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An Exploratory Study of Personal Assistance Service Choice and Decision-Making Among
Persons with Disabilities and Surrogate Representatives

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Abstract

Although persons with disabilities want and expect to control their own lives, not all may be able to express those desires directly. Surrogate representatives are key players in implementing consumer-directed programs. Data made available through the Cash and Counseling Demonstration and Evaluation (CCDE) consumer preference study in New Jersey suggest that surrogates can adequately represent consumer's views about satisfaction with personal assistance, and thus provides encouragement to continued investigation of the utility of surrogate representatives. Study results also replicate previous findings that persons with cognitive impairments and persons with severe disabilities are able to express their preferences for everyday matters. Understanding the perspective of the impaired consumer is important to encouraging consumer independence and control, to improving quality of life and to successfully implementing consumer-directed programs.

Introduction

Advances in consumer direction are perhaps the most exciting and important innovations in long term care and services of the last decade. Characterized by offering an array of choices and varied degrees of consumer control, consumer directed services empower persons with disabilities to meet the challenges of daily living. The Cash and Counseling Demonstration and Evaluation (CCDE), one model for empowerment and choice for long-term care, seeks to provide increased autonomy to consumers by providing them with a cash alternative and information services to purchase the assistance they require for everyday personal care (Mahoney & Simon-Rusinowitz, 1997). Surveys conducted in preparation for the CCDE found that at least one third of elderly adults (65 or older) and one half of younger adults (under 65) with disabilities receiving Medicaid personal care services were interested in this approach (Simon-Rusinowitz, Mahoney, Desmond, Shoop, Squillace & Fay, 1997). Although it is clear that persons with disabilities want and expect to control their own lives, not all may be able to express those desires directly. Thus, the preferences of individuals with cognitive impairments, communication difficulties, and those otherwise unable to make all decisions independently, must sometimes be reflected by surrogate or proxy representatives.

Surrogate representatives may be someone close, like a friend or neighbor; but are often a family caregiver. Balancing the preferences and needs of consumers requiring assistance with those of the family caregiver is complex. The care receiver's situation may change as cognitive function worsens, for example, and factors such as safety are paramount (Feinberg, Whitlach & Tucke, 2000; Zarit & Goodman, 1990); the family

caregiver may have varying levels of ability and senses of obligation (McCullough & Wilson, 1995); and the negative physical, emotional, and financial effects of family caregiving on the caregiver add to the complexity of the additional task of decision-making and representation (Haug, Ford, Stange, Noelker, & Gaines, 1999; Cohen, 1998; Anthony-Bergstone, Gatz, & Zarit, 1998). Although surrogates are often charged with a number of responsibilities, the complexities surrounding representation, even if combined with caregiving, should not limit consumer choice about the most basic and intimate activities of their daily lives -- such as when to bathe, dress, or eat.

Studies have shown that impaired consumers (including those with mild to moderate cognitive deficits) are capable of expressing their preferences for everyday living decisions, health status, and/or quality of life. Friss-Feinberg and Whitlatch (2001) reported in their dyad study of persons with mild to moderate cognitive impairment and their family caregivers (n=51) that impaired individuals were able to state consistent preferences and choices about daily living decisions; and provide accurate and reliable responses to questions about demographics. These researchers emphasize that the impaired individual "...should be encouraged to discuss their everyday care wishes with their family caregiver. In turn, this would assist family members by helping them to better understand the wishes and preferences of their loved ones earlier in the disease process..." (pg. 381). In addition, McHorney (1996) found that mild to moderately cognitively impaired elderly persons (n=36) were as capable as those without cognitive impairments in providing valid and reliable self reports regarding health status and quality of life preferences. That study concludes, in part, that it is inappropriate to

exclude individuals with cognitive impairment from reporting their health status preferences.

However, research has emphasized caregiving practices and outcomes more often than it has emphasized representation of the consumers' perspective (Feinberg & Whitlatch, 2001; Anthony-Bergstone, Gatz, & Zarit, 1998; Whitlatch, Friss-Feinberg, & Sebesta, 1997). Cohen (1991) reports this gap has led to a lack of representation of the consumers' needs in the selection of care strategies. This gap also points to another unanswered question -- when representation does take place, how accurately do surrogates represent consumers' wishes regarding their personal care?

Most choice and representation studies have explored end-of-life and health care decision making issues (Hofmann, Wenger, Davis, Teno, Connors, Desbiens, Lynn, & Phillips, 1997; Zweibel, & Cassel, 1989; Ouslander, Tymchuc, & Rahbar, 1989; Wetle, Levkoff, Cwikel, & Rosen, 1988; and High, 1988). Many of these studies concern high-stake issues (e.g. life and death); medical management and critical care interventions (e.g. chemotherapy or surgery); and legal matters related to advanced planning issues (e.g. advanced directives). In addition, studies examining how well the opinions of proxies correspond to the care receivers' acute care preferences are inconsistent -- preferences vary according to the mode of treatment and scenario; are made with imperfect accuracy and can be unreliable (Sulmasy, Terry, Weisman, & Stallings, 1998; Sulmasy, Haller, & Terry, 1994; and Suhl, Simons, Reedyk, & Garrick, 1994). However, Tomlinson, Howe, Notman, and Rossmiller (1990) found that when respondents representing older persons were explicitly asked to make a "substituted judgement," they came significantly closer

to the older person's preferences than those surrogates who were asked to make their "best recommendations."

Understanding the perspective of the impaired consumer wanting or needing a surrogate; and the extent to which agreement exists between consumers' wishes and surrogates' choices is important to encouraging consumer independence and control and to improving quality of life. To investigate representation practices among consumers and surrogates the present study examines survey data made available through the Cash and Counseling Demonstration and Evaluation (CCDE) consumer preference study in New Jersey.¹ This exploratory study of community-dwelling adults compares responses made by consumers with and without surrogate respondents to examine how well surrogates represent consumers' wishes regarding their satisfaction with personal care.

