MEASURING SATISFACTION WITH CAREGIVING:

A METHODOLOGICAL STUDY

by

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Abstract

This paper discusses the development and testing of a scale designed to measure satisfaction with caregiving as perceived by older persons dependent upon informal care from family members or friends. A 10-item scale was constructed to reflect two dimensions of this construct: 5-items measuring the affective aspects of caregiving, and 5-items measuring the instrumental aspects of informal care. A sample of 38 caregiving/receiving dyads was used for the testing of this instrument. Internal consistency reliability (Cronbach's alpha) for the 10-itme scale was .88, for the affective subscale .84, and for the instrumental .72. Construct validity was supported by a Pearson's correlation of .54 ($p<.001$) between the 10-item scale and a global measure of satisfaction with family caregiving. Additionally, expected correlations between this construct and other caregiving variables such as, caregiver mutuality ($r=.33$), and care receiver health ($r=.34$) were significant ($p<.05$) and provided evidence of the instruments construct validity and utility for measuring satisfaction with caregiving.

Key words: caregiving, aged, satisfaction, informal care.

Measuring Satisfaction with Caregiving: A Methodological Study

Along with nurturing the young, the family unit has been and continues to be a primary source of support for the frail elderly in our society (Shanas, 1979). Indeed, an estimated 60 to 80 percent of the long-term care needs of the elderly are provided informally by family members (Comptroller General, 1977). Yet, recent and projected demographic changes, and socio-political shifts are progressively placing limitations upon the family's ability to conduct the caregiver role.

Currently, our understanding of specific factors which determine and identify successful family caregiving is limited. A number of recent studies exploring family caregiving have focused upon its consequences for the caregiver (Archbold, 1982; Cantor, 1983; Fengler & Goodrich, 1979; Farkas, 1980; Montgomery & Borgatta, 1985; Robinson, 1983; Zarit, 1980). However, little attention has been given to the elderly person as a recipient of this informal care. The literature is replete with studies exploring social and family support networks of the elderly and much has been written regarding the older person's life satisfaction and morale. Yet, studies measuring the satisfaction of the older, frail person dependent upon informal, family care have not been found by this author.

This paper describes the development and pretesting of an instrument designed to measure the construct of satisfaction with caregiving, as expressed by the frail, older person in the care-receiving role. Accurate measurement of care-recipient satisfaction can contribute to a better understanding of the dynamics of the caregiving/receiving dyad. Specifically, the measure may be used as either a dependent variable, to reflect the outcome of care, or possibly as an interactive variable reflective of the dyadic relationship.

Literature Review

Satisfaction is a complex abstraction that is not easily defined or measured. This complexity is reflected by inconsistent operational definitions of the construct, as well as the existence of similar overlapping constructs (e.g., morale, happiness, compatibility, adjustment, etc.) which measure many of the same dimensions found in satisfaction research. Four areas of research in which satisfaction measures are commonly used are job satisfaction, marital satisfaction, life satisfaction and patient satisfaction. Of these, the construct of patient satisfaction is most similar to the one of interest here, with the difference that patient satisfaction typically concerns formal care delivered by professionals, whereas the current study focuses on informal care from nonprofessionals.

Hypothesizing that specific antecedent variables of perception and attitude are determinants of satisfaction, Linder-Pelz (1982) defined the construct of patient satisfaction as "the individual's positive evaluations of distinct dimensions of health care" (p. 580). In their extensive review of patient satisfaction literature, Ware, Davis-Avery, and Stewart (1977) noted eight dimensions of care that were most commonly measured: "art of care, technical quality of care, accessibility/convenience, finances, physical environment, availability, continuity, and efficacy/outcomes of care" (p. 4). Of these dimensions, the first two--the art of care and the technical quality of care--reflect the conduct of the caregiver and appear especially applicable to the delivery of informal care.

