
Decision-making for persons with cognitive impairment and their family caregivers

Lynn Friss Feinberg, MSW
Carol J. Whitlatch, PhD

Abstract

Despite the large number of persons affected by cognitive impairment, very little is known about how they and their families make choices and decisions about everyday living and long-term care. Moreover, few studies have examined the concept of consumer direction, particularly the ability of cognitively impaired persons to delegate decision-making to other persons. This study explored decision-making through personal interviews with 51 respondent pairs, or dyads (i.e., the cognitively impaired person and the family caregiver). Results suggest that persons with mild to moderate cognitive impairment are able to answer questions about their preferences for daily care and to choose a person, usually a spouse or adult child, to make a variety of decisions on their behalf. By recognizing both voices—those of the care receiver and the family caregiver—we can enhance future research and practice, foster the development of consumer direction in long-term care, and advance public policy to support caregiving families.

Key words: Alzheimer's disease, dementia, caregivers, consumer direction, decision-making

Background

Families and informal caregivers play a central role in both the decision making and delivery of long-term care for the estimated 13 to 16 million Americans with adult-onset cognitive impairment (e.g., Alzheimer's disease, stroke, Parkinson's disease, and other dementias).¹ Despite the large number of persons affected by cognitive impairment, we know very little about how their families make choices and decisions about their everyday living.

Lynn Friss Feinberg, MSW, Family Caregiver Alliance, San Francisco, California.

Carol J. Whitlatch, PhD, The Benjamin Rose Institute, Cleveland, Ohio.

According to an AARP survey² of cognitively intact older persons, more than two in three (67 percent) said they had not talked with their baby boomer-aged children about independent living issues, although they thought it would be easy (24 percent) or very easy (56 percent) to do so. Kane³ describes the situation:

In long-term care, both the older person who perceives a need for help and family members who may decide to provide care have decisions to make. One decides whether to accept care, the other whether to give it. Each is influenced by the other, sometimes by explicit advice and sometimes by influences about what is important to the other (p. 89).

This study examines decision-making by community-dwelling persons with cognitive impairment and their family caregivers. The family's role in home or community-based care is complex, and frequently, the family becomes both "decision maker" and "service provider." Moreover, empowering the person with cognitive impairment to make decisions can often imply empowering his or her family support system.⁴ Past research suggests that most, but not all, adults want a family member to make health care decisions for them if they are unable to decide for themselves.^{5,6} Some care receivers, however, have no family, while others have families who are unable or unwilling to assume the decision-making role.⁷ Nevertheless, few individuals make decisions entirely on their own. It is important to understand the role of families and other informal caregivers in the decision-making process when a family member is cognitively impaired.⁸

The trend toward earlier diagnosis of dementia has created an opportunity for earlier and more consistent involvement in everyday care decisions by both the person with cognitive impairment and the family caregiver. As stated by Kapp:⁹

[T]he process of sharing power through frank and concrete discussions between an older person and the family, which take place while the individual is still decisionally capable, should lead to better, more accurate surrogate decision-making if it subsequently becomes necessary as a result of the individual's mental decline. Shared decision-making affords a chance for continued dialogue that informs future proxies more fully about the individual's values and preferences concerning later decisions (p. 785).

A growing number of families are affected by the economic and emotional costs of providing care over the long term. At the same time, people with cognitive and physical disabilities are making strides toward greater autonomy through consumer-directed care. The concept of consumer direction in home and community-based care is premised on the key elements of choice and control, and the philosophy that informed consumers make choices about the services they receive.¹⁰ Thus, the notion of who is the "consumer" in dementia care is an important policy and practice issue for those designing and testing long-term care service delivery systems and interventions for persons with cognitive impairment and their caregivers.