METHODS

Sample

Data for this study come from a telephone survey conducted at The University of Maryland, Center on Aging in 1997. The current study is a secondary analysis of the New Jersey CCDE preference study database. For more information on the primary CCDE preference study in New Jersey see Mahoney, Desmond, Simon-Rusinowitz, Shoop and Squillace (forthcoming). Respondents were selected from the original sample pool via a 100% enumeration of eligibles. The total sample size for the New Jersey database equals 683. There were 526 consumers answering for themselves and 157 consumers with surrogate representatives.

¹The CCDE is a program designed to test the feasibility of a consumer-directed approach to the financing and delivery of personal assistance services (PAS) for Medicaid eligible persons with disabilities in three demonstration states: Arkansas, New Jersey, and Florida. This program is funded as a partnership between the Office of the Assistant Secretary for Planning and Evaluation and the Robert Wood Johnson Foundation.

Instrumentation

Content validity of the instrument was established via an expert panel (n=7) knowledgeable in aging, disabilities, and survey design and evaluation. In addition, the instrument was pilot tested with three disabled and elderly individuals to assess administration time and understanding of the survey items. The final survey instrument consisted of four parts totaling 139-items. The first section asked consumers (or their surrogate representatives) about their satisfaction with their current personal care services (27 items). After being informed about the various cash option features and support services available, the second section asked consumers (or their surrogate representatives) about their perceptions regarding the cash option (33 items). The third section asked consumers (or their surrogate representatives) to provide some information about themselves including age, gender, race, education, and marital status; and about their background (44 items). Background characteristics included measures of functional status based on five activities of daily living (ADL's), an assessment of overall physical health, number of informal caregivers, and experience with interviewing, training, hiring, or supervising workers. The final section asked their surrogates perceptions of the cash option, information about themselves, and their background (35 items).²

Response Rate

The survey response rate was 60%.³ Completed surveys totaled 683 and refusals totaled 457. The primary reasons respondents gave for refusing to participate in the survey were: 1) feeling too disabled or old (n=143, 31%), 2) no interest in participating in

² Due to data collection error, some surrogates were offered an additional "N/A" choice on some items, that was not available to other surrogates or consumers. After determining that the removal of these responses did not introduce sample bias, these responses were removed from analysis.

any survey (n=115, 25%), 3) no interest in changing services (n=107, 24%), and 4) hang-up without providing reason (n=92, 20%).

Data Coding and Operationalization of Constructs

Disability level, a measure of functional status, was calculated by the number of tasks for which consumers “need the help of another person.” Tasks used in the count are activities of daily living (ADL) variables: getting in/out of bed or chair, taking a bath or shower, dressing, eating, and using or getting to the toilet. Consumers were asked if they needed help with each of the tasks, and could respond "yes", "no" or "sometimes" to each task. A "yes" response received a score of 1, a "no" response a 0, and a "sometimes" response a 0.5. The functional status scale could thus range from 0 to 5; consumers scoring between 0 and 1.5 were considered to be mildly disabled, those scoring between 2 and 3.5 were considered moderately disabled, and those scoring between 4 and 5 were considered severely disabled. The ADL scale has been used to quantitatively assess functional status (Katz, Hendrick, & Henderson, 1979) and the reliability and validity of the ADL scale are well-documented (McDowell & Newell, 1996; Spector, 1996; Brorsson & Asberg, 1984).

Given that disabilities are defined in terms of ADL and instrumental activities of daily living (IADL) dependencies, Spector (1991) suggests for populations in need of home and community-based services, the IADL measurement (consisting of eight items – meal preparation, laundry, light housework, grocery shopping, money management, taking medicines, making telephone calls, and getting around outside) is also considered a reasonably good measure of cognitive activity. Spector (1991) suggests that this

³ Non-English speaking respondents were coded as noninterviews and were not included in the denominator of the response rate calculation.

measure is as useful as other mental or behavioral scales, such as the SPMSQ mental status test in screening for cognitive impairment. For this study, due to survey length, all eight IADL measures could not be included in the survey. As such, a subset of two IADL measures that appear most directly related to cognitive disability were used: 1) keeping track of money or bills, and 2) help taking the right amount of prescribed medicine.

In this study, surrogates represented consumers with cognitive impairments, communication difficulties, and those otherwise unable to make all decisions independently. In the primary CCDE Preference Study, surrogates were instructed by interviewers to answer the questions in the way the consumer would answer if capable of doing so and to have the consumer present, when possible, during the interview to provide response clarification as necessary.

RESULTS

Surrogate Characteristics

As seen in Table 1, surrogates (n=157) tended to be under age 65 (74%), and predominantly female (69%). Fifty-nine percent were Caucasian, 24% were African American and 9% Hispanic. In addition, most surrogates had a high school education (30%) or some college (24%). Fifty-four percent were currently married.

[Table 1 here]

As presented in Table 2, 64% of surrogates reported living with a spouse or children. Eighty-four percent of surrogates were related to the consumer and the vast majority of surrogates (97%) reported helping consumers make “all” decisions (e.g.

living arrangements, financial, and medical). Finally, most surrogates (82%) provided assistance with personal care decision-making.

[Table 2 here]

Demographic Characteristics of Consumers

Fifty-seven percent of all consumers (n=683) were 65 years of age or older and the majority were female (76%). Forty-five percent were Caucasian, 34% were African American and 12% Hispanic. The majority of consumers had a high school education (30.9%) or less than a high school education (46%). Thirty-nine percent were widowed and 31% were single (Table 3).

