e.g., work)? What limits are reasonable to set?

4. *Care recipient’s autonomy and safety/decision making.* How do caregivers grapple with decisions to reduce the care recipient’s autonomy and independence in an effort ensure her/his safety and well-being?

5. *Knowing what the care recipient wants.* When should a care recipient (e.g., an elderly mother) authorize a surrogate (e.g., an adult son or daughter) to take care of them? Similarly, when should an adult son or daughter seek authorization to act on behalf of an elderly parent? When an adult child acts on behalf of a parent who is suffering from dementia, how can the adult child know that the parent would want?

6. *Financing the cost of care.* The health-care needs of an older family member can easily strain a caregiver’s financial resources. How does a caregiver decide how many financial resources (either the parent’s resources and/or the adult child’s resources) to invest in care?

To address these dilemmas, therapists can employ five ethical principles as they work with caregiving families. Each principle is addressed in the following sections.
ETHICAL PRINCIPLES

At the critical-evaluative level of ethical decision-making, there are five ethical principles that can guide caregivers: autonomy, beneficence and nonmaleficence, truth-telling, justice, and fidelity/reciprocity/filial obligation (Gatz, 1995; Hasselkus, 1991; Kapp, 1991; Zygmond & Boorhem, 1989). When ethical principles are in conflict (as they often do in the case between autonomy versus beneficence), two additional criteria that can be employed: universalizability and balancing. When utilizing the criterion of universalizability, therapists ask themselves: “would I want this decision applied to me, my family, or all other families in similar situations?” According to the criterion of balancing, “an ethical decision is one that produces the least amount of avoidable harm to all individuals involved, even if the decision limits the amount of possible benefits received” (Zygmond & Boorhem, 1989, p. 275).

Autonomy. The principle of autonomy centers on the care recipient’s right to self-determination, and on a caregiver’s responsibility to permit the care recipient as much independence as possible in order to realize self-determination. Maintaining the principle of autonomy for an older parent difficult for many adult child caregivers because of a strong paternalistic desire (in the interest of fulfilling the principle of beneficence) to do what they feel is in the best interest of the care recipient (Pratt, Schmall, & Wright, 1987). From the perspective of the caregiver, what the care receiver wants may not always be in her or his best interest, at least from the perspective of the caregiver. An example would be an elderly father, suffering from Alzheimer’s Disease, who wants to continue driving even though his mental capacity makes this activity dangerous both to himself and to others. Such situations pose a difficult ethical dilemma for the caregiver: is the care receiver’s autonomy more important (letting the care receiver continue to drive) or is his/her safety and well-being more important (“taking away the keys”)? Often, family members let the principle of beneficence overrule the principle of autonomy while feeling guilty about taking away some of the family member’s independence. Therapists should take the time to assess with the caregiver the care recipient’s abilities, and to review the situations the caregiver feels poses a dilemma between independence and safety. In this way, the caregiver can choose to promote or restrict activities after exploring all the possible options (Hasselkus, 1991).

Roberto (1994) suggests three conditions that can ethically justify a caregiver in restricting the autonomy of a care recipient: (a) the harm prevented or benefit provided to the care recipient must outweigh the
loss of independence; (b) the condition of the person must severely limit
the ability of autonomous choice; and (c) the action must be universally
justified. By utilizing the balancing principle and by examining the
above conditions, therapists can help caregivers discern a course of ac-
tion (or several courses of action) that will assure that the least avoid-
able harm and maximize autonomy.

*Beneficence and nonmaleficence.* The principle of beneficence is de-
fined as making decisions and pursuing courses of action that are in the
best interest of the care recipient. The principle of nonmaleficence in-
volves pursuing a course of action that minimizes harm to the care re-
cipient (embodied in the maxim: "above all, do no harm") (Zygmund &
Boorhem, 1989, p. 273). It is important to note that although the forego-
ing definitions of beneficence and nonmaleficence posit the care recipi-
ent as the primary referent, these principles can also be framed to
emphasize the well-being of the caregiver.