In recent years, there has been a proliferation of research on health care preferences and decision-making. This research, however, has focused largely on consumer direction regarding "end-of-life" medical care in acute settings. In contrast, few studies have examined day-to-day care preferences and decision-making. Yet, some of the most difficult conflicts for persons with cognitive impairment and their families arise in "everyday" care situations at home and in community-based settings, including financial strain about paying for needed care. For example, tremendous family conflict can arise over a person's declining abilities to carry out such daily activities as managing money, driving, or cooking. Deciding when to bathe, what to wear, whether to purchase and use support services (*e.g.*, in-home care or adult day services), or when to accept care from family members, are other examples of everyday care situations. For persons with cognitive impairments, decisions and preferences about everyday care become increasingly difficult to communicate as their disease progresses and their cognitive and functional abilities deteriorate.

The larger research project from which the present study is drawn addressed a wider range of topics related to choice and decision-making in everyday care for persons with cognitive impairment and their family caregivers.^{11,12} In the present study, we examine the ability of persons with cognitive impairment to answer questions about daily care preferences and their involvement in decision-making. The research focuses on three basic questions:

1. Are persons with mild to moderate cognitive impairment able to answer questions about their preferences for their own daily care?
2. From whom do cognitively impaired persons prefer to receive help in their activities of daily living (ADLs), and do the family caregivers know their relative's preferences?
3. How involved are persons with cognitive impairment in making decisions about daily living?

Methods

The sample consisted of 51 respondent pairs or dyads. Individuals with cognitive impairment (N = 51) and their family caregivers (N = 51) were recruited, using client lists from the Family Caregiver Alliance (FCA) in the San Francisco Bay Area and through additional community outreach. In-person interviews with the respondent dyads occurred between July 1998 and April 1999. Entry criteria required that the person with cognitive impairment (1) had a confirmed physician's diagnosis of adult-onset brain disease/disorder; (2) lived at home (*i.e.*, in the community rather than in an institutional setting); and (3) was mildly to moderately cognitively impaired (*i.e.*, Mini-Mental State Examination (MMSE)¹³ score between 13 and 26). To be eligible, the family caregiver had to be (1) the spouse or adult child of the person with cognitive impairment; and (2) the primary caregiver.

Three interviews were conducted per dyad. The interviewing sequence and process required that the care receiver be interviewed first to determine final eligibility based on the MMSE score. Within one week, the family caregiver was interviewed, and the care receiver was interviewed a second time to ensure the reliability and stability of responses¹⁴ and to answer additional questions.¹¹

Procedures

Prospective participants were sent a letter describing the study and were screened by phone to determine preliminary eligibility. Once all eligibility criteria were met, separate in-person interviews were conducted with the caregiver and care receiver, generally in the respondents' homes. (Detailed information about research procedures is provided in a previous study by the authors.¹¹)

Measures

Results are based on measuring four areas drawn from the larger study:

1. Decision-making for personal care;
2. Attitudes toward receiving informal/formal assistance;
3. Caregiver financial strain; and
4. The decision control inventory.

Decision-making for personal care. This measure was adapted from previous studies^{6,15} with additional items developed for this study. Questions were asked of both the care receiver and the caregiver, to identify whom the care receiver preferred to make his or her decisions in six decision areas in the event they could not do so themselves. Items assessed included the dynamics of decision-making about daily care as well as potential nursing home care. The first question was directed to the care receiver, and a second, similar question to the caregiver:

- If there comes a time when you are unable to make decisions for yourself about your health care, who would you want to make these decisions for you? (For each decision area—health care, finances, personal care, social activities, living arrangements, and possible nursing home placement—care receivers were asked to identify the preferred decision-maker and his or her relationship to them.)
- If there comes a time when your relative is no longer able to make health care decisions for him- or herself, whom do you think he or she would want to make these decisions for him/her? (Care receiver and caregiver responses to these questions were compared to determine the level of agreement within the dyads.)

The next three questions assessed how much the respondent pairs had discussed the care receivers' wishes for daily care:

- Have you and your family caregiver ever discussed your wishes concerning daily care? (A four-point scale from "never discussed" to "talked about it a lot" was provided.)
- How well do you feel your family caregiver knows your wishes concerning daily care? (A four-point scale from "very well" to "not at all" was provided.)
- To what extent does your family caregiver currently agree with your wishes for daily care? (A

four-point scale from "agrees a great deal" to "disagrees a great deal" was provided.)