[Table 3 here]

A number of variables were associated with whether consumers answered on their own behalf or preferred to use a surrogate representative. Bivariate analyses revealed that race was related to respondent status⁴ (p<.001). Forty-one percent of consumers answering on their own behalf were African American as compared to 24% of consumers with surrogate representatives; and more consumers with surrogates were Caucasian (64%) as compared to self-respondent consumers (45%). Education was also related to respondent status (p<.001). Sixty-five percent of consumers with surrogates had less than a high school education, as compared to 45% of self-respondent consumers. Finally, marital status was related to respondent status (p<.001). Consumers with surrogates were more likely to be widowed (43%) or single (40%) as compared to self-respondent consumers, where 38% were widowed and 28% single, respectively.

⁴ Respondent status is the comparison made between consumers represented by surrogates and consumers answering on their own behalf.

Background Characteristics of Consumers

As shown in Table 4, 55% of all consumers (n=683) lived alone and 26% percent lived with a friend, partner, or relative. Ten percent of all consumers owned their own home. The majority of all consumers had been employed (76%), however, many were currently retired (67.9%). When consumers (n=683) were asked to rate their overall health status, 64% rated it "fair" or "poor", compared to 33% who rated it "good," "very good" or "excellent." Over half of all consumers (57%) were mildly disabled; 23% were moderately disabled and 20% were severely disabled. Finally, 45% of all consumers reported needing help with keeping track of bills or money, and 42% reported needing help taking the right amount of medicine.

[Table 4 here]

A number of variables were associated with whether consumers answered on their own behalf or preferred to use a surrogate representative. Bivariate analyses revealed that the consumers' living arrangement was related to respondent status ($p < .001$). The majority of self-respondents reported living alone (66%) as compared to consumers with surrogates who reported either living with a spouse and/or children (25%) or a friend, partner, or relative (56%). Previous employment status was also related to respondent status ($p < .001$). Eighty-four percent of self-respondent consumers had been previously employed as compared to 51% of consumers with surrogates. Bivariate analyses also revealed that perceptions of overall health status were related to respondent status ($p < .05$). Self-respondent consumers were more likely to rate their health status as "fair" or "poor" (67%), as compared to consumers with surrogates (56%).

In addition, disability level was related to respondent status ($p < .001$). Thirty-three percent of self-respondent consumers were “moderately” or “severely” disabled; versus 72% of consumers with surrogates. Finally, the need for help keeping track of bills or money and the need for help taking the right amount of medicine were related to respondent status ($p < .001$). Consumers with surrogates were more likely to have need for help keeping track of money or bills (88%) than were self-respondent consumers (33%); and to have need for help in taking the right amount of medicine (83% vs 30%).

As seen in Table 5, the majority all consumers ($n=683$) reported being in the program for 3 years or longer (61%). The majority of the sample also reported they had informal caregivers (60%), and 42% of the sample had an informal caregiver who lived with the consumer (total). Eighty-eight percent of consumers reported that they speak the same language as their worker. In addition, the majority reported feeling “very close” (23%) or “somewhat close” (52%) to their worker. Twenty-three percent had experience hiring, firing, or interviewing workers and 33% had experience supervising or training workers.

[Table 5 here]

A number of variables were associated with whether consumers answered on their own behalf or preferred to use a surrogate representative. Bivariate analyses revealed that the presence of informal caregivers and “live-in” informal caregivers was related to respondent status ($p < .001$). Consumers with surrogates were more likely to have more informal caregivers (87%) than were self-respondent consumers (52%); and more likely to have informal caregivers who lived with the consumer (70% vs. 28%). In addition, experience hiring, firing or interviewing any type of worker was related to respondent

status ($p < .001$). Self-respondents were more likely to have had experience hiring, firing, or interviewing any type of worker (27%) than were consumers with surrogates (10%). Experience supervising or training any type of worker was also related to respondent status ($p < .001$). Self-respondent consumers were more likely to have had experience supervising or training any type of worker (38%) than consumers with surrogates (16%).

Satisfaction with Worker Characteristics

As seen in Table 6, 9% of all consumers reported that their worker is frequently late and 7% reported that their worker hurries too much. Ninety-two percent of all consumers reported that their worker does a good job and 11% of all consumers reported that their worker needs to be more respectful.

[Table 6 here]

Overall, self-respondent consumers seemed happier with their worker, as compared with consumers who had surrogate representatives. Bivariate analyses revealed that more self-respondent consumers “disagreed” that their worker hurries too much (91%), as compared to consumers who had surrogate representatives (84%) ($p < .01$). In addition, more self-respondent consumers indicated that they “disagreed” (87%) that their worker needs to be more respectful, as compared with consumers with surrogates (82%) ($p < .01$).

Multivariate Analysis

Four logistic regression models were calculated to determine if there was a difference in the pattern of responses between self-respondent consumers and consumers with surrogate respondents, on four satisfaction variables: 1) worker is frequently late; 2) worker hurries too much; 3) worker does a good job; and 4) worker needs to be more

respectful. After entering into the model, and controlling for, the following consumer attributes: age, gender, race, education, marital status, disability level (ADL), and level of cognition (IADL); the status of the respondent, e.g., whether a surrogate or the consumer gave the response, was entered. This respondent status variable did not independently predict any of the 4 satisfaction responses (see Table 7).

[Table 7 here]

DISCUSSION & RECOMMENDATIONS

The most salient finding of this study is that respondent status was not found to predict satisfaction with personal care. After controlling for differences in demographics, disability level, and cognition, consumers functioning independently and consumers with surrogate representatives responded similarly to questions about satisfaction with personal care. This finding suggests that surrogates do represent consumers' views in this domain. This finding is encouraging, given that interviewers were trained to ask surrogates to answer the questions in the way the consumer would if capable of doing so, and were reminded of this role throughout the data collection process. In addition, surrogates were asked to have the consumer present, when possible, during the interview to provide response clarification as necessary. Tomlinson, Howe, Notman, and Rossmiller (1990) lend support for that interpretation, reporting that when respondents representing older persons preferences were explicitly asked to make a substituted judgement, they came significantly closer to the elderly person's preferences than those who were asked to make their best recommendation.

