Ethical Dilemmas in Family Caregiving for the Elderly: Implications for Occupational Therapy

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An analysis of 60 ethnographic interviews with family caregivers for frail community-based elderly persons has suggested that ethical dilemmas are an important organizing framework for family caregiving. The present paper explores this conjecture as it relates to the practice of occupational therapy with older clients and their families. Major themes of ethical dilemmas in family caregiving, as derived from the ethnographic data, are described. Verbatim interview data are presented to illustrate the close ties between caregiving activity and the caregiver’s ethical convictions. Occupational therapists are encouraged to seek understanding of their clients’ ethical beliefs in order to maximize the potential for a therapeutic relationship built on mutual understanding and partnership.

In the occupational therapy literature, ethics has been largely addressed from the professional’s perspective. The Occupational Therapy Code of Ethics (American Occupational Therapy Association [AOTA], 1988) provides guidelines with which therapists are to promote and maintain high standards of ethical behavior related to the welfare of clients, level of professional competence, professional relationships, and compliance with laws and regulations. Ethical dilemmas of practice are described as stemming from therapists’ decisions about which type of treatment would be most effective, from constraints imposed by the work setting, and from disagreements between therapists and other professionals and between therapists and their clients about treatment choices and goals (Cassidy, 1988; Hansen, 1988; Neuhaus, 1988).

The client’s engagement in the treatment process and respect for the principle of the client’s autonomy in practice is acknowledged in the occupational therapy literature. For example, Kyler-Hutchison (1988) addressed the participatory role of the patient in the treatment process and the ethics underlying informed consent. Rogers (1983) argued strongly for the need to respect the individual client’s values and goals in treatment planning. “Ethical decision making requires the therapist to search for an understanding of the patient’s life rather than to make an evaluation of it” (p. 608). Watts, Kielhofner, Bauer, Gregory, and Valentine (1986), in devising their long-term-care screening tool, drew upon the Model of Human Occupation (Kielhofner & Burke, 1980) to include clients’ values and interests. These concepts, however, may be extensions of the professional code of ethics in that they continue to address ethics from the professional’s viewpoint. They do not, however, address ethics from the client’s viewpoint.

This paper presents findings from an ethnographic study of family members who were caring for frail older people in the community. Successive levels of data analysis have yielded findings related to the meaning of the caregiving experience and activity in family caregiving (Hasselkus, 1988, 1989). Themes of ethical dilemmas, that is, problem situations that represent conflict between ethical principles, are discussed, and their relationships to the practice of occupational therapy are explored. I propose a need for therapists who work with family members to examine the ethical dilemmas of the caregiving experience and for the professional and the family caregiver to work together toward shared ethical decision making.

The Ethnographic Study

Sixty ethnographic interviews were conducted over a 9-month period with 15 family caregivers of frail elderly persons living in the community. The purpose of the study was to gain understanding of the meaning of the family caregiving experience with the hope that greater...
understanding would assist health professionals in working together with caregivers. All caregivers were adults (ages ranged from 54 to 82 years) who were related by blood or by marriage to the care receivers. Length of time in caregiving varied from 1 to 15 years. Fourteen caregivers were women (8 wives, 1 sister, 1 daughter-in-law, 4 daughters), and 1 was a man (husband). The care receivers were all 60 years of age or older, lived in the community in single-family dwellings or apartments, and required personal assistance, instrumental assistance, or both every day.

The ethnographic interview was a nonstructured interview based on Spradley's (1979) Developmental Research Sequence. I conducted the interviews in the homes of the caregivers and audiotaped and transcribed all of the interviews. Each caregiver was interviewed four times; planning for each interview was based on data from the previous interview. The initial interviews progressed from global questions (e.g., “Can you begin by telling me what your day is like?”) to a more focused delineation of the caregiving experience (e.g., “Could you tell me more about what you do when you’re trying to get her to eat?”). During the third and fourth interviews, card-sorting activities were used to gain more elaborate descriptions of each identified caregiving domain and to gain further understanding of its meanings to the caregiver (Spradley, 1979).

Qualitative data analysis is an iterative process during which the researcher works back and forth between the thick descriptive verbatim data and emerging abstract themes and patterns (Dobbert, 1982; Goetz & LeCompte, 1981; Miles, 1983). Early analysis of the caregiving interview data led to the use of Schön’s (1983) concept of the reflective practitioner as the organizing framework for the data and problem situations as the units of analysis (Hasselkus, 1988). Verbatim data from the 60 interviews were coded into 25 problem situations and subsequently organized into text fields of naming, framing, action, and judgment (Schön's model) (Pra/Term Software, 1985). With the database thus organized, the data could then be analyzed for themes of meaning and activity in caregiving.

