

**This article describes the development and implementation of a brief values assessment protocol to be used by case managers working in community-based long-term care (LTC) for the elderly and presents data on the values and preferences of 790 LTC clients at two locations. The importance that clients placed on selected issues related to their care (e.g., privacy, daily routines, activities, involvement of family in care, the trade-off between freedom and safety) varied as did the specific content of those issues. Associations were found between the content and strength of preferences. The work has implications for research and practice.**

**Key Words:** Case management, Home and community-based services, Assessment, Values, Preferences

# Care-Related Preferences and Values of Elderly Community-Based LTC Consumers: Can Case Managers Learn What's Important to Clients?<sup>1</sup>

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Home and community-based services (HCBS) for elderly people needing long-term care (LTC) are almost always mediated by case managers when state or federal money is used to subsidize services. Case managers authorize in-home and other services based on standardized comprehensive assessments and develop care plans that specify how, when, and by whom that care will be provided. Such assessments rely heavily on standardized batteries of questions about the physical, mental, and social needs and resources of the clients and sometimes they incorporate well-established measurement tools (Rubenstein, Wieland, & Bernabei, 1995; Gallo, Reichel, & Andersen, 1995; Kane & Kane, 1981). But formal assessments typically fail to touch on client values and preferences. Case managers seldom ask clients directly about their values and preferences during the course of their work, instead drawing inferences from cues around them (Kane, Penrod, & Kivnick, 1994; Kane, Penrod, & Kivnick, 1993).

Long-term care services are intimate and personal by their very nature. They entail assisting older peo-

ple with personal care and daily routines, thus inevitably shaping that older person's daily life (Agich, 1993; Collopy, 1995; Collopy, 1988; Kane, 1995a). Case managers and other professionals advising LTC clients have the opportunity and, some might say, the duty to help their clients formulate long-term plans that comport with the clients' individual values and preferences. Yet LTC clients too seldom are afforded the opportunity to make decisions about details of their care and to consciously design plans for that care in light of their own values and preferences (Kane, 1995a; McCullough, Wilson, Teasdale, Kolpakchi, & Skelly, 1993). That failure is evidenced by the long-standing problem of "cookie-cutter" approaches, in which two or three standard service plans are used for virtually all clients regardless of the individual details in the clients' assessments (Frankfather, Smith, & Caro, 1981; Kane, 1995a). Gibson (1990) has argued that older people themselves may be uncertain of their own values and preferences on matters that they have not previously considered; thus, a conscious effort seems needed to bring values and preferences to the attention of professionals and clients themselves.

We developed and tested a brief protocol for exploration of client values and preferences as part of a project to examine the effects of systematic values assessment on clients, case managers, family members, and care plans. This article presents data about client values and preferences as collected by that tool. We examined (1) how clients characterize the content of their values and preferences, (2) what importance clients ascribe to their various values

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and preferences, (3) how the content of a client's value relates to its importance, and (4) differences in values between new and ongoing clients.

### Developing a Values Assessment Tool

**Terminology.** — Following Ogletree (1995), we define *values* as broad beliefs about features in the everyday world to which people attach importance, and *preferences* as more specific choices that flow from values; however, our assessment protocol elicits information about values and preferences in tandem without making distinctions between them. Values and preferences are also related to underlying personality traits and to *attitudes*, often defined as favorable or unfavorable judgments on objects, persons, institutions, or events (Ajzen, 1988). We are not concerned here with making precise distinctions among values, preferences, attitudes, and personality. Rather, the values assessment was meant to help case managers become aware of their elderly clientele as individuals, with their own perspectives on quality of life and with idiosyncratic reactions to and opinions about their care.

**Protocol Development.** — Our developmental work took place in steps during a period of several years. We held an invited working conference in 1990 to discuss the rationale for and the format of a values assessment for LTC (Kane & King, 1991; Caplan, 1992). Next, we conducted long, semi-structured in-person interviews (averaging about 2½ hours) with a convenience sample of 12 consumers from a local case-managed LTC program. We then piloted two versions of a shorter structured values assessment with a convenience sample of 50 local case managers. To assess the validity of the shorter values assessment, we administered it to the same clients who had earlier been interviewed in depth. That early work confirmed the feasibility of incorporating questions about values and preferences into case managers' assessments, and suggested topics to include. From it, we also derived practical principles for an operational values assessment protocol: (a) To focus attention, it should be a self-contained battery rather than be scattered throughout the assessment; (b) it should depict values at a middle level of detail, avoiding large abstractions (e.g., friendship or justice) and minute preferences (e.g., a bed by the window); (c) it should be short enough to be tolerated by busy case managers; and (d) it should combine a rating of the strength or importance of each value with open-ended accounts of its actual content.

We then identified two operational case management programs in two different states to participate in a demonstration project in which case managers would actually apply a systematic values assessment: a 10-county mixed urban and rural site in a Midwestern state (Site A) and an urban single-county site in a Western state (Site B). In both programs, case managers allocated services for the home- and community-based Medicaid waiver,

though their program parameters and agency scale differed considerably. Viewing the project as an "action-research" project, we used, at each site, agency-wide workshops and discussion to engage case managers in designing the content of the values assessment protocol to be used at their sites, with the preliminary work serving as a starting point to generate items. After the protocols were designed, we conducted extensive training with the case managers, including role-playing of how to introduce the values assessment and how to probe without leading as well as practice in recording verbatim client responses rather than summarizing them.