A common dilemma faced by caregivers is finding a balance be-
tween autonomy and pursuing a beneficent course of action that the
caregiver feels is in the best interest of the care recipient. Permitting a
level of autonomy that exceeds the care recipients functional abilities
may jeopardize a care recipient’s well-being. On the other hand, sacri-
ficing the care recipient’s autonomy in favor of restrictions (e.g.,
institutionalization) that are in the recipient’s best interest may be preju-
dicial to the care recipient’s well-being as well. From the point of view
of many caregivers, principle of beneficence often outweighs the princi-
ple of autonomy (Hassellkus, 1991). Because many caregivers struggle
with ethical decision making regarding autonomy versus beneficence, it
is important for therapists to be sensitive to the caregiver’s ethical val-
ues. The goal should be to maximize the autonomy of the care recipient
(even the dementia-impaired care recipient) while protecting the care recipi-
ent against self-inflicted harm. This requires an exploration of the
least restrictive alternatives. To this end, even when beneficence has
overruled autonomy in a certain situation, there may be therapeutic so-
lutions for restoring autonomy while maintaining the beneficence
sought by the caregiver. Therapists can use the balancing principle to
achieve constructive collaboration about the negotiation of such issues,
which can lead to more cooperation among family members as well as
decreased guilt about foregoing the care receiver’s autonomy (Hassellkus

It is important to note that a critical element in balancing beneficence
with autonomy is evaluating the decisional capacity of the care recipi-
ent. The details of such a task are beyond the scope of this article, but we
wish to mention that assessing the minimal threshold level of decision-making capacity can be very imprecise. Decision-making capacity often varies for an individual over time and depends on such factors as medications taken, physical surroundings, methods of communication utilized, etc. Decision-making capacity is not a global, or all-or-nothing matter, but rather is dependent on the complexity of the particular decision confronting the care recipient at the time. As Kapp (1991) has observed, “perhaps most important, decisional capacity depends on the person’s functional ability to engage in a rational thinking process, and not necessarily whether formal or informal caregivers agree with the result of outcome of that thinking process” (Kapp, 1991, p. 18).

For some caregivers, a focus on the principle of nonmaleficence can obscure the principle of beneficence. According to Hasselkus (1991), it is not uncommon for family caregivers to, first, do no harm, and then, do good. The prevention of harm can be so consuming that energy is not expended in doing good. This is particularly true in instances where perceptions of what might do harm are based on inaccurate or incomplete information, or on fears regarding lack of experience. Time spent in sensitive education by a therapist, with special attentiveness to the caregiver’s fears and beliefs about what would be harmful, might appropriately allay some of the focus on doing no harm so that an equal amount of energy can be directed to caregiving actions (e.g., treatments prescribed by a physician or occupational therapist) that will “do good.” Discussions between the caregiver and the family therapist regarding the weighing of harm and good may be helpful for the caregiver.

Truth-telling. This principle refers to communicating openly and honestly with the elderly care recipient, and avoiding manipulation. Informing a patient about a dementing condition such as Alzheimer’s Disease can present an ethical dilemma for many family caregivers. Family caregivers are usually in control of the flow of information from the health care professionals to the care recipient. With regard to a parent with dementia, adult children are generally in a position to monitor mail, telephone calls, visitors and other sources who might provide the parent with information about her/his condition and prognosis. How much information should the parent be given? Often families may choose to withhold medical information from an elderly parent in order to protect them from the adverse effects of hearing distressing news. However, the withholding of such information offends the ethical principle of beneficence, since for most elderly family members, being given truthful information about medical conditions is of therapeutic benefit rather than detriment (Kapp, 1991). Under the principle of au-
tonomy, the care recipient is seen as having a moral right to know. Furthermore, in a survey conducted by Erde, Nadan and Scholl (1988), 92% of individuals stated that they would want to be informed of the diagnosis so they could plan for financial and personal care, seek a second opinion, and settle family matters. Therapists can encourage the disclosure of medical information to the elderly family member.

The ethical caregiver (therapist) balances the burden of being the bearer of bad tidings with a sensitivity to the care recipient's and family's needs—for timely presentation of small 'parcels' of information, for support and information at times when they request it and are able to accept and process it, and for help in coping with the signs and symptoms of the disease and in preparing for its progression. (Turnbull, 1994, p. 291)

*Justice.* The principle of justice refers to the act of doing the most good for the most people, or it can mean doing the most amount of good for those who most need it. The principle can also refer to the ideal of fairly distributing caregiving responsibilities across family members. The different perspectives of the ethical principle of justice are briefly discussed in this section.