This study also found evidence that many consumers with cognitive impairments and many of those with severe disabilities were able to express their preferences for

everyday personal care when responding to the New Jersey telephone survey independently (without a surrogate representative). Thus, our results also support previous research that concludes the impaired individual is capable of stating everyday preferences and choices (Friss-Feinberg, 2001; McHorney, et al, 1996).

Practice and Program Implications

There are a number of strategies that might be employed to maximize the impaired consumer's ability to express his or her wishes regarding PAS care, to enhance communication between consumers and surrogates, and to improve the quality of services delivered. Surrogates may be provided with information and/or training programs that teach consumer-directed principles to enhance consumer autonomy and to allow for meaningful PAS decision making. In addition, regular dialogue should be encouraged between consumers and surrogates to improve the caregivers' understanding of consumers' PAS care preferences. Discussions and strategy planning sessions may be especially important for consumers with early stages of dementia, to identify their preferences while they are able to express them (Friss-Feinberg & Whitlach, 2001; Breechling & Schneider, 1993; Cotrell & Schultz, 1993; McAfee, Ruh, Bell & Martichuski, 1989).

Consultants and service providers, who work with consumers in developing a care plan and provide training in consumer tasks, need education and training regarding aspects of their job that affect consumer autonomy. These individuals can also be trained to identify factors associated with poor substituted judgements, to improve consumer-surrogate communications, and to assist caregivers in making more accurate substituted judgements.

Policy Implications

The dominant perspective in consumer-direction has been that it is only for those who can totally self-direct. Some researchers purport that “the pure model of consumer-directed services assumes a cognitively intact individual who has the energy, determination, and intelligence to take on the responsibilities of hiring, training, directing, and firing workers” (Weiner, Clauser & Kennell, 1995, p.312). We know from a growing body of literature that it’s not an “all-or-nothing” proposition. Researchers have shown that consumers with cognitive impairments should be considered legitimate consumers of long-term care (Friss-Feinberg & Whitlatch, 2001; McHorney, et al, 1996). The present study adds evidence that when surrogates were instructed to represent the consumer -- they seemed to do so -- suggesting the idea of substituting judgement has promise for consumers who need assistance in directing their services.

Research Recommendations

It is always more difficult to ensure that consumers’ preferences are embodied in caregiving decisions when someone else must speak for them. This study indirectly examined the representation issue, relying on information from a single source (consumers’ preferences as seen through the eyes of the surrogate) as opposed to examining both perspectives separately (the impaired consumer and their surrogate representative). Future studies should involve both members of the dyad.

Future research should also explore surrogate interests and motivations regarding PAS choice and decision-making. If differences exist in the consumers’ and surrogates’ opinions regarding PAS preferences, this contrast may suggest that surrogates are not completely attuned to the wishes of the consumers they represent, or surrogates are

misinterpreting consumers' wishes. In addition, other important domains related to consumer preferences should be explored to identify where it may be "easier" or "harder" for surrogates to represent consumers' views adequately.

Conclusion

Many consumers with cognitive impairments and many of those with severe disabilities were able to express their preferences for everyday personal care when responding to the New Jersey telephone survey independently (without a surrogate representative). However, surrogate representatives remain key players in implementing consumer-directed programs. Consumer-directed programs cannot exist for consumers who are represented by surrogates if the surrogate is not representing the consumer's views adequately. This study provides evidence that surrogates can adequately represent consumer's views about satisfaction with personal care, and thus provides encouragement to continued investigation of the utility of surrogate representatives.

Table 1. Demographic Characteristics of New Jersey Surrogates

| Characteristic | Surrogate (N=157) |
|----------------------------|------------------------------|
| | N (%) |
| Age of Surrogate | |
| Under 65 | 117 (74.0) |
| 65 Or Older | 36 (26.0) |
| Gender | |
| Male | 48 (30.6) |
| Female | 109 (69.4) |
| Race/Ethnicity | |
| African American/Black | 39 (24.8) |
| Native American | 00 (00.0) |
| Asian | 05 (03.2) |
| Hispanic | 15 (09.6) |
| Caucasian/White | 93 (59.2) |
| Biracial | 01 (00.6) |
| Don't Know | 02 (01.3) |
| Refused Question | 02 (01.3) |
| Education | |
| Less Than High School | 15 (09.6) |
| High School Graduate | 48 (30.7) |
| Trade Or Vocational School | 11 (07.0) |
| Some College | 39 (24.8) |
| Baccalaureate Degree | 20 (12.7) |
| Some Graduate School | 04 (02.5) |
| Graduate Degree | 19 (12.1) |
| Refused Question | 01 (00.6) |
| Surrogate Marital Status | |
| Married | 85 (54.2) |
| Widowed | 16 (10.2) |
| Divorced | 18 (11.5) |
| Separated | 06 (03.8) |
| Single | 28 (17.8) |
| Partnered | 01 (00.6) |
| Refused Question | 03 (01.9) |

Table 2. Background Characteristics of New Jersey Surrogates

| Characteristic | Surrogate (N=157) N (%) |
|---|--|
| Surrogate Living Arrangement Alone With spouse and/or children With friend or neighbor | 06 (03.9) 101 (64.3) 50 (31.8) |
| Relationship to Consumer Spouse Relative Friend or neighbor Other | 10 (06.4) 133 (84.7) 03 (01.9) 11 (07.0) |
| What kinds of decisions do you help the consumer make? All Living arrangements Financial Medical Other | 130 (97.7) 00 (00.0) 00 (00.0) 00 (00.0) 03 (02.3) |
| Type of Surrogate Personal care decisions Language problems Hearing problems Don't know Refused question | 130 (82.8) 19 (12.1) 05 (03.2) 02 (01.3) 01 (00.6) |