The art of care, or the degree to which care is delivered in an affectively positive manner, is the most frequently measured dimension of patient satisfaction. It is described as "the amount of 'caring' shown toward patients" as an "aspect of provider conduct" (Ware et al., 1977, p. 4). This dimension can be viewed as the manner in which care is delivered. Included in this dimension are positive aspects such as, "concern, consideration, friendliness, patience, and sincerity;" and negative aspects such as "abruptness, disrespect, and the extent to which providers embarrass, hurt, insult, or unnecessarily worry their patients"

(Ware et al., p. 4). The technical quality of care is a dimension which is largely concerned with the instrumental aspects of care delivery, such as the skill the caregiver exhibits. This dimension also reflects caregiving aspects such as "ability, accuracy, experience and thoroughness" (Ware et al., p. 5).

Two similar dimensions of caregiver behavior impacting patient satisfaction have been found in a study by Ben-Sira (1976). The "mode" or affective behavior of the service provider, defined by Ben-Sira as "the degree of emotional support...that accompanies the course of treatment" (p. 5), is analogous to the art of care. Similar to the technical quality of care is the "content" or skill and technical activities exhibited by the professional.

Method

This study comprises a portion of a larger methodological study involving the development and pretesting of new measures for 16 caregiving constructs. Recognizing the need "to improve the measurement and longitudinal analysis of family caregiving variables" (p. 34), Archbold and Stewart (1984) developed a comprehensive pretest interview schedule which included measures focusing on both the caregiver and the older person receiving informal care. Among the newly developed measures included in this interview schedule was the measure of interest, satisfaction with caregiving. These pretested and refined measures are

currently being used in a longitudinal study entitled, "The Effects of Organized Family Caregiver Relief."

The development and evaluation of the pretest versions of these measures occurred in two phases: Phase I, the construction of the measures, and Phase II, the psychometric evaluation of the measures. The study reported here focuses on Phase I and Phase II activities for the development and pretesting of the Satisfaction with Caregiving scale.

Phase I: Construction

Definition and dimensions. The development of measures for the construct of satisfaction with caregiving involved both deductive and inductive activities. Initially, the definition and dimensions were drawn from the patient satisfaction literature. The construct, satisfaction with caregiving, was accordingly defined as, a positive evaluation and expressed contentment regarding the care received from a family member or friend. Additionally, the construct was thought to contain two dimensions--satisfaction with the instrumental aspects and satisfaction with the affective aspects of care received. These are analogous to the patient satisfaction dimensions--art of care and technical quality of care. During Phase I, the definition of satisfaction with caregiving was further refined as, a positive evaluation of the instrumental aspects of care received, and an

expressed contentment with the affective aspects of caregiving.

Open-ended interviews. Because little is known about satisfaction within the context of informal caregiving, an inductive process proved useful for identifying the domain of the construct. An initial interview schedule with open-ended questions was constructed and administered to 32 individuals, of whom 17 were family caregivers to an impaired older person, 2 were health care professionals knowledgeable of informal family care, and 13 were older persons in the care-recipient role. These subjects were chosen on the basis of convenience and willingness to participate. Questions were asked regarding satisfaction and the 15 other constructs for which measures were being developed. These open-ended questions were designed to elicit responses that would make apparent the key words and components of the construct and to explore the two dimensions, as defined.

Those questions asked of the care receiver reflecting the instrumental aspects of care included: "The things (caregiver) does the best in helping me are...;" and "The things I'd like to see (caregiver) change in what (s/he) does to help me are..." Items reflecting the affective aspects of care were: "What I enjoy most about the way (caregiver) helps me include...;" and "What I enjoy least about the way (caregiver) helps me include..."

Qualitative analysis of the responses of care receivers to

these questions and additional responses provided by the other interviews (caregivers and health professionals) substantiated the construct definition and dimensions. A content analysis of these statements and previous patient satisfaction literature provided the basis for the construction of a closed-ended instrument.

Instrument draft. The initial closed-ended instrument was drafted and revised several times. Two major considerations in composing the closed-ended items were: maintaining simplicity to ensure comprehension and avoiding socially desirable responses. Because the population of interest was composed of frail, older persons with a range of cognitive abilities, it was considered necessary to make the administration of the scale as simple as possible while maintaining precision. For that reason, items were developed in the form of questions which required a 'yes/no' response from the care receiver. Because dichotomous response choices lack precision and restrict the range of responses, a 'yes' response from a care receiver was followed by an additional question which asked the care receiver if that aspect of care was true "sometimes," "most of the time," or "always."