The actual protocols used for the demonstration are found in Figure 1. The top portion of the figure contains the 9-item protocol used at Site A; the bottom portion shows questions used only at Site B. The first 7 items and the Site B items entailed both a rating of importance and an elaboration of content,

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The next questions are about the kinds of choices that might be important to you as you plan your care now and in the future. I would like to know how important each topic is to you and more about what the topic means.

Thinking about your care, now and in the future, how important would it be to: <sup>a</sup>	How important is this issue?
1. "... organize your daily routines in a particular way?	v   s   n
2. "... participate in particular activities, either in your home or outside your home?	v   s   n
3. "... involve or <i>not</i> involve particular family or friends with your care?	v   s   n
4. "... complete some project, attend some future event, or do something you look forward to?	v   s   n
5. "... have personal privacy?	v   s   n
6. "... take steps to avoid pain or discomfort?	v   s   n
7. Would it be more important to have the freedom to come and go and do as you please or would it be more important to be safe and accept some restrictions on your life?	Come & go ____ Restrictions ____  v   s   n
8. If you could not make decisions about your care, whom would you want to make them?	
9. What in your life (what activities or experiences) makes you feel most like yourself?	

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The following two questions were included at Site B only:

Inserted between questions 3 and 4:

If somebody not related to you was helping with your care, or with services in your home, what kind of a person or personality would you be hoping for?	v   s   n
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Inserted between questions 7 and 8:

What, if anything, do you prefer in a home or place where you live? What makes it a home for you?	v   s   n
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Figure 1. Values assessment protocol.

<sup>a</sup>The actual form contained space for notes.

and were anchored by a reference to “thinking about care you might need now and in the future.” The concrete question on choice of proxy–decision makers is different in kind; and did not include a rating. The final open-ended item, “What makes you feel most like yourself,” was suggested by earlier work on sense of identity (Erikson, Erickson, & Kivnick, 1986; Kivnick, 1993); the earlier pilot had shown that clients were interested in responding to that item. The questions specific to Site B concerned preferences regarding a person who provides help or care, and preferences about where one lives when receiving care; at Site B, case managers could authorize payment to client-employed home care workers selected directly by clients and could also pay for services in foster homes and other residential settings.

## Methods

### *Data Collection and Sample*

During a 6-month start-up period for the demonstration, all case managers were asked to administer the values protocols in the course of their regular work with all new clients and with all ongoing clients receiving reassessments, excluding only those who were too cognitively impaired to be interviewed. For the first 6 months after implementation, one copy remained in the client’s record to be used to inform the case manager’s work, and another (with identifying information omitted to protect client and case manager confidentiality) was sent to the researchers for analysis. That procedure allowed us to accomplish two aims: to examine the quality and content of information about values and preferences derived from the protocols and to provide ongoing feedback to the programs about the quality of the assessments and the results. Such feedback, in turn, was expected to help maintain enthusiasm for continued values assessments and to foster reflections about how well the program as a whole was able to respond to client values.

At Site A, 421 values assessments were returned to the researchers during the 6-month start-up period: 244 (58%) with new clients, 143 (34%) with ongoing clients, and 23 (5%) with clients with undocumented admission status. Eleven (11) protocols (3%) were returned blank, 6 because clients were too confused and 5 because of client refusal. At Site B, 410 values assessments were returned: 123 (30%) with new clients, 96 (23%) with ongoing clients, and 150 (37%) without designation. Forty-one (10%) were returned blank for a variety of reasons: client confusion (16), a language barrier and no translator (13), client illness (5), client refusal (5); and other (2). At Site B only, case managers recorded the setting where the interview with the client took place. The most common setting for the assessment was clients’ homes (238, 65%), followed by adult foster homes (49, 13%), residential care facilities (20, 5%), nursing homes (15, 4%), case managers’ offices (7, 2%), home of a son or daughter (3, 1%) and a hospi-

tal (2, 1%). The setting where the values assessment was done was missing in 35 (10%) of cases. The 779 clients with completed values assessments (410 from Site A and 369 from Site B) during the start-up period constitute the sample.

### *Coding*

The open-ended questions were coded qualitatively, following an iterative process of developing categories, coding, refining the categories, and repeating the process with a new group of protocols. Rater bias was reduced by having a second rater review the coded responses; inconsistent ratings were reconciled through discussion and consensus. For quantitative treatment, we combined categories further. Chi-square tests were conducted to detect associations between variables, as appropriate.

## Results

### *Description of Participating Case Managers*

We compared the 19 case managers at site A and the 41 at Site B who worked directly with clients and were thus eligible to be in the study. The case managers were largely college-educated (95% at Site A, 85% at Site B) women (95% at Site A and 70% at Site B) with an average of 3.7 years of experience at Site A and 7.8 years at Site B ( $p < .01$ ). At Site A, caseloads averaged about 100 clients per case manager. At Site B, specialization occurred that affected caseloads. For example, the 8 case managers who did only intake had about 18 clients at any given time. The 11 with ongoing caseloads of home care clients and foster home residents under Medicaid waivers averaged about 114 cases; the 11 who worked in sub-contracted, sliding-fee programs did both intake and ongoing case management for clients whose incomes exceeded Medicaid and they had an average caseload of 54; and the 8 with ongoing caseloads of long-stay nursing home residents averaged 141 cases. Case managers who worked only with adult protective services and high-risk clients (3 at Site A and 4 at Site B) had no fixed caseloads.