Table 3. Demographic Characteristics of New Jersey Consumers (total), Self-Respondent Consumers, and Consumers with Surrogates

| Characteristic | Consumers (total) (N= 683) | Self-Respondent Consumers (N=526) | Consumers with surrogates (N=157) |
|----------------------------|----------------------------------|---|---|
| | N (%) | N (%) | N (%) |
| Age | | | |
| Under 65 | 286 (41.9) | 218 (41.4) | 068 (43.3) |
| 65 Or Older | 391 (57.3) | 302 (57.8) | 089 (56.7) |
| Don't Know | 01 (00.1) | 01 (00.1) | 00 (00.0) |
| Refused Question | 05 (00.7) | 05 (00.7) | 00 (00.0) |
| Gender | | | |
| Male | 164 (24.0) | 119 (22.6) | 045 (28.7) |
| Female | 519 (76.0) | 407 (77.4) | 112 (71.3) |
| Race/Ethnicity | | | |
| African American/Black*** | 233 (34.1) | 197 (37.5) | 36 (22.9) |
| Native American | 09 (01.3) | 08 (01.5) | 01 (00.6) |
| Asian | 07 (01.0) | 02 (00.4) | 05 (03.2) |
| Hispanic | 82 (12.0) | 66 (12.5) | 16 (10.2) |
| Caucasian/White *** | 312 (45.8) | 218 (41.4) | 94 (59.9) |
| Biracial | 07 (01.0) | 06 (01.1) | 01 (00.6) |
| Don't Know | 18 (02.6) | 16 (03.1) | 02 (01.3) |
| Refused Question | 15 (02.2) | 13 (02.5) | 02 (01.3) |
| Education | | | |
| Less Than High School *** | 316 (46.3) | 226 (43.0) | 90 (57.3) |
| High School Grad *** | 211 (30.9) | 177 (33.6) | 34 (21.7) |
| Trade Or Vocational School | 16 (02.3) | 09 (01.7) | 07 (04.5) |
| Some College *** | 81 (11.9) | 73 (13.9) | 08 (05.1) |
| Baccalaureate Degree *** | 23 (03.4) | 17 (03.2) | 06 (03.8) |
| Some Graduate School | 03 (00.4) | 02 (00.4) | 01 (00.6) |
| Graduate Degree | 20 (02.9) | 15 (02.9) | 05 (03.2) |
| Don't Know | 12 (01.8) | 06 (01.1) | 06 (03.8) |
| Refused Question | 01 (00.1) | 01 (00.2) | 00 (00.0) |

*** p<.001

Table 3. Demographic Characteristics of New Jersey Consumers (total), Self-Respondent Consumers, and Consumers with Surrogates (continued)

| Characteristic | Consumers (total) (N= 683) | Self-Respondent Consumers (N=526) | Consumers with Surrogates (N=157) |
|----------------|----------------------------------|---|---|
| | N (%) | N (%) | N (%) |
| Marital Status | | | |
| Married | 51 (07.5) | 36 (06.9) | 15 (09.6) |
| Widowed *** | 271 (39.8) | 202 (38.5) | 69 (43.9) |
| Divorced *** | 103 (15.1) | 96 (18.3) | 07 (04.5) |
| Separated *** | 43 (06.3) | 41 (07.8) | 01 (01.3) |
| Single *** | 213 (31.3) | 149 (28.4) | 64 (40.8) |

*** p< .001

Table 4. Background Characteristics of New Jersey Consumers (total), Self-Respondent Consumers, and Consumers with Surrogates⁵

| Characteristic | Consumers (total) (N= 683) | Self-Respondent Consumers (N=526) | Consumers with Surrogates (N=157) |
|----------------------------------|----------------------------------|---|---|
| | N (%) | N (%) | N (%) |
| Living Arrangement *** | | | |
| Alone | | | |
| With spouse and/or children | 371 (55.0) | 343 (66.0) | 28 (18.1) |
| With friend, partner or relat. | 122 (18.1) | 82 (15.8) | 40 (25.8) |
| | 182 (27.0) | 95 (18.3) | 87 (56.1) |
| Do you own your own home? | | | |
| Yes | 73 (10.7) | 56 (10.6) | 17 (10.8) |
| No | 607 (88.9) | 467 (88.8) | 140 (89.2) |
| Refused question | 03 (00.4) | 03 (00.6) | 00 (00.0) |
| Have you ever been employed? *** | | | |
| Yes | 522 (76.8) | 441 (84.2) | 81 (51.9) |
| No | 158 (23.2) | 83 (15.8) | 75 (48.1) |
| Employment Status | | | |
| Employed full time | 06 (01.2) | 06 (01.4) | 00 (00.0) |
| Employed part time | 13 (02.5) | 10 (02.3) | 03 (03.7) |
| Unemployed | 131 (25.5) | 112 (25.3) | 19 (23.2) |
| Retired | 349 (67.9) | 291 (67.4) | 58 (70.7) |
| Full time student | 00 (00.4) | 02 (00.5) | 00 (00.0) |
| Part time student | 00 (00.2) | 01 (00.2) | 00 (00.0) |
| Homemaker | 08 (01.6) | 07 (01.6) | 01 (01.2) |
| Volunteer | 04 (00.8) | 03 (00.7) | 01 (01.2) |

*** p<.001

⁵ Significant levels reflect the comparison made between self-respondent consumers and consumers with surrogates. Regarding “consumer employment status,” n’s vary due to a skip pattern response (some consumers did not answer this question).