The principle of justice in the context of family caregiving is a complex concept. Veatch (1981) has identified several theories of justice, not all of which are compatible. The fact that different views of justice as an ethical principle are incompatible is a source of dilemmas for caregivers. One example is cited here.

The utilitarian theory of justice argues that the key ethical tenet is to do the greatest good for the greatest number (the needs of the many outweigh the needs of the one). The maximin theory of justice argues that those who are most burdened and least advantaged should be benefitted more than the needs of the whole community (the needs of the one—if she/he be the most disadvantaged—outweigh the needs of the many).

In a qualitative study of caregivers, Hasselkus (1991) reported that family caregivers seem to be intuitively aware of both interpretations of the ethical principle of justice. At some point in the caregiving experience, the focus is on pursuing a course of action that would derive net benefit for the whole family. This often involves thinking about decisions that would lead the caregiver to consider her or his own well-being in equal portion to that of the care recipient. The line of reasoning here is that, if the caregiver is worn out, there is potential threat to the aggregate good of the entire family system. A course of action that will
preserve the well-being of the caregiver (and the caregiver’s family) is considered. But they are also aware that in pursing a course of action that benefits the whole family, the care recipient’s autonomy may be at risk. Among the 60 caregivers interviewed by Hasselkus (1991), most—although recognizing the value of the utilitarian theory—are most likely to uphold the maximin theory. They placed the care recipient’s needs above their own or above their family’s needs. This did not occur without feelings of resentment and guilt.

One important implication of the foregoing is that it is of considerable value for family therapists to explore caregivers’ beliefs about justice. Such an exercise may help reveal a caregiver’s implicit ethical code, and illustrate for the caregiver the reasons underlying feelings of resentment and/or guilt.

Family mutuality is another dilemma regarding justice felt by some caregivers. Many caregivers feel that the duty or responsibility of caregiving should be shared by other family members. However, caregiving is usually provided by one caregiver who takes on the responsibility for as long as possible at which point a new caregiver is substituted (Pratt et al., 1987).

Fidelity, reciprocity, and filial obligation. The principle of fidelity refers to being faithful, keeping promises, being loyal, and being respectful of the care recipient’s rights. Related to this principle is the norm of reciprocity and the concept of filial obligation. As the norm of reciprocity is played out in the context of intergenerational relationships, adult children often feel that providing care for an older parent is a form of payback—a moral obligation—that is owed to the parent in exchange for benefits the parent earlier conferred on the adult child (Kapp, 1991; Pratt et al., 1987). Family caregiving in this view is a way of evening the ethical score.

Selig et al. (1991) frame filial obligation as an ethical issue involving lifelong parental reverence. This is not just true for caregivers of a given religious orientation. Virtually all religions espouse filial obligation in one form or another. Judaism and Christianity are clear about the moral importance of filial duty, rooted in teachings at the heart of their common theological-ethical heritage. The Fifth Commandment in the Decalogue is explicit: “Honor thy father and thy mother that your days may be long.” Buddhism stresses solemn filial obligation and, particularly, the eternal and fathomless love of the mother, which even the most filially pious children would not be able to repay fully. Similarly, Islam and Hinduism stress the duty of children to love, respect, and support their parents.
Consequently, many caregivers may feel that parents are owed a debt of gratitude for the care they (the parents) have provided for their children, and that this debt can be repaid—at least in part—by adult children caring for parents in later life. The challenge for many caregivers is to fulfill filial obligations against the backdrop of many competing demands for time, energy, and financial resources. Further, some filial caregivers never feel they have done—or are doing—enough to reciprocate. Guilt and indebtedness are often mentioned by caregivers. A common refrain is, “I know I am doing everything I can for my mother, but somehow I still feel guilty” (Brody, 1985, p. 26). On this point, one is reminded of the following observation by the German sociologist, Georg Simmel:

Once we have received something good from another person, once he has preceded us with his action, we no longer can make up for it completely, no matter how much our own return gift or service may objectively or legally surpass his own. The reason is that his gift, because it was the first, has a voluntary character which no return gift can have. For, to return the benefit we are obliged ethically; we operate under a coercion which, though neither social nor legal but moral, is still a coercion. The first gift is given in full spontaneity; it has a freedom without any duty, even without the duty of gratitude... Only when we give first are we free, and this is the reason why, in the first gift, which is not occasioned by any gratitude, there is an opening up and flowering from the “virgin soil” of the soul, as it were, which cannot be matched by any subsequent gift, no matter how superior its content. (Simmel, 1950; cited in Blau, 1973, p. 47)

There are two ways for therapists to address the personal and family stresses that are created by demands that compete with filial obligations to elderly parents. The first is to help adult child caregivers accept the perceived obligation as fixed and devise strategies that reduce the difficulty or stress of carrying out this obligation. The second is to help caregivers explore how perceived filial obligation can be better understood, so that the moral demands that caregivers make on them can be adjusted. In order for this approach to be most effective, however, caregivers must gain a better understanding of the ethical reasons that permit them to expect less of themselves (Selig et al., 1991). Therapists must also help families to explore their own family values about caregiving. For example, if the family perceives a boundary around that
family that keeps them from receiving community services, a discussion about family boundaries might lead to the family gaining some community assistance. Family caregivers may also be motivated by compassion for the present vulnerability of the disabled relative. Many times families feel that serious dementia requires a caregiver that will treat the family member as a person rather than an object of professional concern. It is the great vulnerability of the patient which contributes to the family’s moral obligation to care for its members (Kapp, 1991; Pratt et al., 1987).

For caregivers that embrace a reciprocity view of their filial duties, the justified limits of those burdens may be bound by reflecting on the sacrifices that their parents made for the sake of benefits that the child accepted. Finally, ideas about love and friendship do not create duties of limitless sacrifice, because the ruling principle in loving relationships is mutuality of concern. It is thus by identifying and honoring the parent’s concern for the child’s welfare that the loving child can find limits of sacrifice for the parent (Selig et al., 1991).

CARING FOR OLDER FAMILY MEMBERS WITH DEMENTIA: EXAMPLES OF ETHICAL DILEMMAS

With the aging of the population, the number of older people with Alzheimer’s disease and related disorders is expected to increase from nearly two million Americans age 65 and over afflicted with the disease in 1995, to nearly three million by the year 2015 (General Accounting Office, 1998). The personal, social, and financial impacts of dementia caregiving have been well documented (Schulz, O’Brien, Bookwala, & Fleissner, 1995). Dementia caregivers are the focus of this portion of the article because the stresses associated with caregiving are presumably greater given the characteristic cognitive, behavioral, and affective losses associated with the progression of the disease. It is assumed family therapists are most likely to encounter family caregivers who are caring for loved ones with Alzheimer’s disease or a related dementia. Several ethical dilemmas encountered by dementia caregivers are briefly discussed: making decisions about humane care, patient autonomy and decision making, advanced planning, making decisions about medical care, including financing, and the decision to participate in research.
Humane care. Many families struggle over what constitutes humane care in the later stages of Alzheimer’s disease. For example, artificial feeding may be considered the ultimate indignity inflicted on a demented person who has no essential need for it. It would seem appropriate that basic natural satisfactions like eating and drinking should be maintained to the very end for the person with Alzheimer’s disease. “Thoughtful though painful reflection by Alzheimer patients and their caregivers on what constitutes humane care in the later stages of the disease may rescue many a victim from technical forms of care, and assure that compassion will be the primary concern” (McGovern, 1996, p. 196). When making these decisions, the balancing principle becomes perhaps the most helpful, as therapists help families balance the personal dignity of the aging family member with their overall well-being.