As of this writing, three levels of analysis have been completed (see Figure 1): (a) themes of meaning across caregivers, (b) goals of caregiving activity, and (c) ethical dilemmas of caregiving. Qualitative data analysis is a spiral-like process. Each analytical foray into the data results in new understandings and a restructuring, thereby urging the researcher on to the next level of analysis. Geertz (1973) stated, “Studies do build on other studies, not in the sense that they take up where the others leave off, but in the sense that, better informed and better conceptualized, they plunge more deeply into the same things” (p. 25). As depicted in Figure 1, the analyses of this study have plunged deeper and deeper into these same data, in accord with the naturalistic research paradigm. This paper provides a summary of the results of the final level of analysis and explores the implications of ethical dilemmas for occupational therapy practice.

Ethical Dilemmas in Caregiving

I've got my ails. too. I have a rapid heart, and it scares the life out of me. Sometimes I can feel it coming on and if I change my position or take an extra heart pill it corrects it quite soon, but the last couple times it's lasted all day. No doctor gets excited about it, but of course I get concerned about it and then that doesn't help. Yesterday, I had just about had it, wondered how long I could do this, I am so tired. I think I'm just worn out. But this is the way I want it. I am so determined that my mother not have to go to a nursing home. I guess I'll do anything that's possible to keep her at home. (Mary [Caregiver 10])

Mary is a 72-year-old retired administrative secretary who shares her apartment with her 94-year-old mother.

Figure 1. Levels of analysis of ethnographic caregiver data. The three levels depict the process of plunging deeper and deeper into the data, with each analysis resulting in new insights and understandings.

The American Journal of Occupational Therapy

207

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Mary and her mother have lived together for almost 9 years, since the death of Mary's father. Mary's mother has had a series of strokes. When they first lived together, Mary's mother was able to walk around the apartment with a walker, could carry on a conversation, and was able to go places in the car. Gradually, as her mother became less and less mobile and required more lifting, Mary began to call on friends to help and eventually hired personnel from a medical pool for the weekends. At the time of the study, Mary's mother could no longer walk, needed the assistance of two people to stand and move from the bed to the chair, and was dependent in dressing, toileting, personal hygiene, and eating. Additionally, Mary stated, "We could visit before, but now she spends most of her time with her eyes closed and is not too responsive—She doesn't talk much, you know. She's no company."

During the interviews, Mary described a complicated weekly schedule of volunteers and paid helpers who assist with the daily tasks of transferring and toileting her mother and with the upkeep of the apartment:

I really don’t have any time for myself. When I get out I really am so weary that I wonder why I make the effort. I'm a church person but I'm afraid I'm not getting there anymore. I think what I miss is not hearing good music or seeing a good show. Sometimes it gets so and when that happens it's not good—I don’t want to get to the point where I'll say I can’t do it anymore.

The above data sample, taken from the interviews with Caregiver 10, illustrates the derivation of the primary goals of activity in family caregiving for the elderly: getting things done, maintaining health and well-being for the care receiver, and maintaining health and well-being for the caregiver. The theme of ethical dilemmas emerged from the analysis of these goals of caregiving activity. The family caregivers were caught in an ongoing tug-of-war between competing goals in caregiving.

Ethical dilemmas occur in problem situations for which there are no clear right or wrong answers. Judgments regarding right and wrong are guided by four basic ethical principles: autonomy (the right of the individual to self-determination), beneficence and nonmaleficence (the promotion of good and absence of harm), fidelity (truthfulness and maintenance of confidences), and justice (the act of doing the most good for the most people) (Francesco, 1983; Kyler-Hutchison, 1988). Options that exist in problem situations may be mutually exclusive and lead to conflict within or between the basic ethical principles. The result is an ethical dilemma in which all options seem equally unsatisfactory.

In the data sample above, Mary is struggling to maintain the principle of beneficence for both her mother and herself. Because of her own health problems (i.e., the "rapid heart"), her ability to maintain the well-being of both herself ("I am so tired") and her mother ("I am so determined that my mother not have to go to a nursing home") are clearly perceived to be in jeopardy. Mary is in a situation for which, to her, there are no clear right or wrong answers; she strives desperately to uphold her ethical principles of beneficence and justice.