Table 4. Background Characteristics of New Jersey Consumers (total), Self-Respondent Consumers, and Consumers with Surrogates (continued) ⁶

| Characteristic | Consumers (total) (N= 683) | Self-Respondent Consumers (N=526) | Consumers with Surrogates (N=157) |
|--|----------------------------------|---|---|
| | N (%) | N (%) | N (%) |
| Perception of overall physical health * | | | |
| Excellent | 26 (03.8) | 22 (04.1) | 06 (02.5) |
| Very Good | 50 (07.3) | 34 (06.5) | 16 (10.2) |
| Good | 152 (22.3) | 105 (20.0) | 47 (29.9) |
| Fair | 226 (33.0) | 184 (35.0) | 42 (26.9) |
| Poor | 215 (31.5) | 169 (32.1) | 46 (29.3) |
| Don't know | 06 (00.9) | 05 (01.0) | 01 (00.6) |
| Refused Question | 05 (01.2) | 07 (01.3) | 01 (00.6) |
| Disability level *** | | | |
| Mild | 388 (56.8) | 346 (65.8) | 42 (26.8) |
| Moderate | 156 (22.8) | 108 (20.5) | 48 (30.6) |
| Severe | 139 (20.4) | 72 (13.7) | 67 (42.7) |
| Cognition - help keeping track of bills or money *** | | | |
| Yes | 309 (45.8) | 175 (33.3) | 134 (88.2) |
| No | 338 (50.1) | 325 (62.3) | 13 (08.6) |
| Sometimes | 27 (04.0) | 22 (04.2) | 05 (03.3) |
| Cognition – help taking medicine *** | | | |
| Yes | 285 (42.1) | 157 (30.0) | 128 (83.1) |
| No | 359 (53.0) | 335 (64.1) | 24 (15.6) |
| Sometimes | 33 (04.9) | 31 (05.9) | 02 (01.3) |

* p<.05 *** p<.001

⁶ Significant levels reflect the comparison made between self-respondent consumers and consumers with surrogates.

Table 5. Background Characteristics Related to Cash & Counseling of New Jersey Consumers (total), Self-Respondent Consumers, and Consumers with Surrogates⁷

| Characteristic | Consumers (total) (N= 683) | Self-Respondent Consumers (N=526) | Consumers with Surrogates (N=157) |
|--|----------------------------------|---|---|
| | N (%) | N (%) | N (%) |
| Length of time in program | | | |
| < 6 months | 16 (02.3) | 15 (02.9) | 01 (00.6) |
| 6 to 11 months | 35 (05.1) | 28 (05.3) | 07 (04.5) |
| 1 to 2 years | 193 (28.3) | 143 (27.2) | 50 (31.8) |
| 3+ years | 423 (61.9) | 327 (62.2) | 96 (61.1) |
| Don't know | 16 (02.3) | 13 (02.5) | 03 (01.9) |
| Do you have informal care givers? *** | | | |
| Yes | 414 (60.9) | 276 (52.8) | 138 (87.9) |
| No | 266 (39.1) | 247 (47.2) | 19 (12.1) |
| Does informal worker live with you? *** | | | |
| Yes | 175 (42.3) | 78 (28.3) | 97 (70.3) |
| No | 239 (57.7) | 198 (71.7) | 41 (29.7) |
| Do you and your worker speak the same language? | | | |
| Yes | 602 (88.2) | 480 (91.3) | 122 (77.7) |
| No | 61 (08.9) | 38 (07.2) | 23 (14.6) |
| Not Certain | 13 (01.9) | 06 (01.1) | 07 (04.5) |
| Refused Question | 07 (01.0) | 02 (00.4) | 05 (03.2) |

***p<.001

⁷ Significant levels reflect the comparison made between self-respondent consumers and consumers with surrogates. Regarding “does informal caregiver live with you,” n’s vary due to a skip pattern response (some consumers did not answer this question).

Table 5. Background Characteristics Related to Cash & Counseling of New Jersey Consumers (total), Self-Respondent Consumers, and Consumers with Surrogates (continued)⁸

| Characteristic | Consumers (total) (N= 683) | Self-Respondent Consumers (N=526) | Consumers with Surrogates (N=157) |
|---|----------------------------------|---|---|
| | N (%) | N (%) | N (%) |
| How's your relationship with your worker? | | | |
| Very Close | 160 (23.4) | 131 (24.9) | 29 (18.5) |
| Somewhat Close | 359 (52.6) | 273 (51.9) | 86 (54.8) |
| Employer/Employee | 129 (18.9) | 102 (19.4) | 27 (17.2) |
| Unfriendly | 06 (00.9) | 06 (01.1) | 00 (00.0) |
| Hostile | 01 (00.1) | 01 (00.2) | 00 (00.0) |
| N/A | 12 (01.8) | 01 (00.2) | 11 (07.0) |
| Don't know | 09 (01.3) | 06 (01.1) | 03 (01.9) |
| Refused Question | 07 (01.0) | 06 (01.1) | 01 (00.6) |
| Any experience hiring, firing or interviewing any type of worker? *** | | | |
| Yes | 159 (23.6) | 142 (27.5) | 17 (10.8) |
| No | 514 (76.4) | 374 (72.5) | 140 (89.2) |
| Any experience supervising or training any type of worker? *** | | | |
| Yes | 224 (33.2) | 198 (38.2) | 26 (16.6) |
| No | 451 (66.8) | 320 (61.8) | 131 (83.4) |

*** p<.001

⁸ Significant levels reflect the comparison made between self-respondent consumers and consumers with surrogates.