Although simplicity is important, it was necessary for the tool to have adequate complexity in order to discourage socially desirable responses. The introduction, for example, is rather lengthy, but was worded in a manner meant to encourage frank

responses. Additionally, because the instrument is asking older persons to evaluate individuals upon whom they are dependent, it was thought best do so only indirectly, that is, by asking the care-receiver to evaluate the care [italics added] received rather than the person [italics added] who was giving the care.

During this drafting and revising phase, several versions of the scale were administered to five older persons, four of whom were institutionalized and one who was at home receiving care from a family member. These persons were selected on the basis of convenience, willingness to participate, and adequate cognitive ability. The intent of this initial administration was to test the clarity of the wording of the items, as well as the relevance (as perceived by the respondents) of the items to the construct. Except for minor wording changes, the clarity of the language appeared acceptable, as did the relevance of the items to the construct of satisfaction with caregiving.

Additionally, a panel of 15 experts, who are themselves knowledgeable regarding instrument construction and the field of gerontology and/or family caregiving, evaluated the items in the pretest interview schedule. Specifically, the experts were asked to judge: the 'fit' of the items to each specific construct, whether the items adequately sampled the domain of the construct, and whether any items were measuring a construct outside the

domain of interest. Finally, they were asked to evaluate the clarity of the items. This review by the experts provided the basis for establishing the content and face validity of the instrument.

The final draft of the pretest instrument (see Figure 1) consisted of a 10-item scale, comprised of two subscales. Five items (#3,4,6,9,10) measured the affective dimension and five items (#1,2,5,7,8) measured the instrumental aspects of family caregiving. Each of the 10 items had a 4-point response range with "no" (0) indicating a lack of satisfaction with that aspect of care, and 1 through 3 indicating increasing degrees of satisfaction ("sometimes," "most of the time," and "always"). In addition, a global measure of satisfaction with family caregiving (item 11) was added to provide one means of testing the construct validity of the scale.

Phase II: Psychometric Evaluation

The final draft of the Satisfaction with Caregiving scale was pretested together with measures of the 15 other constructs under development. These new measures along with other existing measures relevant to the caregiving situation were included in the pretest interview schedules. Two interview schedules were created--one to be administered to the caregiver and the other to the care receiver. The latter included the Satisfaction with

Caregiving scale. The purpose of Phase II was to determine the internal consistency reliability of all the new measures, including the Satisfaction with Caregiving scale and to obtain initial evidence for construct validity.

Sample. The sample chosen for this phase of the study consisted of 50 caregiving dyads. These were composed of the older, frail person receiving supportive care at home (care receiver) and the family member or friend administering the care (caregiver). Face-to-face interviews with both the caregiver and care receiver were administered by two nurses, or a nurse and a psychologist at the caregiver's and care receiver's place of residence. Having two interviewers enabled the caregiver and care receiver to be interviewed separately and privately. This convenvience sample was selected to include a broad range of caregiving situations. Approximately one third of the participants were accessed from a Parkinson's clinic, one third were from the home health services of a large metropolitan health maintenance organization, and one third were referrals from nurses in other clinical settings.

Of these 50 dyads, 11 care receivers were unable or unwilling to participate in the interviews due to frailty and/or cognitive impairment. In these cases, basic demographic and health characteristics of the care receiver were obtained from the

caregiver via a proxy interview schedule. However, the Satisfaction with Caregiving scale and other care receiver variables thought inappropriate to ask the caregiver were excluded from the proxy interview. Also eliminated were data from the first care receiver interviewed, as changes were made in the wording of the response options for the satisfaction scale subsequent to that interview. The final subsample for the psychometric evaluation of the Satisfaction with Caregiving scale, therefore, included 38 dyads.

Descriptive data. The following is a description of the care receiver sample (n = 38). Because the construct of interest in this study focuses on the care receiver, caregiver demographic data are not included. The care receivers in this study consisted of 47% (18) males and 53% (20) females. Their ages ranged from 44 to 89 with the mean age being 76 years. While 11% (4) attended college, and 16% (6) were college graduates, half (19) did not complete high school. The average annual income of these subjects ranged from under $3,000 to over $45,000. Twenty-four percent (9) received less that $15,000, 24% (9) received over that amount, and 53% (20) didn't know or refused to answer. Only 5% (2) said they couldn't make ends meet, 42% (16) had "just enough" to "a little extra sometimes," and 42% (16) indicated they "always have money left over."