Yet another ethical dilemma comes when a family caregiver has the desire to keep the dementia victim at home, yet the dementia patient’s behavior becomes difficult to control (Walsh, 1999). In this case, the family must decide whether or not to place the person in an institution. Reluctance to do so comes from financial considerations as well as concerns about restricted autonomy for the individual. Another option is to ask doctors for psychotropic drugs or mechanical restraints in order to manage behavior. According to Kapp (1995), these kinds of restraints should be used as a last resort. Indeed, patients may have more autonomy in a nursing home than at home in restraints or drugged into a stupor. An ethical decision about restraints would demand the use of the least restraint possible to ensure safety, not simply the management of “bothersome” behavior (Turnbull, 1994). Again, the therapist and family can utilize the balancing principle in ensuring that the least restraint is used to ensure that there is the least amount of avoidable harm.

In addition, it is difficult for caregivers to know when incompetence exists. Indeed, a precise definition of such a state does not exist. This alone raises many ethical questions for caregivers as they struggle to help the patient maintain as much autonomy as possible (McGovern, 1996). For example, it is often a difficult decision for caregivers to know when the patient has reached a state of incompetence where institutionalization is necessary. Family caregivers may also be motivated by compassion for the present vulnerability of the disabled relative, a phenomenon that has been labeled the “power of dependency” (Callahan, 1985; as cited in Kapp, 1991, p. 7; also see Lustbader, 1991). Many times families feel that serious dementia requires a caregiver that will treat the family member as a person rather than an object of professional concern. It is the great vulnerability of the patient which
contributes to the families’ moral obligation to care for their members (Kapp, 1991; Pratt et al., 1987). This emphasis on compassion and dependency may make the decision to institutionalize a family member even more difficult. According to Turnbull (1994), a patient’s autonomy and individuality is restricted when they are institutionalized. The staff of the care center regulates almost all aspects of the patient’s life. Because health care, by its very nature, is paternalistic, this attitude cannot be totally avoided. However, family members should try to keep paternalism within proper bounds by carefully choosing an institution that offers the elderly family member dignity and humane care (Turnbull, 1994).

**Patient autonomy and the ability to make decisions.** Decision making capacity often varies for an individual over time and depends on environmental factors such as drugs taken, physical surroundings, methods of communication utilized, and other persons nearby. Most importantly, “decisional capacity depends upon the person’s functional ability to engage in a rational thinking process, and not necessarily whether formal or informal caregivers agree with the result or outcome of that thinking process” (Kapp, 1991, p. 18). As long as dementia patients retain their decision-making capabilities, they should be encouraged to make as many decisions as possible for present and future care. By allowing a patient to maintain these capabilities, the dignity and autonomy of the individual person is retained (McGovern, 1996). Once a patient is no longer able to make decisions or act for him or herself, the patient’s autonomy may be threatened by family members who are trying to protect the care receiver. For example, a family caregiver may hide a patient’s car keys so that he cannot drive, a caregiver may take away his candy so he cannot upset his blood sugar. Even more complicated are behavioral strategies (e.g., physical restraints, tranquilizers, locked doors) that some families may use to manage the patient longer in home care rather than transferring the client to an institutional setting (Kapp, 1991).

Many times family caregivers struggle to know how much decision making the dementia victim is able to do by him or herself. Often times the patient must rely on the family caregiver’s opinion. Indeed, “many cognitively impaired individuals may find it hard to make adequately competent decisions on their own, but may be made capable ‘enough’ with the support and assistance of family caregivers” (Kapp, 1995, p. 38). While caregivers may feel that the patient should make all the decisions so long as they are competent, it is important for the caregiver to be included in decision making. Since they will be carrying out
some of the plans and decisions during the later stages of dementia, their agreement and cooperation is a source of empowerment for enabling the dementia patient to carry out personal desires.

Dubler (1990) states that the dementia patient is the decisive moral agent possessing the most important moral agency or authority. Yet family caregivers in the home have moral claims that are weightier than in an institutional setting.