Table 6. Satisfaction with Worker Characteristics - Perceptions of New Jersey Consumers (total), Self-Respondent Consumers, and Consumers with Surrogates⁹

| Characteristic | Consumers (Total) N = 683 | Self-Respondent Consumers N = 526 | Consumers with Surrogates N = 157 |
|---|--|--|--|
| My worker... | N (%) | N (%) | N (%) |
| Is frequently late | | | |
| Agree | 67 (09.9) | 53 (10.1) | 14 (09.5) |
| Disagree | 597 (88.6) | 465 (88.4) | 132 (89.2) |
| Don't Know | 10 (01.5) | 08 (01.5) | 02 (01.4) |
| Hurries too much** | | | |
| Agree | 52 (07.7) | 43 (08.2) | 09 (06.1) |
| Disagree | 613 (91.2) | 480 (91.4) | 133 (90.5) |
| Don't Know | 07 (01.0) | 02 (00.4) | 05 (03.4) |
| Does a good job | | | |
| Agree | 619 (92.3) | 486 (92.6) | 133 (91.1) |
| Disagree | 41 (06.1) | 32 (06.1) | 09 (06.2) |
| Don't Know | 11 (01.6) | 07 (01.3) | 04 (02.7) |
| Needs to be more respectful of me ** | | | |
| Agree | 76 (11.3) | 64 (12.2) | 12 (08.2) |
| Disagree | 590 (87.8) | 460 (87.6) | 130 (88.4) |
| Don't Know | 06 (00.9) | 01 (00.2) | 05 (03.4) |

** p<.01

⁹ Significant levels reflect the comparison made between self-respondent consumers and consumers with surrogates.

Table 7. Final Logistic Regression Models: Respondent Type as a Predictor of Satisfaction with Worker Characteristics

| Dependent Variable | Significance Level (Predictor Variable) | Significance Level (Control Variables) | Exp (B) |
|--|--|---|--|
| Q.32 – Worker is frequently late N=647 | Respondent Type (.362) | -- Age (.286) Gender (.889) Race (.890) Education (.255) Marital Status (.800) Disability Level (.419) Cognition/Money (.848) Cognition/Meds (.954) | 1.445 1.008 1.049 1.039 .652 .880 .740 1.066 .981 |
| Q.33 – Worker hurries too much N=645 | Respondent Type (.726) | -- Age (.613) Gender (.965) Race (.235) Education (.585) Marital Status (.187) Disability Level (.069) Cognition/Money (.101) Cognition/Meds (.920) | 1.002 1.004 .984 1.439 1.207 .471 2.012 1.912 1.439 |
| Q.34 – Worker does a good job N=644 | Respondent Type (.688) | -- Age (.923) Gender (.426) Race (.034) Education (.063) Marital Status (.492) Disability Level (.061) Cognition/Money (.518) Cognition/Meds (.319) | 1.004 1.001 1.381 2.111 1.923 1.547 2.005 .786 1.485 |
| Q.37 – Worker needs to be more respectful N=645 | Respondent Type (.196) | -- Age (.624) Gender (.068) Race (.844) Education (.170) Marital Status (.740) Disability Level (.002) Cognition/Money (.159) Cognition/Meds (.286) | 1.616 1.003 1.698 .950 1.490 .867 2.636 1.575 .719 |

REFERENCES

- Anthony-Bergstone, C. R., Gatz, M., & Zarit, S. H. Symptoms of psychological distress among caregivers of dementia patients. *Psychology and Aging*, 3, 245-248, 1998.
- Benjamin, A.E., Matthias, R. & Franke, T.M. Comparing consumer-directed and agency models for providing supportive services at home. *Health Services Research*, 35, 351-366, 2000.
- Breechling, B. G., & Schneider, C. A. Preserving autonomy in early stage dementia. *Journal of Gerontological Social Work*, 20, 17-33, 1993.
- Brorsson, B., & Asberg, K. H. Katz index of independence in ADL: reliability and validity in short-term care. *Scandinavian Journal of Rehabilitative Medicine*, 16, 125-132, 1984.
- Cohen, D. The subjective experience of Alzheimer's disease: The anatomy of an illness as perceived by patients and families. *The American Journal of Alzheimer's Care and Related Disorders & Research*, 5, 6-11, 1991.
- Cohen, M. A. Emerging trends in the finance and delivery of long-term care: Public and private opportunities and challenges. *The Gerontologist*, 38, 80-89, 1998.
- Cotrell, V. & Schultz, R. The perspective of the patient with Alzheimer's disease: A neglected dimension of dementia research. *The Gerontologist*, 33, 205-211, 1993.
- Desmond, S.M., Shoop, D.M., Simon-Rusinowitz, L., Mahoney, K.J, Squillace, M.R. and Fay, R.A. Consumer preferences for a cash option versus traditional services: New Jersey Elderly and Adults with Physical Disabilities. Telephone Survey Technical Report. Background Research for the Cash and Counseling Demonstration and Evaluation. University of Maryland, Center on Aging, College Park, MD. Fall, 1998.
- Feinberg, L.F. & Whitlach (2001). Are persons with cognitive impairment able to state consistent choices? *The Gerontologist*, 41, June, 2001.
- Feinberg, L.F., Whitlach, C.J., & Tucke, S. (2000). Making Hard Choices: Respecting Both Voices. Final Report. San Francisco, CA: Family Caregiver Alliance.
- Harris, P. B. Listening to caregiving sons: Misunderstood realities. *The Gerontologist*, 38, 342-352, 1998.
- Haug, M. R., Ford, A. B., Stange, K. C., Noelker, L, S., & Gaines, A. D. Effect of giving care on caregivers' health. *Research On Aging*, 21, 515-538, 1999.

High, D. M. All in the family: Extended autonomy and expectations in surrogate health care decision-making. *The Gerontologist*, 28, 46-51, 1988.

Hoffmann, J. C. Wenger, N. S., Davis, R. B., Teno, J., Connors, A. F., Desbiens, N., Lynn, J. & Phillips, R. S. Patient preferences for communication with physicians about end of life decisions. *Annals of Internal Medicine*, 127, 1-12, 1997.

Hosmer, D. W. & Lemeshow, S. *Applied Logistic Regression*. New York: John Wiley & Sons, 1989.

Kapp, M. B. Enhancing autonomy and choice in selecting and directing long-term care services. *The Elder Law Journal*, 4, 54-97, 1996.