In the analysis of the ethnographic data for ethical dilemmas, I returned to the verbatim interview data as it was organized into problem situations. Data that represented dilemmas were identified and coded as either ethical or nonethical. Nonethical dilemmas were those that were not derived from a sense of right or wrong. Nonethical themes included learning how to do something (e.g., submitting bills to Medicare), making a process easier (e.g., arranging for at-home haircuts for the care receiver), and finding and hiring people to do odd jobs (e.g., painting, snow shoveling). Five themes of ethical dilemmas were generated from the data: (a) fear of violating an ethical principle; (b) a sense of current violation of an ethical principle; (c) negotiation within a principle; (d) negotiation between principles; and (e) one principle overruling another.

The caregivers' most prominent fear of violation was that of violating the principle of beneficence for the care receiver. Mary's fear of someday needing to place her mother in a nursing home is an example of this anticipatory fear. "I pray every night that the Lord will let me take care of her."

Expressions of the second ethical theme, that is, a sense of current violation of an ethical principle, were largely violations of the principle of justice. Mary came close to this when she said, "I really don’t have any time for myself," although she quickly followed the statement with the disclaimer, "but I'm not complaining, I'm not complaining." Other caregivers made statements such as "I resent this, I really resent this" (Caregiver 15) or "I feel like a prisoner" (Caregiver 13). Anxiety was expressed by the caregivers when they perceived themselves to be violating beneficence to the care receiver:

I think the feeding is the hardest part right now, it really is. I'm sorry to say my patience runs out and sometimes I just give up. I wish I wouldn't understand why she doesn't open her mouth and why she doesn't swallow. (Mary)

Negotiation within the principle of beneficence toward the care receiver was the most prominent component of the third ethical theme. As illustrated above, this was derived in part from the tension between competing goals of health and well-being for the caregiver and the care receiver. As Mary stated regarding lifting her mother from the bed to the commode, "I can't, I shouldn't do it, and I don't do it anymore... except in an emergency. But I try not to do it because I can tell [from] my own body that I shouldn't do any lifting." For some caregivers, the importance of getting things done competed with maintaining beneficence for the care receiver and led to compromised strategies: "If I need to go out to get something done, I put him in bed. I wouldn't leave him in the wheel-
Ethical Dilemmas Relevant to Occupational Therapy

The Occupational Therapy Code of Ethics (AOTA, 1988) is an example of normative professional ethics. "Normative ethics does not have as its task to discover what we actually value, but rather what we ought to value, or what we should do. It attempts to define both the morally acceptable ends of human actions, as well as the means by which these ends can be ethically pursued" (O'Donohue, Fisher, & Krasner, 1987, p. 388). The code of ethics of occupational therapy does exactly this—It attempts to define the ethical guidelines for the therapeutic process (i.e., the means) and the therapeutic outcome (i.e., the ends of human actions). It provides guidelines for what therapists ought to value and what they ought to do.

Descriptive ethics, on the other hand, is empirical; it seeks to answer questions about what people actually value (as opposed to what they ought to value), what standards people actually use to judge their acts, and what people condemn as unethical (O'Donohue et al., 1987). Descriptive ethics is the ethics of everyday life. It has been suggested that little is known regarding the descriptive ethics of the elderly or of long-term care (Holland, 1988; O'Donohue et al., 1987).

Data from the present ethnographic study of family caregiving for the community-based elderly reveal the descriptive ethics of the everyday life of caregiving. Whereas health professionals are likely to have an explicit professional code of ethics to guide their practice, informal family caregivers draw on implicit ethical convictions for their practice. These convictions are revealed in the descriptive ethics of each caregiver. The way caregivers defined the problems of caregiving, their understanding of the care options available, and their judgments about what ought to be done were all guided by this underlying ethical code. As Mary stated, "I am so determined that my mother not have to go to a nursing home, I guess I'll do anything that's possible to keep her at home."

The principle of justice in family caregiving appears to be a complicated concept that leads many caregivers to both tolerate and resent its violation. Veatch (1981) discussed various theories of justice, not all of which are compatible. Herein lies the family caregiver's dilemma. The utilitarian theory of justice is represented in the belief in serving the greatest number with the greatest good. It focuses on net, or aggregate, benefits. Achieving net benefits for the whole family as a moral community would be the guiding ethical principle in family caregiving, and the caregiver would feel bound to consider his or her own needs and well-being in equal portion to the care receiver's, because they both contribute to this aggregate benefit. (If the caregiver is worn out, this is a potential threat to the aggregate good of the family, and the situation must be reevaluated to bring about a better balance.) Some-what at odds with the utilitarian theory of justice is the maximin theory (Veatch, 1981), in which the person seeks to maximize not the net benefit of a moral community, but those members of society who are the most burdened and least advantaged. In the maximin theory, "the fair thing to do in a society is to arrange social institutions and practices so as to improve the lot of the least well off" (pp. 262–265).