In home care, the interests of the patient-client in self-determination and autonomy must be balanced against (1) the ability of the patient, the family, or society to pay for what may be as much a lifestyle decision as a care decision; (2) the competing interests and obligations of family, neighbors, and community whose functioning and whose lives may be altered by the client’s being cared for in the home; (3) the scope of any publicly funded benefit and the contest for scarce resources. Because of the scarcity of trained personnel, expert supervisors, and resources, there are always more requests for home services than can be adequately met; (4) the caregivers’ misgivings about possible compromises of professional responsibility where care is delivered in a non-medical space beyond their supervision and control. (Dubler, 1990, p. 148)

Advanced planning. The literature regarding ethical dilemmas is in agreement that many dilemmas can be anticipated and planned for by dementia victims and their families while the patient is still mentally capable to be a part of the planning. To do so, families and professionals must work together to formulate, discuss, and document preferences about the conduct of future medical, financial, and personal matters (Kapp, 1991; Pratt et al., 1987; Turnbull, 1994). Indeed, Kapp (1991) states that “policymakers should encourage professional and popular education about such advance planning devices as durable powers of attorney, living trusts, and living wills” (p. 22). In the end, this can save families a great deal of heartache as they struggle to make ethical decisions for a loved one who is no longer able. Family therapists can spend time with their clients discussing and documenting the preferences of the care receiver and the family. Then the therapist should encourage the family to finalize these plans in a legal document.

Decisions such as future health care, participation in research, the choice of a nursing home, and the manner of care as death approaches should be addressed in therapy while the patient retains competency. Many of the ethical dilemmas faced by families in later stages of the dis-
ease could have been anticipated if the patient’s wishes had been determined prior to the onset of incompetence. While involving the dementia patient in making decisions, it is important to be sensitive enough to not deprive a person of the hope needed for day-to-day living. In general, our society is reluctant to discuss the types of care or medical interventions we would desire in the final stages of our lives. However, as much as possible should be discussed ahead of time. In the end, a mentally competent caregiver should determine the specific measures to be taken in medical care as death approaches (McGovern, 1996). It is important for families to decide who will be making those decisions prior to a crisis period. Advanced planning in decision making helps caregivers preserve the autonomy of the aging person, as they can then follow the wishes of the person. However, the issue of fidelity may come up if changes in condition occur such that the caregiver does not believe that he or she can follow those advanced planning wishes. Again, the balancing principle comes into play as caregivers attempt to make decisions that entail the least avoidable harm.

Medical decision making. "The main safeguard to assure that medical decisions are not overridden by family caregivers with their own agendas rests with the ethical commitment to the client’s autonomy exhibited by family caregivers and by the formal caregivers who are asked to carry out the family’s instructions" (Kapp, 1991, p. 18). When the client is no longer able to make decisions, family members are given the burden of making such decisions under the ethical presumption that families are most likely to know and follow the preferences of the client and most likely to make decisions in the client’s best interests. The decision about institutional care in the later stages of dementia is particularly difficult for family members who struggle to respect the wishes of their loved ones. The selection of health care facilities is important for guaranteeing humane surroundings. “Assurances that the final stages of one’s life will be spent in humane surroundings could add immeasurably to the quality of life enjoyed by a person in the early stages of the disease” (McGovern, 1996, p. 196).

Decisions about whether to initiate, continue, withhold, or withdraw life-sustaining medical treatments are not limited to institutional settings. Home care providers and family caregivers are confronted with these questions when end-of-life medical decisions are both made and carried out in the patient’s home (Kapp, 1995). At times, a family member must decide whether to withhold treatment. According to Turnbull (1994), the patient’s wishes should be respected in this case. Whether the patient’s requests were expressed while he or she was still compe-
tent or if the person is incompetent, the patient still has the right to refuse life-extending treatment. Although caregivers have an ethical duty not to force treatment against a patient's wishes, they also have the obligation of helping to educate the patient and helping him or her to work through the reasons for refusal. Morally, a patient is justified in refusing treatment: (a) if the treatment is useless, or (b) if it involves a grave burden for the patient or another.

Finally, it is helpful if the ethical dilemma of deciding when to discontinue life-sustaining treatment can be shared by multiple persons, such as family members and medical personnel. Indeed, there may be various points at which judgment about medical treatments will need to be made. Even when the care recipient made their wishes known prior to incompetence, decisions will need to be made about whether the next life-sustaining procedure is the one the person would have preferred to avoid. Relieving a primary caregiver from the duty of making a solo decision regarding this matter can increase the chance that a truly ethical decision will be made for the benefit of the patient (Dyck, 1984).