A similar set of questions assessed how much the respondent pairs had discussed the care receiver's wishes in the event he or she ever needed nursing home care, and the final question asked respondents about the care receiver's actual preferences should they need such care. The choices included remaining at home and cared for by family, remaining at home with the assistance of paid home care, moving to an apartment that provided meals, or moving to a nursing home.

Attitudes toward receiving assistance. This area assessed the care receiver's preferences, and the caregiver's perception of the care receiver's preferences, regarding five categories of assistance (*i.e.*, shopping and cooking, laundry and housekeeping, getting up and dressing, bathing and toilet care, and taking medications) from either family and friends or paid helpers. In addition, if respondents generated the response "no preference," this was recorded. Care receiver and caregiver responses to these questions were compared to determine the level of agreement within the dyads.

Caregiver financial strain. Financial burden¹⁶ was assessed using a 10-item scale ($\alpha = .89$) that included statements such as "we dipped into our savings," "we had enough money for basic needs," and "we had enough money for little extras." Response categories ranged from "strongly agree" = 3 to "strongly disagree" = 0. Summary scores could range from 0 to 30, with higher scores indicating higher levels of perceived financial strain.

Decision control inventory (DCI). The care receiver's level of involvement in 15 areas of daily decision-making were assessed (*e.g.*, what to spend money on, when to get up). The DCI was adapted from a previous version used for persons with developmental disabilities.⁷ Care receivers were asked to describe their level of involvement in decision-making in each area on a four-point scale: 0 = not at all involved; 1 = a little involved; 2 = fairly involved; 3 = very involved. The caregiver also was asked how involved their relative was in the 15 decision areas. The summary scores were calculated by combining the 15 items separately for the care receiver and the caregiver, with a potential range of 0 to 45 (higher scores indicating greater involvement). Internal consistency as measured by Cronbach's alpha was .79 for the care receiver and .86 for the caregiver.

Results

Sample characteristics

The majority of the persons with cognitive impairment were male (68.7 percent), white (74.5 percent),

Table 1. Care receiver (CR) and caregiver (CG) responses as to who would make decisions about different tasks if the care receiver was unable to do so (%)

Task	Primary family caregiver		Other family member		Paid provider		No response		Total percent in agreement	Kappa	P value
	CR	CG	CR	CG	CR	CG	CR	CG			
Health care (Percent in agreement)	75 (73)	84 (73)	20 (12)	14 (12)	6 (2)	2 (2)	0 (n/a)	0 (n/a)	(87)	.601	.00
Finances (Percent in agreement)	78 (73)	84 (73)	20 (10)	16 (10)	0 (n/a)	0 (n/a)	2 (0)	0 (0)	(83)	.427	.00
Personal care (Percent in agreement)	73 (67)	80 (67)	22 (12)	16 (12)	4 (0)	0 (0)	2 (2)	2 (2)	(81)	.487	.00
Social activities (Percent in agreement)	75 (69)	84 (69)	22 (10)	14 (10)	0 (n/a)	0 (n/a)	4 (0)	2 (0)	(79)	.368	.00
Living arrangements (Percent in agreement)	67 (61)	82 (61)	24 (12)	18 (12)	2 (0)	0 (0)	8 (0)	0 (0)	(73)	.330	.00
Possible nursing home (Percent in agreement)	65 (61)	76 (61)	24 (12)	18 (12)	0 (n/a)	0 (n/a)	12 (2)	6 (2)	(75)	.442	.00
Average percent in agreement	(67)		(11)		(1)		(0)				

Note: Summed percentages do not always equal 100% because of missing values or rounding.

married (78.4 percent), and averaged 75.6 years of age (SD = 10.0, range 39-89 years). Most (68.6 percent) had at least some college education. The most commonly diagnosed brain disease/disorder was Alzheimer's disease (51.0 percent), followed by other dementias such as frontal lobe, Lewy body, or vascular dementia (13.7 percent); stroke (11.8 percent); nonspecific dementia (9.8 percent); Parkinson's disease (7.8 percent); and other disorders (5.9 percent). The average MMSE score of care receivers was 20.8 (SD = 4.06, range 13-26) with two-thirds (67 percent) considered mildly cognitively impaired (MMSE score between 20 and 26) and one-third (33 percent) considered moderately impaired (MMSE score between 13 and 19).