The family caregivers in this study seemed to be intuitively aware of both interpretations of justice, but many felt a stronger obligation toward upholding the maximin theory than the utilitarian theory. The bitter statement, "It's always him first and me second" (Caregiver 2) illustrates a caregiver's sense of upholding the maximin theory of justice toward the least advantaged but violating the utilitarian theory of aggregate justice. The caregiver may assume that the maximin theory of justice is indeed justice and that there are no other legitimate dimensions to this ethical principle. His or her underlying sense of resentment about caregiving may lead only to feelings of guilt about that resentment and an even stron-
ger commitment to focus all resources toward the benefit of the care receiver. A vicious, closed cycle would result.

Alternatively, at least one caregiver seemed to view justice in caregiving more from the utilitarian perspective. Caregiver 1’s increased sense of aggregate justice was reflected in her statement, “Sometimes I think, ‘Now here I am stuck taking care of him.’ But we get along better now than we ever did before. He wouldn’t talk back now. He always says, ‘Whatever you say, whatever you say’.”

In his discussion of the limits of morality in family caregiving, Callahan (1988) stated, “That we are called upon to respond to someone else’s vulnerability means that, in turn, we become vulnerable also. Something is going to be taken from us as the ineluctable price of self-giving, perhaps something as central as our hopes and our identity” (p. 327). Exploration of the caregiver’s beliefs about justice may help reveal his or her implicit ethical code to the therapist and the caregiver. The therapist could then work toward reinterpretation of that code and compatibility with the therapist’s code when recommending caregiving actions. Perhaps in this way we can help transform the caregiving responsibilities from “a stark and unpalatable moral demand to a satisfying moral vocation” (Callahan, 1988, p. 327).

The principle of beneficence, that is, do good and do no harm, appeared to be the most overriding and powerful ethical principle of family caregiving. The caregivers’ sense of commitment to this ethical principle was axiomatic. For the caregivers, however, the principle of beneficence seemed to be conceptually reversed, that is, first, do no harm, and then, do good. The prevention of the care receiver’s falling, getting bed sores, choking on food, getting an infection, being constipated, and having to go to a nursing home were guiding maxims of care. “If he’d fall and break something, then I couldn’t take care of him anymore and he’d have to go to a nursing home” (Caregiver 13). Perceptions of what might constitute harm were sometimes based on inaccurate or incomplete information and fears regarding lack of expertise. Caregiver 6 described her note taking of the nurse’s instructions when her husband was about to be discharged: “I would jot down step for step what I was supposed to do so I didn’t make a mistake and kill him or do whatever it would do to him.” The fears of Caregiver 5 when her husband first came home from the hospital seemed to stem from cautionary instructions from a therapist: “When he first came home, I think I was nervous and thought I was going to maybe even pull his arm out of the socket, you know, in trying to get him up.” Perhaps the maxim to do no harm is especially strong during the early or learning phases of caregiving.

Time spent in sensitive education of the caregiver by health professionals, with special attentiveness to the caregiver’s fears and beliefs about what might be harmful, might appropriately allay some of the focus on doing no harm so that an equal amount of energy could be directed toward carrying out treatment regimens to do good. The caregiver who lived by the maxim, “When he gets up, I get up,” was clearly expending considerable energy on doing no harm; one wonders how much energy was left for carrying out rehabilitative activities, for attending to her own health and well-being, and for getting things done.

A large body of interview data reflected these negotiations within the principle of beneficence regarding the weighing of harm and good. Though not systematically elicited, the caregivers’ data included many descriptions of interactions with health professionals in the hospital and home. Prescriptions by professionals regarding home treatment regimens were subjected to scrutiny regarding their effect on the three goals of caregiving and their fit with the caregiver’s view of beneficence for the care receiver:

The therapist said to always turn the wheelchair and put it back against the wall to get him up from bed, but I have to move the right side every time I do that. So I just get him under the left arm and kind of whirl him right around into the wheelchair. It’s a lot easier and a lot faster, and it seems like I can get him up a lot better this way. (Caregiver 1)

In this instance, the therapist’s method had interfered significantly with the caregiver’s ability to get things done, whereas her own method did not. Additionally, the caregiver viewed her alternative transfer method as no threat to the beneficence of the care receiver (the therapist might disagree). This latter point is of particular interest. The caregiver data provided many examples of modifications that caregivers had made in treatment regimens prescribed by health professionals. These care modifications all upheld, in the caregiver’s view, the axioms of beneficence. They seemed to represent a different way of maintaining beneficence while also helping to achieve the other goals of caregiving, that is, getting things done and maintaining the caregiver’s own health and well-being. How much better it might have been if the therapist above had incorporated the caregiver’s perspective into the transfer instructions so that the final choice of method represented a collaborative decision, satisfactory to both.