The 7 case managers who worked exclusively with protective services clients quickly decided not to actively participate in the project because of the quasi-legal nature of their work; thus, we assume they contributed only a few values assessments, if any. Also, the 7 intake case managers and the 8 nursing-home case managers at Site B were less engaged in the project than others. The bulk of the assessments, therefore, come from 16 case managers at Site A and the 22 case-managers at Site B with ongoing caseloads in the Medicaid waiver and subcontracted programs. Because the values assessments were not identified by case manager, we cannot analyze results by case manager characteristics.

### *Importance Ratings*

Figure 2 presents the proportions of all clients (new and ongoing) by site who viewed each topic as

“very important.” Certain topics received high importance ratings, particularly privacy, family involvement, freedom and safety, characteristics of a home, and characteristics of a helper (the latter two questions were asked at Site B only). In general, the clients at Site B attributed higher importance to all the areas compared with clients at Site A, with the exception of involving family members in care, which was viewed as very important by an equal percentage at each site. At Site A, the issue that the most people found to be very important was involving family or friends in their care (about 70%), followed by the trade-off between freedom and safety (68%). In the middle were activities (45%), future event (47%), privacy (55%), and avoid pain (51%). At both sites, organization of daily routines generated the fewest clients who rated the area as very important. The two areas that were unique to the Site B protocol were among the three most important topics at that site.

Table 1 compares the importance ratings of new and ongoing clients at each site. At Site A, ongoing clients rated all issues but one as more important than did new clients (involvement of family was the exception), whereas at Site B, more new clients found all issues to be very important than did ongoing clients. At Site A, three of these contrasts (daily routines, activities, and the freedom/safety trade-off) reached statistical significance, whereas at Site B only one contrast, activities, reached statistical significance.

### Content of Values

We classified the content of clients’ responses

broadly to capture the central tendencies in the responses to each question. For some topics, such as daily routines and family involvement, we created dichotomous, mutually exclusive categories (e.g., routines were coded as either organized or flexible). For other topics, however, such as privacy or the nature of a home, we used nonexclusive categories to capture the meaning of peoples’ responses. Figure 3 illustrates how we moved from actual responses on the protocol to coded categories. Selected specific topics are discussed below. The first and fifth columns of Table 2 show the distributions for the 6 out of 9 items coded with nonexclusive categories.

*Routines.* — For the issue of daily routines, clients’ responses fell into two exclusive categories which we labeled ‘flexible’ and ‘organized’ (see Figure 3). Responses that reflected a sense of flexibility ranged from pleasantly unstructured (e.g., “I’m retired — I can do what I want when I want.”) to indifferent (e.g., “It doesn’t matter how things get done, just that they get done.”). At Site A, 41% and, at Site B, 58% of responses fell into that category. Responses that described how clients’ days are organized, or elaborated on why it was important for them to be organized were classified as organized (e.g., “I get up, get my breakfast, and take my medicine.” “I try to have a regular routine. That way you can get things accomplished”). Some clients attributed their routines to a lifelong pattern, and some to current medications or dietary restrictions. Some said that if their days are not well organized they tend to get confused. At Site A, 59% and, at Site B, 42% of responses fell into that category.