The family caregivers were mostly female (78.4 percent), white (78.4 percent), married (80.4 percent), and were on average 64.5 years of age (SD = 14.6, range 30-90 years), although over half (51 percent) were at least

65 years of age. More than two-thirds (68.7 percent) were spouses and one-third (31.3 percent) were adult children caring for a parent or parent-in-law. The majority (84.3 percent) had at least some college education. Most (23.5 percent) reported an annual family income of between \$40,000 and \$49,000 a year (1997 dollars), with nearly two-thirds (62.6 percent) reporting annual family incomes over \$30,000. Almost half were retired (49.0 percent), while one-third (33.3 percent) were in the labor force. On average, caregivers had been caring for their relatives for 3.1 years (SD = 3.4, range 1-23 years).

Decision-making on personal care

In each of the six areas surveyed, at least 90 percent of care receivers were able to identify someone they preferred to handle decision-making. The greatest numbers were able to name a person to make health care decisions

Table 2. Care receiver (CR) and caregiver (CG) responses as to who would make formal and informal ADL decisions if the care receiver were unable to do so

Task	Family/friends		Paid helper		No preference		Total percent in agreement	Kappa
	CG	CR	CG	CR	CG	CR		
Shopping and cooking (percent in agreement)	78 (60)	78 (60)	14 (0)	10 (0)	8 (0)	12 (0)	(60)	-.087
Laundry and house cleaning (percent in agreement)	45 (28)	61 (28)	41 (8)	26 (8)	14 (0)	12 (0)	(36)	-.065
Getting up and dressed (percent in agreement)	57 (45)	75 (45)	24 (4)	14 (4)	18 (2)	8 (2)	(51)	.086
Bathing and toilet care (percent in agreement)	47 (31)	61 (31)	33 (10)	31 (10)	18 (0)	4 (0)	(41)	.033
Taking medications (percent in agreement)	69 (61)	86 (61)	2 (0)	2 (0)	12 (2)	12 (2)	(63)	.045
Average percent in agreement	(45)		(4)		(1)			

Note: Summed percentages do not always equal 100% because of missing values or rounding.

(100 percent), followed by finances (98 percent), personal care (98 percent), social activities (96 percent), living arrangements (92 percent), and the possibility of nursing home placement (89 percent). The person most often chosen by care receivers to make these decisions was the primary family caregiver (74 percent), followed by another family member (19 percent) or a paid service provider (2 percent). The remaining care receivers did not name anyone (5 percent).

Caregivers were also asked to name whom they thought their cognitively impaired relative would want to make decisions for them. As shown in Table 1, caregivers' responses were congruent with the receivers' responses (kappa values ranging from .33 to .60, $p < .00$) in all six domains. Specifically, the majority of the dyads agreed that the care receiver would want their primary caregiver to make decisions (61 percent to 73 percent), whereas 10 to 12 percent of dyads agreed that the care receiver would want other family members to help.

Both care receivers and family caregivers were asked the extent to which they had discussed feelings about daily care and nursing homes with each other, and how well caregivers knew the care receiver's preferences

regarding these two issues. The results of a paired t-test revealed that care receivers felt they had discussed preferences about daily care significantly more often than nursing home care. ($M = 2.91$ vs. 2.50 , $t = 3.08$, $p < .01$). Despite this, when care receivers were asked how well they felt their family caregivers knew their wishes, there were no differences between daily care and nursing home care ($M = 3.35$ vs. 3.46). In other words, although care receivers felt they had discussed preferences regarding daily care more than feelings about nursing home care, they felt their caregivers knew their wishes in both areas equally well.