Health-care financing. The health-care needs of an elderly person could financially strain and even impoverish a caregiving family. How does a caregiver decide how much money to invest? It is difficult for adult children or spouses to decide how to balance the dementia patient's need for care with the needs of their own children and their own support in old age. Unfortunately, the system fails to provide the resources needed by dementia patients and family caregivers. Thus, this ethical dilemma is a common and stressful event in the lives of many family caregivers (Pratt et al., 1987).

Research participation. The decision to participate in research is another ethical question for many dementia patients and their families. Patients in early or middle stages of dementia should be able to make personal informed decisions concerning their participation in research. Competent persons can consent to participation in research situations once the patient is no longer able to make these decisions, so long as guarantees exist that research procedures do not violate individual dignity, expose the person to unnecessary risks, or greatly distress the patient.

The Use of Community Services

According to King, Collins, and Liken (1995), family caregivers of a loved one suffering with a dementing disease shoulder enormous responsibilities, yet these families have very low rates of community ser-
vice use. Indeed, the caregiving of a dementia patient causes high levels of physical and emotional strain. However, the usage of community services by caregivers of dementia patients has been consistently documented as being lower than that found in groups of family members caring for persons with physical disabilities (Collins, Stommel, King, & Given, 1991). Several values were found to be important to families that chose to undertake caregiving independently from outside services. These families felt a sense of family obligation and viewed boundaries around the family system that kept them from obtaining outside help. They also believed that families are the owners of their own difficulties, and others should not be burdened. Family caregivers felt a need for control over caregiving so that they could protect the vulnerable member of the family. Finally, a view of reciprocity made family caregivers feel obligated to those who helped them.

As therapists, it is important to guide families toward long-term planning of service options and living arrangements for loved ones. Often, caregivers struggle with gaining community support because they do not have accurate information available to make informed choices. Because of the increased burden of maintaining care for a dementia patient, they spend less time gathering information. Therapists should refer caregiving families to social service providers that have the knowledge to assist them in accessing appropriate services. “In addition, they usually have professional contacts that are a source of information about the quality of facilities or services that generally is not available to family caregivers” (Roberto, 1994, p. 57). It is a therapist’s responsibility to help a caregiving family find out what care options are available to them. This will aid the family in making more responsible, ethical decisions.

**FAMILY THERAPY AND CAREGIVING FOR DEMENTIA PATIENTS**

The family therapist working with caregiving families should explore ethical issues and values with clients. It is important to remember that no clear ethical code exists to guide the ethical decisions of caregivers and their families. Thus, therapists must be willing to recognize individual differences and pluralism in caregiving families (Selig et al., 1991). Family caregivers may differ in the value they place on the person with advanced dementia. For many caregivers, caring for the body of the patient is a metaphor for taking care of the mind and the spirit of
the whole person. Another caregiver, however, might emphasize the loss of personhood and identity of the patient as a way to diminish guilt and frustration in him or herself. Sometimes this may result in reduced stress and produce more effective care. However, therapists need to be careful when encouraging this view because seeing the dementia victim as less than a person can quickly lead to their total devaluation as nonpersons. "The status of nonperson is perilous because such a being does not enjoy the privileges and rights of human beings and, as such, is easily discounted" (McGovern, 1996, p. 199). Therapists can encourage humane care by helping caregivers to have values of compassion, honesty, and humility (McGovern, 1996).

Faced with a patient's disintegration, many family caregivers need help finding what their goals for care should be. The therapist can help the caregiver define these goals. Possible suggestions, according to Turnbull (1994), are to assist the family and friends in celebrating the individual personhood and in grieving its passing and to help make each moment for the patient as gentle and kind as it can be. One possible therapy technique could consist of a ritual marking the passage of a person from the semi-competent stage to the demented stage (possibly from the home to the nursing home). Such a ritual would express a belief in the dignity of the person, would give thanks for the blessings of the person's life with special reference to the meaningful times enjoyed since the onset of the disease, and would contain a commitment to the care of the person in the new surroundings. This ritual could help ease the burden of institutionalization that is often wrought with guilt and other negative feelings (McGovern, 1996).