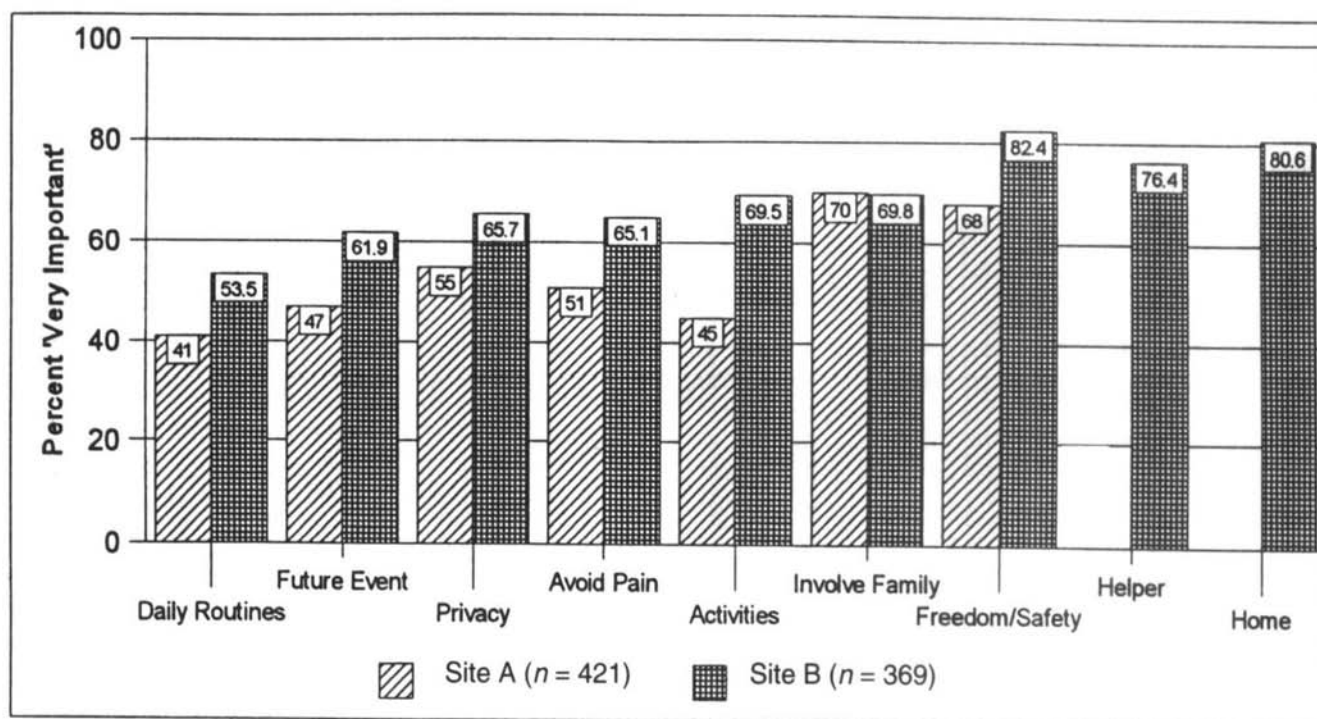


Figure 2. Percent of clients at Site A and Site B who rated each item as “very important.”

**Freedom and Safety.** — The question about the tradeoff between freedom and safety called for a discrete choice between “safety and protection” or “freedom to come and go” and a qualitative elaboration. We categorized the qualitative responses as reflecting a preference for freedom, safety, or a combination of the two. We then reconciled the qualitative coding with the discrete choices. Cases with no discrete choice were given the category from the qualitative coding, and vice versa. If the two pieces of information were different, or the qualitative code reflected a desire for both freedom and safety, the case was placed in a third category that reflected ambivalence. At Site A, 49% of clients preferred to have the freedom to come and go, 41%

preferred to accept some restrictions and be safe, and 11% were ambivalent. At Site B, 62% of clients preferred to come and go, 26% preferred to be safe, and 2% were ambivalent.

**Goals and Projects.** — A large proportion of clients (41% at Site A and 40% at Site B) indicated

**Table 1. Percent of Clients Responding ‘Very Important’ by Timing of Assessment**

Issue	Site A		Site B	
	New (n = 244)	Ongoing (n = 143)	New (n = 123)	Ongoing (n = 96)
Daily Routines	35	45**	57	54
Activities	39	53**	78	61*
Involvement	71	61*	76	68
Future Event	43	53	63	62
Privacy	54	58	71	66
Avoid Pain	51	51	70	63
Freedom/Safety	63	76*	86	83
Helper	—	—	77	75
Home	—	—	85	76

\*p < .05; \*\*p < .01, based on Pearson’s Chi-Square.

Issue	Sample Statement	Category
• Daily Routines	“I get up late and eat when I want to. I like to take things slow. I’m easy-going like my dad.”	► Flexible
	“I try to have a regular routine. That way you can get things accomplished.”	► Organized
• Privacy	“I like my privacy. My home is my castle. I don’t like people poking around. I had enough of that in the Army and the government.”	► General Privacy
	“I don’t like undressing in front of others.”	► Personal/Body
	“It doesn’t bother me to have to divulge my finances.”	► Financial
• Criteria for Home	“I like to be out and about with people.”	► Social
	“Having flowers”	► Physical
	“Having family around.”	► Social
	“It’s not a home without love.”	► Atmosphere

Figure 3. Coding of open-ended responses.

**Table 2. Content of Preferences and Relation to Importance Levels by Site**

Item	Site A				Site B			
	% in cat.	Not Imp	Somewhat Imp	Very Imp	% in cat.	Not Imp	Somewhat Imp	Very Imp
Daily Routines			(n = 385)				(n = 315)	
Flexible	41	56	37	7 *	58	22	43	35 *
Organized	59	7	30	63	42	2	19	79
Involve Family			(n = 389)				(n = 295)	
Do not involve	28	33	24	43 *	25	19	28	53 *
Involve	73	3	20	77	75	2	20	78
Activities			(n = 389)				(n = 326)	
No specific activity mentioned	37	33	24	43 *	22	23	33	44 *
Some specific activity mentioned	63	3	20	77	78	3	20	78
Future Event			(n = 378)				(n = 243)	
Nothing to look forward to	41	63	17	21 *	40	45	23	32 *
An activity or event mentioned	59	4	28	68	46	2	23	75
Getting better	—	—	—	—	14	6	14	80
Avoid Pain			(n = 367)				(n = 288)	
Avoids pain	62	2	31	67 *	78	1	30	69 *
Puts up with pain	28	25	52	24	15	10	31	60
Describes pain	10	32	24	43	7	29	24	48
Freedom/Safety			(n = 382)				(n = 258)	
Come and go	49	1	17	82 *	62	3	11	86
Accept restrictions	41	2	40	58	26	2	18	81
Ambivalent	11	8	48	45	12	—	30	70

Note: New, ongoing, and clients whose status was not documented were combined for these analyses, making a potential sample size of 421 at Site A and 369 at Site B. The actual sample available for each contrast varied because of missing data. Percentages may not add to 100% due to rounding.

\*p < .001, based on Pearson’s Chi-Square for n × 3 contrast.

that they had no events, projects, or goals to anticipate. That is even more striking because we coded rather minimal answers (e.g., the arrival of spring, Thanksgiving dinner) as positive responses along with completion of substantial projects or expectation of major events (e.g., an extensive trip or the birth of a great-grandchild). At Site A, 9% of those who had nothing to anticipate commented that they would like to be involved with something "if I could." At Site B, 14% of the clients were looking forward to a rehabilitation goal or improvement of their physical conditions, a response that never occurred at Site A.