On the other hand, family caregivers reported no significant differences in the amount of discussion of feelings about daily care and nursing home care ($M = 2.73$ vs. 2.61). They did believe, however, that they knew significantly more about their relative's daily care issues than nursing home issues. ($M = 3.41$ vs. 3.10 , $t = 2.53$, $p < .05$). When dyads with spouse caregivers ($n = 35$) were compared to those with adult child caregivers ($n = 16$), no differences were found in the care receivers' responses to questions regarding the amount of discussion about daily or nursing home care.

Attitudes toward receiving informal/formal assistance

For all categories of daily living, care receivers preferred help from family and friends over help from paid assistants, and caregivers were generally aware of this preference. (Total agreement ranged from 36 to 63 percent. See Table 2.) Specifically, the respondent pairs were most likely to agree on the person who would help in taking medications (63 percent), shopping and cooking (60 percent), getting up and getting dressed (51 percent), bathing and toilet care (41 percent), and laundry and housecleaning (36 percent). More often than not, when the caregiver and care receiver were in agreement, the care receiver had expressed a preference to receive help from family or friends.

Financial strain

Indicators of financial strain were assessed using a 10-item scale that included questions about decreased earnings, out-of-pocket expenditures for care, and related issues. Summary scores ranged from 0 to 24 with a mean summary score of 10.2 (SD = 5.5) and a mean item score of 1.0 (SD = 0.6). Responses from both care receivers and caregivers on the amount of discussion of daily care or potential nursing-home care did not significantly correlate with financial strain, nor did the level of agreement about daily care preferences. Significant correlations were found, however, between financial strain and the care receiver's responses to the question, "How well do you feel your caregiver knows your wishes for daily care?" For example, the more financial strain caregivers reported at the end of the month, the less the care receivers felt the caregivers knew their preferences for daily care ($r = -.286, p = .046$). The lower the care receiver's income, the less the care receivers felt the caregivers knew their wishes ($r = .663, p = .014$) when the caregiver was an adult child. A similar correlation was found between the care receiver's income and how much knowledge the care receiver felt the adult-child caregiver had about their nursing home care preferences ($r = .734, p = .004$). A final correlation indicated that higher out-of-pocket monthly caregiving expenses for adult child caregivers were associated with caregivers who knew more about the care receiver's preferences for nursing home care ($r = .553, p = .033$).

Correlations were also used to test the relationship between financial strain and differences in decision-making scores within the dyad. Scores were computed by subtracting the care receiver's responses to care-preference questions from the caregiver's responses to the same questions. For example, if a caregiver believed he

knew his relative's preference for daily care very well (response = 4), but the care receiver believed the caregiver did not know his wishes at all (response = 1), the difference score would be high ($4 - 1 = 3$), and the dyad was considered incongruent. Difference scores from the question "How well does the caregiver know the care receiver's wishes for daily care?" were significantly correlated with two of the financial strain variables, *i.e.*, "Compared to a year ago, are your monthly expenses more or less?" ($r = .381, p = .007$), and the summary score of financial strain ($r = .329, p = .021$). Both correlations indicate that, as financial strain increased, the dyad's responses became less congruent.

Decision control inventory

In responding to questions assessing the care receiver's level of involvement in 15 dimensions of daily living decisions, summary scales ranged from 13 to 42 for the care receiver and from 5 to 41 for the caregiver. As shown in Table 3, care receivers believed they were more involved in decision-making than caregivers think they are ($M = 28.42$ vs. $M = 25.07, t = -2.76, p < .01$). However, at the item level, care receivers reported being significantly more involved in six activities than their caregivers reported they were (*i.e.*, what to spend money on, visiting with friends, what foods to buy, being physically active, choosing places to go, and getting medical care). Only two activities (*i.e.*, when to go to bed and whether to have a pet) showed significant differences in the other direction, with the caregiver reporting the care receiver more involved than the care receiver reported him- or herself. No differences were found in the seven remaining activities.