Kapp, M. Healthcare in the marketplace: Implications for decisionally impaired consumers and their surrogates and advocates. *Southern Illinois University Law Journal*, 24, 1-50, Fall, 1999.

Katz, S., Hedrick, S., & Henderson, N. S. The measurement of long-term care needs and impact. *Health Medical Care Service Review*, 2, 1-21, 1979.

Mahoney, K. J. & Simon-Rusinowitz, L. Cash and counseling demonstration and evaluation start-up activities. *Journal of Case Management*, 6, 25-30, 1997.

Mahoney, K. J., Simon-Rusinowitz, L., Desmond, S. M., Shoop, D. M., Squillace, M. R., & Fay, R. A. Determining consumers' preferences for a cash option: New York telephone survey findings. *American Rehabilitation*, 4, 24-36, 1998a.

Mahoney, K. J., Simon-Rusinowitz, L., Desmond, S., Shoop, D., Squillace, M. R., and Fay, R. Synthesis of key telephone survey findings: Arkansas, New York, New Jersey, and Florida elders and adults with disabilities. Presented at : The American Public Health Association annual meeting, Washington, DC, November 17, 1998, 1998b.

Mahoney, K.J., Desmond, S.M., Simon-Rusinowitz, L., Shoop, D., & Squillace, M.R. Consumer preferences for a cash option versus traditional services: Telephone survey results from New Jersey elders and adults. *The Journal of Disability Policy Studies*, forthcoming.

McAfee, M. E., Ruh, P. A., Bell, P., & Martichuski, D. Including persons with early stage Alzheimer's disease in support groups and strategy planning. *The American Journal of Alzheimer's Care and Related Disorders & Research*, 2, 18-22, 1989.

McCullough, L. B., & Wilson, N. L. *Long-Term Care Decisions*. Baltimore, MD: The Johns Hopkins University Press, 1995.

McDowell, I., & Newell, C. *Measuring Health-A Guide to Rating Scales and Questionnaires*. New York: Oxford University Press, 1996.

- McHorney, C. A. Measuring and monitoring general health status in elderly persons: Practical and methodological issues in using the SF-36 health survey. *The Gerontologist*, 36, 571-583, 1996.
- Mittelman, M. S., Ferris, S. H., Shulman, E., Steinberg, G., Ambinder, A., Mackell, J. A., & Cohen, J. A comprehensive support program: Effect on depression in spouse-caregivers of AD patients. *The Gerontologist*, 35, 792-802, 1995.
- Ouslander, J. G., Tymchuk, A. J., & Rahbar, B. Health care decisions among elderly long-term care residents and their potential proxies. *Annals of Internal Medicine*, 149, 1367-1372, 1989.
- Simon-Rusinowitz, L., Mahoney, K. J., Desmond, S. M., Shoop, D. M., Squillace, M. R., and Fay, R. A. Determining consumer preferences for a cash option: Arkansas survey results. *Health Care Financing Review*, 19 (2), 73-96, 1997.
- Simon-Rusinowitz, L., Mahoney, K.J., Desmond, S.M., Squillace, M.R., Shoop, D.M., & Fay, R.A. Determining consumers' preferences for a cash option: Background research to support the Cash and Counseling Demonstration and Evaluation. Synthesis of key telephone survey findings: Arkansas, New York, New Jersey, and Florida elders and adults with disabilities. Paper presented at The Gerontological Society of America 51st Annual Scientific Meeting, Philadelphia, PA. November 1998.
- Spector, W. D. Functional disability scales. In Spilker, B. *Quality of Life and Pharmacoeconomics in Clinical Trials*. Philadelphia: Lippincott-Raven Publishers, 1996.
- Spector, W. D. Cognitive Impairment and Disruptive Behaviors Among Community-Based Elderly Persons: Implications for Targeting Long-Term Care. *The Gerontologist*, 31, 51-59, 1991.
- Tomlinson, T., Howe, K., Notman, M., & Rossmiller, D. An empirical study of proxy consent for elderly persons. *The Gerontologist*, 30, 54-60, 1990.
- Wetle, T., Levkoff, S., Cwikel, J. & Rosen, A. Nursing home resident participation in medical decisions: Perceptions and preferences. *The Gerontologist*, 28, 32-38, 1988.
- Whitlatch, C. J., Friss Feinberg, L., & Sebesta, D. S. Depression and health in family caregivers. *Journal of Aging and Health*, 9, 222-243, 1997.
- Wiener, J. M., Clauser, S. B. & Kennell, D. L. *Persons with disabilities: issues in health care financing and service delivery*. Washington, DC: The Brookings Institution, 1995.
- Zarit, S.H. & Goodman, C.R. Decision making and dementia. *American Journal of Alzheimer's Care and Related Disorders and Research*, 5, 22-28, 1990.

Zacharias, B. L.: Cash and counseling demonstration and evaluation Personal Preference: Report on New Jersey Post-Survey Focus Groups. The University of Maryland, Center on Aging, College Park, MD, 1998a.

Zacharias, B. L.: Cash and counseling demonstration and evaluation Report on New York Post-Survey Focus Groups. The University of Maryland, Center on Aging, College Park, MD, 1998b.

Zacharias, B. L.: Cash and counseling demonstration and evaluation Independent Choices: Report on Arkansas Post-Survey Focus Groups. The University of Maryland, Center on Aging, College Park, MD, 1998c.

Zacharias, B. L.: Cash and counseling demonstration and evaluation Consumer Directed Care: Report on Florida Post-Survey Focus Groups. The University of Maryland, Center on Aging, College Park, MD, 1998d.

Zweibel, N. R. & Cassel, C. K. Treatment choices at the end of life: A comparison of decisions by older patients and their physician-selected proxies. *The Gerontologist*, 29, 615-621, 1989.