*Family Involvement.* — We coded family involvement dichotomously; if the client indicated a preference to have no family involved or a preference to exclude a particular family member from care, we coded the item as "do not involve family." Though most wanted to involve their family members (73% at Site A, 75% at Site B), those who did not varied in their reasoning: Some preferred not to be a burden to relatives, whereas others had specific relatives whom they did not trust or like. Usually, but not always, the clients who expressed a negative attitude about family involvement localized that sentiment to one particular relative.

*Activities.* — We coded the item on activities dichotomously by whether the client mentioned one or more specific activities in his or her life or gave no examples. We did not code the actual activities because they ranged widely, including activities pursued in and out of the home. Religiously oriented activities such as reading the Bible or listening to religious programming figured highly.

*Pain and Discomfort.* — The large majority of clients at both sites preferred to avoid pain and discomfort. Only 28% at Site A and 15% at Site B indicated that they would rather put up with pain than avoid it by taking medicine or restricting their activities. Ten percent (10%) of clients at Site A, and 7% at Site B interpreted the question literally, and either said that they were not in any pain or described whatever pain they had.

*Privacy.* — Clients' responses to the question about privacy were coded with four non-exclusive categories depending on what types of privacy were mentioned, namely, general privacy, personal/body privacy, financial privacy, and social aspects of privacy (not shown on Table 2). At Site A, 8% did not elaborate at all, and 28% of responses fell into two or more categories. At Site B, where responses in general were more sparse, 13% did not elaborate at all, and only 6% fell into two or more categories. The distribution of responses about privacy differed between Site A and Site B. At Site B, the most common privacy category was "social" (56%), a category not used at all at Site A. Examples of the social category are wanting to have contact with other people, wanting to have time alone, or wanting to have per-

sonal space. At Site A most responses were coded in the general privacy category (63%), characterized by statements such as "I like my privacy." At Site B, the general privacy category was the second most common (23%). The personal privacy category was used for 39% of responses from Site A and 14% from Site B and mainly had to do with allowing other people to see your body or help with personal care tasks such as bathing or dressing. Finally, the financial privacy category was used for 23% of responses from Site A and 11% from Site B. Responses placed into this category had to do with handling money, business affairs, or finances.

*Criteria for a Home or Place to Live.* — For 32% of the clients, no elaboration was recorded on this issue. We coded the actual comments into three nonexclusive categories (not shown on Table 2): 56% mentioned intangible aspects of the atmosphere (e.g., feelings of ownership, freedom, or love), 49% mentioned physical surroundings, and 24% mentioned the social relationships or interactions associated with the place (e.g., living with their spouse, having visitors).

*Criteria for a Helper.* — We categorized the preferences for the characteristics of helpers into three nonexclusive categories (not shown on Table 2). With 9% not elaborating at all, almost all those who commented (88% of the entire sample) expressed preferences related to their helper's personality traits (e.g., an honest person, a caring person, a friendly person). About one third (32%) indicated the importance of competence or task proficiency, and 10% expressed preferences for the demographic characteristics of their helpers (e.g., race, gender, age, religion). The latter raised a sensitive issue for case managers, who then needed to consider whether it was appropriate to honor a discriminatory preference.

#### *New Versus Ongoing Clients*

At Site A, statistically significant differences between new and ongoing clients were found in the content of the preferences on three issues: involving family in their care, participating in future events, and avoiding pain (not tabled). Thirty-seven percent of ongoing clients, compared with 20% of new clients ( $p = .000$ ) indicated a preference that one or more family members *not* be involved in their care. Sixty-five percent (65%) of new clients mentioned something specific they were anticipating, compared with 48% of ongoing clients ( $p = .005$ ). Finally, 74% of ongoing clients indicated that they take steps to avoid pain, compared with 57% of new clients ( $p = .006$ ).

At Site B differences emerged between new and ongoing clients with respect to daily routines and to the issue of freedom and safety (not tabled). Fifty-one percent of new clients, compared with 31% of ongoing clients indicated that they preferred to have their daily routine organized ( $p = .004$ ). New

clients were also more likely to state that they preferred to have the freedom to come and go (64%) compared with ongoing clients (57%;  $p = .014$ ). Also, 18% of ongoing clients were ambivalent on this issue compared with only 5% of new clients.

#### *Association Between Importance Level and Content*

Combining new and ongoing clients from each site, we cross-tabulated the importance ratings given to each item with the qualitative coding of the long responses and performed chi-square tests. As shown in columns 3–5 and 7–9 of Table 2, chi-square tests revealed a consistent pattern of associations between the importance level and the category of the content of the response. Usually the findings followed logical patterns. To illustrate, at Site A, 63% of clients who indicated that they prefer their daily routines to be organized said that this issue was very important, whereas only 7% of those who indicated that they preferred their day to be flexible stated that this issue was very important, a pattern also observed, though less strikingly, at Site B. Similarly, those who wanted family and friends involved were more likely to view the matter as very important than those who wanted noninvolvement, but some of the latter also viewed this issue as very important. At Site A we also found an association between preferring the freedom to come and go and rating the topic as very important; this did not reach statistical significance at Site B.