Hanna (1997) also discusses the use of rituals in working with families with older adults, particularly to help facilitate transitions. Hanna notes that rituals can be helpful in facilitating changes in hierarchy and the transfer of power, and can be helpful in building social support in cases of isolation. Finally, rituals can help in mourning and grief (Hanna, 1997). Imber-Black (1999) can also serve as a resource for designing rituals within the context of the family life cycle—she provides guidelines for rituals to help with identity development, transitions, and healing.

Family therapists need to encourage caregivers to take care of themselves, especially in the middle to later stages of the disease when the patient's demands often exhaust time for the caregiver to take care of their own health and mental well-being. Caregivers will be better able to take care of themselves if they are empowered to seek help through adult day care programs or if they are able to attend support groups. It is
important to discuss methods of coping with caregiving clients so that they feel encouraged to take care of their own needs without feeling guilty (Ballard, 1989). Therapists should encourage family members to share responsibility for care. Even when one member may provide daily care, other family members can assist by “taking over some of the tasks that use to be performed by the person with Alzheimer’s disease, gathering information about care options, and providing short-term respite for the primary caregiver” (Roberto, 1994, p. 58). Solutions to help family members share responsibilities should be explored in therapy. Furthermore, it will also be important for professionals to help family members explore their beliefs about justice. Theories about justice may need to be reinterpreted so that family caregivers can take their own needs into account, helping them to feel better about making decisions to relinquish caregiving tasks when the burden becomes too great (Hasselkus, 1991). By exploring these issues, clients will be given the permission to interpret ethical principles and can be helped to set appropriate boundaries that will enable them to responsibly limit the caregiving role when doing so is ethically defensible and important for the caregiver (Selig et al., 1991).

Family therapists who are knowledgeable about the ethical dilemmas faced by family caregivers can encourage caregivers to spend time asking questions and stating their own opinions to health care providers. Caregivers often make modifications to treatments prescribed by health care professionals because those professionals did not take the time to collaborate on a plan with clients (Hasselkus, 1991). A constructivist view of family therapy would require family therapists to help family caregivers understand the benefits of finding a collaborative health care provider. Being able to follow a collaborative plan would require less ethical decision making on the family’s part because the caregiver would not need to choose between the treatment plan of the health care provider and their own method of following through on that treatment plan. Shields and Wynne (1997) stress the importance of looking at strengths and health-enhancing factors as well as vulnerability and risk in working with aging families. It may be important for the family therapist working with the aging family to develop contacts that support collaborative and strengths-based medical care in order to help families make such connections.

In discussing the ethical struggles of family members, it is necessary for therapists to keep a systemic view of the family in mind. Many medical clinicians tend to be problem oriented. By focusing on family problems caused by the dementia patient, clinicians tend to offer ad-
service based on experience and judgment of what has worked for other families. According to Harrison (1993), "a better alternative would be a person-oriented approach, which would also identify the positive experiences of the patient. Rather than focusing entirely on problems and deficits, therapists would also identify positive behaviors, abilities, values and experiences. Such an approach would enable health care providers to have a deeper understanding of their patients as persons" (p. 437). Certainly, these ideas are consistent with a solution-focused approach to family therapy (see Bonjean, 1997, for a discussion of solution-focused family therapy with the aging family). By looking at the strengths of each family member, including the dementia patient, solutions that benefit the individual family's experience can be explored within family therapy.

CONCLUSION

Families with elderly members experiencing illness or dementia face a number of ethical dilemmas in their caregiving. Family therapists are in a unique position to help families make ethically sound decisions as they struggle with caregiving. Family members and family therapists must attend to issues of autonomy, beneficence and nonmaleficence, truth-telling, justice, and fidelity/reciprocity/filial obligation, and must balance all of these issues in order to produce the least amount of avoidable harm, and to make decisions that could be considered universal. Families may struggle with many health care and caregiving decisions that have the potential to reduce autonomy but at the same time increase physical well-being. Family therapists should explore these ethical issues with families in their care, and are also obligated to have the knowledge and competence to help families in these areas. Family therapists can help families explore each of these ethical issues in their ongoing decision-making processes in many ways, and can also follow guidelines for care that can help promote healthy growth and development in this latter stage of the family life-cycle.

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