Discussion

The results of this study indicate that persons with mild to moderate cognitive impairment are able to communicate preferences for daily care and to choose a person to make a variety of decisions for them in the event they no longer are able to do so themselves. At least 90 percent of the care receivers were able to identify a person to make decisions for them in the areas of health care, finances, personal care, social activities, living arrangements, and potential nursing home placement. In almost all cases (93 percent), the identified person was the family caregiver or another family member. Moreover, caregivers' responses were congruent as to who they thought their relative would want to make decisions in all five areas of daily living. In all aspects of personal care, care receivers preferred help from family and friends to paid help. These findings support prior research suggesting

Table 3. Decision control inventory: Mean scores* and t-values

Decision	Caregiver	Care receiver	t-value
What to spend money on	0.78	1.82	-6.10 ^a
Visiting with friends	1.39	1.75	-1.84 ^b
What foods to buy	0.90	1.62	-4.82 ^a
Being physically active	1.73	2.20	-2.83 ^a
Choosing places to go	1.20	1.84	-3.67 ^a
Getting medical care	1.61	2.16	-2.94 ^a
When to go to bed	2.49	2.18	2.31 ^c
Having a pet	1.65	1.34	1.76 ^b
Expressing affection	2.15	2.14	.06
What to eat at meals	1.51	1.73	-1.32
Participating in religious or spiritual activities	1.64	1.47	.84
What clothes to wear	2.00	2.12	-.78
Choosing where to live	1.90	1.86	.20
When to get up	2.20	2.24	-.35
What to do in spare time	1.96	2.04	-.68
Summary score	25.07	28.42	-2.76 ^a

* Scale: 0 = not involved at all; 1 = a little involved; 2 = fairly involved; 3 = very involved; ^a p < .01; ^b p < .10; ^c p < .05.

that older persons who have families prefer to pass decision-making and daily care responsibilities on to family members.^{4,6}

Results also showed that care receivers were able to voice specific preferences about whom they wanted to make decisions for them in broad categories of care. Their responses were congruent with the caregivers' perception of their preferences. However, the dyads were not in agreement on questions requiring them to choose between informal or formal care providers and who would help with specific activities of daily living (*e.g.*, shopping, dressing, bathing). One explanation for these divergent findings is that care receivers may be able to name a trusted individual to make broad care decisions for them but not to assist them with specific day-to-day tasks.

Our findings suggest that persons with cognitive impairment discussed their wishes about daily care with their family caregivers more often than they discussed their preferences about nursing home care. Yet, care receivers felt that their caregivers knew their wishes concerning both aspects of care equally well. Conversely, caregivers felt they had discussed the care receiver's wishes in both areas equally but that they knew the care receiver's wishes for daily care better. This difference may be because family caregivers deal with the challenges of in-home care on a daily basis. Nursing home issues are neither immediate nor paramount when care receivers are still fairly high-functioning. Moreover, families often avoid talking about difficult matters, such as out-of-home placement. (In this study, the vast majority—73 percent—of care receivers said it was very important to them not to live in a nursing home.)

The potentially negative effect of financial strain on the dyads' level of congruence was also a significant finding. Specifically, care receivers with financially strained caregivers reported feeling that their caregivers did not know their wishes for daily care. Increased financial strain among caregivers was also associated with disagreement on how well the caregiver knew the care receiver's preferences. Families experiencing the multiple and long-term stressors that accompany caregiving may find that discussions about the care receiver's daily care wishes are not a priority. Instead, they worry about how they are going to get through each day. Care receivers who feel their caregiver is experiencing financial strain may not want to "make matters worse" or more stressful for the caregiver, so they do not make their preferences known. Unfortunately, if the dyad does not discuss these issues, they will not engage in advance planning; this, in turn, could cause increased strain and impoverishment over the long term.

In conclusion, we found that, overall, care receivers perceived they were more involved in making decisions than their caregivers felt they were. Further study is needed to know whether these differing perceptions reflect the care receiver's wish to stay involved in decision-making rather than their actual involvement in it.