#### *Qualitative Impressions*

In the process of examining 790 client values protocols generated in everyday practice, we noted disparities in the detail with which values and preferences were recorded. In general, Site A protocols offered more detail than Site B protocols. Variations were seen within the sites as well. Although case managers were anonymous for this exercise, handwriting differences showed that some case managers were characteristically more or less detailed in their recording.

Other impressions were generated in the tool development, training, and feedback processes. Even though the case managers involved in this project were largely seasoned human service professionals with substantial assessment experience, training proved difficult.

To complete values protocols case managers were required to perform in a way discordant with many of their own established patterns. Several case managers said they thought it was more natural to insert questions about values and preferences when they seemed to be indicated rather than adhering to a fixed series of items. It also became apparent that case managers used considerable license in the way they administered the state-mandated comprehensive assessment, so that for many the values assessment was the most strictly structured component. Other concerns included general time pressures; possible redundancy if preferences had been revealed earlier in the interview; concerns about open-

ing up client preferences that case managers felt important to address; and, in some instances, reluctance to lead clients into a discussion of disheartening material. For example, one case manager said that asking clients about plans, projects, and anticipated events was cruel because many clients would be forced to reveal their low expectations.

#### **Discussion**

This project identified topics at a mid-level of detail around which to assess the values and preferences of LTC clients sufficiently cognitively intact to be interviewed. It demonstrated that case managers vary in their willingness to incorporate values assessments in their work. However, when case managers could be convinced to ask the questions, most clients proved willing to answer them. Moreover, clients seemed to answer the questions with considerable thought and differentiation among the items. Respondents seldom checked everything as “very important” or, conversely, as “not important.” Content analysis of the responses revealed interesting distinctions in the substance of preferences, pointing out the danger of jumping to conclusions about what clients mean by abstractions like “privacy” or “safety.”

Dominant patterns were found for most items, linking the likelihood of rating a topic as important to the content of the client’s preference. However, the minority opinion was also present for most items. Some of these minority views might have real importance for case management: for example, consider the implications of the clients who attached great importance to having some or all family members involved in their care. Some importance and content differences were found across sites and between ongoing versus new clients.

#### *Limitations*

The methods by which we secured and analyzed the data were designed to provide an easy and unthreatening approach to obtain information in an ongoing way and enable us to provide regular feedback to the programs. Therefore, we did not collect detailed client data (which would have involved case managers in more steps), nor did we identify case managers. This limited the analyses that we could perform and the conclusions we could draw about how client characteristics or case manager characteristics affected the client values recorded.

This was not an observational study. We cannot know how well and carefully the protocol was administered, how well the leads were followed with subsequent probing, and the extent to which case managers refrained from jumping to conclusions. When we have a sparse values protocol, moreover, we cannot know how much the paucity of material is related to what the client chose to say versus what the case manager chose to record. Had our main purpose been to test a measurement tool, these circumstances would have been too uncon-



trolled. On the other hand, our approach does indicate what might happen when values and preferences are assessed in ordinary practice. All the complexity and variation resulting from clients' health, disability, family, and living environment may affect the quality of the values assessment, as well as the willingness of the client to discuss these abstract, personal issues and the case managers' ability to elicit the information. Also, case managers typically conduct comprehensive assessments when the health, physical function, mental function, or family support of the elderly person is at some stage of a crisis. Although we believe case managers must begin assessing values before they start an initial plan, this timing may not be the most conducive to thoughtful inquiry on the part of the case manager or reflection on the part of the client.

Given the lack of client-level data and the lower completion rates at Site B, we cannot easily interpret site-specific differences. And the cross-sectional nature of the data makes interpreting differences between ongoing and new clients difficult; we do not have repeated assessments from the same client at two points in the process. Possibly real client differences existed by site, or there may have been idiosyncratic site-specific differences in the way cases were assigned that led to a different quality of assessment and recording at either the initial or follow-up assessments by site. At Site B, there was specialization of cases with intake workers and ongoing workers seeing clients at different stages. This implies that the distinction between new and ongoing may have a different meaning at Site A and Site B. Also at Site B, many more clients were living in specialized care settings such as adult foster care homes, a fact which may reflect a client population that is somewhat more disabled than at Site A. There may have been a ceiling effect at Site B, since virtually all clients rated the "home" issue as very important.

### *Research Implications*

The accuracy and depth of insights into client values and preferences gained through the use of a values protocol depend on the interaction of both client and case managers. It is apparent that case managers need to have the comfort, interest, and time to pursue a values protocol seriously. We have no data on client disability levels or other client characteristics for this study, but can speculate that client factors might make a difference in the extent to which case managers engaged in the values assessment. That would be a topic for another study. Observational and ethnographic approaches, in particular, might yield useful insights into the phenomenon of professionals interacting with LTC clients about their values.

The differences that emerged between new and ongoing clients, particularly at Site A, suggest that clients' responses may differ depending on how long a client has been receiving in-home services. Longitudinal applications of values assessments are,

of course, needed to examine the extent to which the kinds of values and preferences reported are stable. The greater proportion of ongoing compared with new clients finding freedom/safety, daily routines, and activities to be very important may reflect a recognition that LTC services can support and enable them to have the life and lifestyle they want. The lower level of importance placed on involvement of family and friends may be the result of having adjusted to having formal care providers. Future studies that explore clients' values before and after experience with the health care system, both acute and long-term care, will shed light on that issue.