Eighteen percent (7) of the respondents rated their health as poor, 34% (13) as fair, and 42% (16) as good or excellent. Half (19) indicated that their health was "the same" to "much better than" one year ago, while 24% (9) indicated that their health was a "little worse," and 26% (10) indicated it was "much worse." Mobility, rated on a 6-point scale, from "have to stay in bed all or most of the time" to "I'm not limited in any of these ways," had only 13% (5) with "no limitations," 21% (8) had "trouble getting around freely," and 23 or 61% "need the help of some special aid" or "person." Five percent (2) are confined in the house or bed "all or most of the time." Finally, the relationships of most of these caregiving and care receiving dyads were spousal with 74% (28) of the care receivers being either a husband or wife. Twenty-one percent (8) were cared for by offspring and only two (5%) were cared for by a nonrelative or friend.

Analysis

Reliability

Internal consistency reliability. Cronbach's alpha was calculated to determine the internal consistency reliability of the 10-item scale and the two 5-item subscales. Cronbach's alpha for the overall total scale was .88 with a mean inter-item correlation of .47 (see Table 1). The alpha coefficient for the

5-item instrumental subscale was .72, and for the 5-item affective subscale .84, with mean inter-item correlations of .39 and .56 respectively. Except for two nonsignificant correlations in the instrumental subscale (the "thorough" item with "skillful" and "promptly"), all the items correlated significantly ($p<.05$) with each other within each respective subscale (see Table 2).

However, the instrumental and affective items were significantly correlated across subscales as well. the correlation between the two subscales was .79 ($p<.001$). As depicted by Table 3, the correlations of four of the instrumental items ("skillful," "promptly," "appropriate," "dependable") and one of the affective items ("patiently") were greater in magnitude with items outside their respective subscale than the correlations within the same subscale. Combining all 10 items in the total scale results in an increased corrected item-total correlation for all but two of the affective items (see Table 1). The alpha coefficient, likewise, increases with the combination of all the items into one scale.

Interrater reliability. To estimate interrater reliability, a case study interview was performed and taped. The responses of all five raters who listened to the taped interview were 100% in agreement in their ratings of the 10 items of the Satisfaction with Caregiving scale and the global satisfaction measure.

Computation and Distribution of Scores

Scores for the total scale and the two subscales were computed by averaging responses to the items on each scale. A care receiver with responses missing on more than 25% of the items for the total scale or either subscale was assigned a missing value for that respective scale or subscale. For care receivers answering at least 75% of the items on the total scale or subscale, average scores were computed based on those items answered. As shown in Table 4, the distribution of scores for the total scale and the subscales were negatively skewed (-1.2) with mean values ranging from 2.62 to 2.68.

Construct Validity

Construct validity was approached in two ways. The first method was by correlating the subscales with the global rating of satisfaction with caregiving (item 11). This item asked the care-receiver to rate his/her overall satisfaction with the care received from his/her caregiver on a range from 1 to 10. The total 10-item scale was correlated (r=.54, p<.001) with the global rating (see Table 5). In addition, the two satisfaction subscales were also significantly correlated with the global rating: the affective subscale r=.57, (p<.001); and the instrumental subscale r=.45, (p<.005).

The second method for establishing evidence of construct validity was by looking at the correlations of the satisfaction

subscales with other scales and items measuring constructs and variables which should logically have a relationship to Satisfaction with Caregiving. These hypothesized relationships fall within the general categories of caregiver variables, care receiver variables, and the variables of the dyadic relationship. Only those scales with a reliability of .70 or greater were used in these analyses, and correlations with single, dichotomous items were avoided. Additionally, measures that were otherwise considered methodologically weak were excluded from these analyses.

Caregiver variables. As depicted in Table 6, the antecedent variables of the caregiver (caregiver age, gender, education, income and health) were not significantly correlated with the two satisfaction subscales. These were single item measures, excluding the Number of Health Problems and Subjective Health scales. The former consisted of a scale of 18 health problems common to caregivers and the latter contained two items--one asking caregivers to rate their health from "poor" to "excellent" in relation to others their age, and an item asking the caregivers to compare their health now to what it was one year ago.