One other striking difference between therapists’ and caregivers’ perspectives is suggested in the data. Occupational therapists place a high value on independence and autonomy. Respect for a client’s autonomy is part of our code of ethics, and independent function is the hallmark goal of rehabilitation. Family caregivers do not appear to share this view:

They told me to let him do some of that [washing up and dressing] by himself, but he’s so slow and he gets up so late it’d be forever—He’d never get his breakfast if I waited for him to get washed and everything. So I like to do it myself and I [do] a better job—use soap and things. (Caregiver 1)

Once again, the therapist’s instructions have been modified; from the caregiver’s perspective, beneficence to the
care receiver has been maintained (even enhanced), and the other goals of the caregiver’s activity have also been achieved. The therapist’s valuing and inclusion of the client’s autonomy and independence in activities of daily living seems to be entirely missing in the caregiver’s deliberations about the good and harm of the self-care routine. In incidents such as this, issues that were ethical to the therapist have been reduced to procedural issues by the family caregiver. (This is similar to what Reid [1979] stated about professionals, that is, that they often respond to uncertain moral problems by reducing them to questions about what to do and how to do it.)

Thus, the meaning of autonomy in long-term care continues to be an enigma (Collopy, 1988; Hofland, 1988; Kane, 1988). In the caregiving data, beneficence was the preeminent principle on which judgments about what should be done were based, and the promotion of the care receiver’s autonomy was only rarely concomitant to the caregiver’s view of beneficence. But, as Collopy stated, “Beneficent intentions can breed unchecked authority over those who are served or helped” (p. 10). Occupational therapists’ awareness of the possible disparity between their own views and the caregiver’s view of autonomy might be the first step toward a more mutually agreeable treatment outcome.

In occupational therapy, considerable research energy has been directed toward the study of clinical reasoning by health professionals (Cohn, 1989; Gillette & Mattingly, 1987; Parham, 1987; Rogers, 1983; Rogers & Masagatani, 1982). Pellegrino (1979) stated that the process of clinical reasoning includes three generic questions: (a) What can be wrong? (b) What can be done? and (c) What should be done? The final question is the “most prickly” (p. 182). The closer a person is to the end of the clinical reasoning process, that is, the right action, the less useful is the scientific contribution to the process and the more important is the dialectic contribution of ethics and art. In other words, once the facts are in, final judgment regarding what should be done depends on how those facts are filtered through the values and ethical codes of the therapist–practitioner.

Family caregivers for older people in the community are also practitioners involved in clinical judgment (Hasselkus, 1988, 1989). They, too, ask the generic questions regarding what is wrong, what can be done, and what should be done. “For the family member, then, as well as for the professional, there is seldom one right answer, and reasoning is adjusted as new information and experience are accumulated. Actions and judgments result from the caregiver’s applying his or her own code of ethics to caregiving practices” (Hasselkus, 1989, p. 653).

Freedman (1978) argued that professional morality and ordinary morality are distinct from each other and that they are organized in such a way as to be in conflict with each other. “Professional morality places professional values at a higher position in the ethical hierarchy” (p. 10). At the same time, however, the two distinct moralities are not separate in that “in the realm of the decisive oughts, professional and nonprofessional moralities intermingle in the process of decision-making” (p. 10).

Thus, in the context of the family caregiver and the occupational therapist, the caregiver’s ordinary ethics and the therapist’s professional code of ethics are, paradoxically, both distinct and unified. In the decision-making stage of the clinical reasoning process, when decisions are being made about what should be done, professional ethics and ordinary ethics must intermingle. The therapist’s role becomes one of assisting clients “in discerning and clarifying their values” and helping them “in examining available options in light of their values” (Gadow, 1981, p. 137).

Data from the present ethnographic study provide insights into the ethical filter through which caregivers screen the facts derived from the first two questions of clinical reasoning and then make judgments and decisions about the final question, that is, “What should be done?” Because the process of clinical judgment is dialectic, especially in the final stages, it is vital that we understand as best we can the values and ethical themes that our clients bring to these deliberations. It seems likely that this principle of shared ethical decision making in occupational therapy is applicable to other therapeutic relationships, for example, with parents of pediatric clients and with adult clients themselves as they apply their own code of ethics to their self-care. Otherwise, the therapeutic actions that we propose will be ignored or quickly modified by each client to better fit his or her unique social context and ethical framework.

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References


The American Journal of Occupational Therapy

211
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