The question of whether people's values and preferences are indeed stable is of some importance to Bioethics. The movement to have people document in advance their preferences for acute care at the end of life is based on the notion that they not only know what they would want, but that their preferences are stable. Peoples' lifelong values and preferences are given moral priority because they represent peoples' autonomous desires. Research into this area is mixed, however, with some studies showing stability over time (Schneiderman, Pearlman, Kaplan, Anderson, & Rosenberg, 1992; Everhart & Pearlman, 1990; Emanuel, Emanuel, Stoeckle, Hummel, & Barry, 1994) and others finding instability (Pearlman, Cain, Starks, Patrick, Core, & Uhlman, 1995).

In the context of case-managed LTC, an important normative question is raised. That is, should the system place greater weight on preferences people form before they have had experience with receiving services or, alternatively, should the system attend to people's subsequent, or more mature preferences, developed once they have learned the potential as well as the limitations of the service system? Perhaps providers should strive for continuous monitoring and adjustment. More empirical research into preferences for LTC, and theoretical advances in the formation of preferences, are needed to help inform this issue.

Work of the type reported here could help inform scale development to measure selected abstractions such as "privacy preferences" or "valued characteristics in a helper." Though our focus was not to develop psychometrically acceptable tools to measure particular values, asking large numbers of LTC clients about their values and subjecting the results to content analysis suggested that many of these concepts are multidimensional and gave insights into where one might start in an item pool to develop formal measurements.

Finally, the difficulties we encountered in implementing the project suggest that organizational theory might shed valuable light on facilitators and obstacles to implementing accurate values assessments in case management practice. Site A had a much lower staff to supervisory ratio than Site B. That led to a greater degree of independence at Site B, with less emphasis on group problem solving and less reliance on supervisors or the director for guidance



with difficult cases. At Site A, case managers were more accustomed to using assessment tools with standardized wording of questions, and were therefore less affronted when asked to use the values assessment protocol as written. By contrast, at Site B, case managers felt that their clinical skills were constrained by having to use standardized questions, and the values assessment was the only standardized instrument that they regularly used. That greater degree of autonomy and independence at Site B was associated with poor enthusiasm and low levels of participation. The strong and cooperative supervisory structure at Site A reinforced the importance of the project and helped maintain enthusiasm.

### *Practice Implications*

This brief values protocol yielded information that should enable case managers to improve their practice with individual clients and should enable programs to improve the way they meet the needs of all clients. We were struck that the information generated provided a way of identifying clients who had no meaningful activities or projects filling their days and, more important, provided clues to the types of activities that might please the clients or capture their interest. Some questions (such as those on daily routines, privacy, pain, help, and living environments) could lead to a dialogue that would shape or reshape the care that the client was receiving.

The question about trade-offs between freedom and safety revealed considerable ambiguity in clients' responses, reflecting, we believe, that the topic itself inherently generates ambivalence. Clients want to be free to come and go, but they also want to be safe. For example, often clients described deliberate decisions they had made to balance those two values (e.g., "That's why I moved here [senior high-rise] — so I could wander around freely, but still be safe in the apartment building."). That ambivalence is also reflected in the views of case managers. Clemens and colleagues (1994) studied one case management program intensively, finding that case managers adhered to a "politically correct" view about client freedom, yet also acted to maximize safety. Similarly, in a poll of professionals done as a precursor to the "1995 White House Conference on Aging" (Kane, 1995b), the most common response to a question about the conditions under which a client should be able to act against the advice of professionals regarding their own safety was "when it will not harm them or others." Our difficulty in classifying clients dichotomously on this dimension may reflect their struggle to achieve a compromise between those two poles.

More probing and discussion on subsequent home visits or telephone conversations by case managers are probably needed to further pinpoint and clarify a client's preferences in the area of freedom and safety. What risks is the client willing to take? What activities does the client want to avoid?

How safe is safe? Determining what services or programs are available may require considerable creativity on the part of the case manager, and the increased attention to values and preferences can enhance the case manager's ability to support a risky decision. It is unclear whether case managers are positioned well by their training or the structure of their work to pursue those topics fully.

Certainly, practice implications are prominent in the challenges we found when implementing the values protocol. It was challenging to train case managers, who are generally pragmatic, practical, and problem oriented, to explore clients' more abstract values and preferences. Our experiences suggest that any case management program wishing to incorporate a values assessment protocol needs to build in a long time line for training as well as policies and procedures for using the information. Providing feedback on client values and preferences in the aggregate does encourage case managers to continue collecting the data. Such tabulations also highlight any systemic divergence between typical preferences and typical care plans, which may in turn suggest changes in administrative or public policies.

Perhaps the most important practice-oriented work that lies ahead is demonstrating to case managers that it is indeed possible to shape care plans that are more consistent with clients' values and to work in other ways that help clients realize their own preferences. In some instances, program rules may need to be changed (e.g., to permit a wider range of purchasing, to permit case managers to work directly with the in-home workers employed by provider agencies, or to reduce caseloads). But without changing policy, it is possible in a myriad of small ways for case managers to respond more fully to client preferences and to develop more detailed, sensitive care plans. Over time, a repository of practice ideas and models of preference-sensitive care plans could be developed in terms of their referral practices, the way they themselves behave with clients and families, and the suggestions they make. Also, the difficult cases in which client preferences are at loggerheads with program possibilities form the grist for wider discussion at case conferences and by ethics committees.