Although similar to many samples in the literature,^{7,14} our relatively small, nonrandom, and cross-sectional sample limited this study's ability to be generalized to the larger, more diverse population. However, the findings add to the growing body of evidence that persons with early to moderate cognitive impairment are able to articulate choices and preferences for themselves, and prefer that family members act as consumers on their behalf if they cannot do so. In other words, the care receiver was able to make a consumer-directed choice to have a family member act as a consumer on his or her behalf. This is particularly important in home and community-based care programs, where the goal of practitioners may be to maintain the well-being of the family caregiver so that they can continue to provide care to their relative and honor the care receiver's preferences to live at home.

The challenge is to educate practitioners, policymakers, and researchers to balance the preferences of the person with cognitive impairment and the needs and of the family caregiver. Reconciling these sometimes divergent perspectives will continue to challenge those who work with persons with cognitive impairment and their family caregivers. By recognizing and respecting both voices—those of the care receiver and the caregiver—we can enhance future research and practice, foster the

development of consumer direction in long-term care, and advance public policy to support caregiving families.

Acknowledgment

This study was supported by a grant from The Robert Wood Johnson Foundation under its national initiative, Independent Choices: Enhancing Consumer Direction for People with Disabilities. The assistance of Julie Amberg and Deborah Barnes in data collection, and Shandra Tucke in data analysis, is gratefully acknowledged.

References

1. Family Caregiver Alliance: *Incidence and Prevalence of the Major Causes of Adult-Onset Brain Impairment in the United States*. San Francisco: Family Caregiver Alliance, 2001.
2. American Association of Retired Persons: Boomers and their parents experience a new generation gap. Washington DC: AARP News release, January 28, 1999.
3. Kane R: Decision-making, care plans and life plans. In McCullough LB, Wilson, NL (eds.): *Long Term Care Decisions: Ethical and Conceptual Dimensions*. Baltimore: The Johns Hopkins University Press, 1995.
4. Kapp MB: Enhancing autonomy and choice in selecting and directing long-term care services. *The Elder Law Journal*. 1996; 4: 55-97.
5. Harris L, et al.: Views of informed consent and decision-making: Parallel surveys of physicians and the public. In *President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Making health care decisions*. Washington DC: US Government Printing Office, 1982.
6. High D: All in the family: Extended autonomy and expectations in surrogate health care decision-making. *Gerontologist*. 1988; 28(Suppl.): 46-51.
7. Feinberg LF, Whitlatch CJ: *Family Caregivers and Consumer Choice: Options for In-Home Respite Care, Final Report*. San Francisco: Family Caregiver Alliance, 1996.
8. Feasey JC: *Health Outcomes for Older People: Questions for the Coming Decade*. Washington DC: National Academy Press, 1996.
9. Kapp MB: Who's the parent here? The family's impact on the autonomy of older persons. *Emory Law J*. 1992; 41: 773-803.
10. National Council on the Aging: *Principles of Consumer-Directed Home and Community-Based Services*. Washington DC: National Institute on Consumer-Directed Long Term Care Services, July, 1996.
11. Feinberg LF, Whitlatch CJ: Are persons with cognitive impairment able to state consistent choices? *Gerontologist*. 2001; 41: 374-382.
12. Feinberg LF, Whitlatch CJ: *Making Hard Choices: Respecting Both Voices*. San Francisco: Family Caregiver Alliance, 2000.
13. Folstein MF, Folstein S, McHugh PR: Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975; 12: 189-198.
14. Sansone P, Schmitt RL, Nichols JN: *The Right to Choose: Capacity Study of Demented Residents in Nursing Homes*. New York: Frances Schervier Nursing Care Center, 1996.
15. Cicerelli VG: *Family Caregiving: Autonomous and Paternalistic Decision-making*. Newbury Park: Sage Library of Social Research, 1992.
16. Aneshensel CS, Pearlin LI, Mullan JT, et al.: *Profiles in Caregiving: The Unexpected Career*. New York: Academic Press, 1995.
17. Conroy JW, Yuskas A: *Independent Evaluation of the Monadnock Self-Determination Project*. Ardmore, PA: The Center for Outcome Analysis, 1996 (Available online at www.nhdds.org/programs/osd/mdseval.pdf).