Some case managers and their supervisors expressed worry that values assessments might lead to "unrealistic expectations" on the part of clients. That is a legitimate concern, and one that in itself is related to broader social values about how to provide publicly subsidized services. A rejoinder to that concern would be that it is desirable for consumers to develop enhanced expectations and to challenge providers to meet them. Yesterday's unrealistic expectations can be tomorrow's standard practice. Certainly, the hope that consumers would develop expectations based on their values and preferences was one rationale for the demonstration project. Another was that providers would become more attentive to issues raised by the values assessment.

## References

- Agich, G. J. (1993). *Autonomy and long-term care*. New York: Oxford University Press.
- Ajzen, I. (1988). *Attitudes, personality and behavior*. Chicago: Dorsey Press.
- Caplan, A. L. (1992). Can autonomy be saved? In A. L. Caplan (Ed.), *If I were a rich man could I buy a pancreas? and other essays on the ethics of health care* (pp. 256-281). Bloomington: Indiana University Press.
- Clemens, E., Wette, T., Feltes, M., Crabtree, B., & Dubitzky, D. (1994). Contradictions in case management: Client centered theory and directive practice. *Journal of Aging and Health*, 6(1), 70-88.
- Collopy, B. (1988). Autonomy and long-term care: Some crucial distinctions. *The Gerontologist*, 28, 10-17.
- Collopy, B. J. (1995). Safety and independence: Rethinking some basic concepts in long-term care. In L. B. McCullough & N. L. Wilson (Eds.), *Long-term care decisions. Ethical and conceptual dimensions*. Baltimore: Johns Hopkins University Press.
- Emanuel, L. L., Emanuel, E. J., Stoeckle, J. D., Hummel, L. R., & Barry, M. J. (1994). Advance directives. Stability of patients' treatment choices. *Archives of Internal Medicine* 154(2), 209-17.
- Erikson, E. H., Erikson, J. M., & Kivnick, H. Q. (1986). *Vital involvement in old age. The experience of old age in our time*. New York: W.W. Norton & Company.
- Everhart, M. A., & Pearlman, R. A. (1990). Stability of patient preferences regarding life-sustaining treatments. *Chest*, 97(1), 159-64.
- Frankfather, D. L., Smith, M. J., & Caro, F. G. (1981). *Family care of the elderly: Public initiatives and private obligations*. Lexington, MA: Lexington Books.
- Gallo, J. J., Reichel, W., & Andersen, L. M. (1995). *Handbook of geriatric assessment* (2nd ed.). Gaithersburg, Aspen.
- Gibson, J. M. (1990). National values history project. *Generations*, XIV(Suppl.), 51-64.
- Kane, R. A. (1995a). Decision making, care plans, and life plans in long-term care: Can case managers take account of clients' values and preferences? In L. B. McCullough & N. L. Wilson (Eds.), *Long-term care decisions: Ethical and conceptual dimensions*. Baltimore: Johns Hopkins University Press.
- Kane, R. A. (1995b). *Quality, autonomy, and safety in home and community-based long-term care. Toward regulatory and quality assurance policy* (Submitted to: Robert Blacato, Executive Director, White House Conference on Aging). Minneapolis: University of Minnesota National LTC Resource Center.
- Kane, R. A., & Kane, R. L. (1981). *Assessing the elderly: A practical guide to measurement*. Lexington, MA: Lexington Books.
- Kane, R. A., & King, C. D. (1991). *Assessing values and preferences in long-term care: Is it feasible and is it desirable?* Minneapolis: University of Minnesota Long-Term Care DECISIONS Resource Center.
- Kane, R. A., Penrod, J. D., & Kivnick, H. Q. (1993). Ethics and case management: Preliminary results of an empirical study. In R. A. Kane & A. L. Caplan (Eds.), *Ethical conflicts in the management of home care* (pp. 7-225). New York: Springer.
- Kane, R. A., Penrod, J. D., & Kivnick, H. Q. (1994). Case managers discuss ethics: Dilemmas of an emerging occupation in long-term care in the United States. *Journal of Case Management*, 3(1), 3-12.
- Kivnick, H. Q. (1993). Everyday mental health: A guide to assessing life strengths. *Generations*, 12(1), 13-20.
- McCullough, L. B., Wilson, N. L., Teasdale, T. A., Kolpakchi, A. L., & Skelly, J. R. (1993). Mapping personal, familial, and professional values in long-term care decisions. *The Gerontologist*, 33(3), 324-32.
- Ogletree, T. W. (1995). Values and valuation. In W. T. Reich (Ed.), *Encyclopedia of Bioethics: Revised Edition* (Vol. 5, pp. 2515-2520). New York: Macmillan.
- Pearlman, R. A., Cain, K. C., Starks, H. E., Patrick, D. L., Core, W. G., & Uhlman, R. F. (1995). *Predictors of instability in life-sustaining treatment preferences*. Paper presented at the 48th annual meeting of the Gerontological Society of America, Los Angeles, CA.
- Rubenstein, L., Wieland, D., & Bernabei, R. (Eds.). (1995). *Geriatric assessment technology*. State of the art. Milan, Italy: Kurtis.
- Schneiderman, L., Pearlman, R., Kaplan, R., Anderson, J., & Rosenberg, E. (1992). Relationship of general advance directive instructions to specific life-sustaining treatment preferences in patients with serious illness. *Archives of Internal Medicine*, 152(October), 2114-2122.

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