The Nature of the Role scale consisted of 42 dichotomous items measuring common caregiving dimensions including personal care, housekeeping, protection, financial and legal assistance,

transportation, medically related tasks, handling behavior problems, little extras, and miscellaneous tasks. Neither the affective nor the instrumental subscales were significantly correlated with the nature of the role. Duration of the caregiving relationship, or how long the caregiver had been giving care, also did not show a significant relationship to satisfaction.

Following each item of the Nature of the Role scale was a related question that asked the caregiver to rate how hard each relevant task was to perform. These were rated on a 1 to 4 scale using the response options "easy," "not too hard," "pretty hard," and "very hard." This overall scale of 42 items measuring caregiver role strain related to these direct care activities was not significantly related to satisfaction with caregiving. No significant correlations were found between satisfaction and two other multi-item scales measuring dimensions of caregiver role strain: strain associated with worry was a 10-item scale asking the caregiver to rate over a 4-point range ("not at all," "a little," "some," "a lot") how much they worried about the well-being of the care receiver; for example, "how much do you worry about (care receiver)'s health condition?..." Additionally, a 5-item scale measuring strain due to stress in the relationship was also not significantly correlated with either dimension of satisfaction.

However, a significant correlation (r=.34, p<.05) was found with a single global measure of caregiver role strain and the affective aspects of satisfaction. This global measure asked the caregiver to estimate overall, whether the positive aspects of caregiving "outweigh the negative" (3), "the negative outweigh the positive" (1), or whether the positive and negative aspects were "about equal" (2). Also, both dimensions of satisfaction were significantly negatively correlated with an item asking the caregiver if the care receiver "seems like a different person" (2), or "pretty much the same as before" (1) caregiving began (instrumental r=-.40, p<.05 and affective r=-.39, p<.05). Qualitative data by Phillips (personal communication with P. Archbold, 1984) suggests that this perception of "difference" may be an indicator of potential abuse and thus, may be related to satisfaction with caregiving.

Additional caregiver variables of interest were items asking the caregiver to rate (on a 4-point scale) "how much was learned" about caregiving from various sources. A significant negative correlation (p<.05) was found with both dimensions of satisfaction (instrumental r=-.29; affective r=-.35) and the extent to which the caregiver learned to take care of the care receiver by "trial and error." The extent to which the caregiver "learned from health professionals" regarding community services for the care receiver was positively correlated with the affective dimension.

Finally, a 4-item scale measured the extent (over a 4-point range) of preparedness for the caregiving role (including: how well-prepared for the care receiver's physical and emotional needs, stress of caregiving and overall preparedness). This was significantly correlated (r=.34, p<.05) with the affective aspects of care, but not with the instrumental subscale.

Care receiver variables. Measures in the care receiver interview schedule included antecedent variables (care receiver age, gender, education, income, health) and care needs (see Table 7). Compared to younger care receivers, older care receivers reported significantly higher satisfaction with the instrumental aspects of care (r=.28, p<.05). No other antecedent variables were significantly related to satisfaction with caregiving except for a subjective health measure. The three health measures were single items: mobility, subjective health compared to others the same age, and subjective health as compared to one year ago. Only the last variable was significantly correlated with satisfaction. Care receivers who reported that their health now was better than one year ago expressed more satisfaction with the affective aspects of care than did care receivers who reported their health was worse (r=.34, p<.05).

The total care needs as perceived by the care receiver included items that mirror those in the caregiver subscales

measuring the nature of the caregiving role: i.e., housekeeping, protection, financial/legal assistant, transportation, personal care, little extras, medically related and miscellaneous tasks. This 36-item scale measuring the amount of care that the care receiver felt was needed, did not correlate significantly with the satisfaction perceived with the instrumental or affective aspects of this care.

Dyadic relationship variables. The items and scales measuring aspects of the caregiver/care receiver relationship were those of status of the relationship, duration of the relationship and caregiver/care receiver mutuality (see Table 8). For the 36 family caregiving dyads, the status of the dyadic relationship was either spousal (1) or child/parent (2). Most (78%) of the dyads were spousal. The type of dyadic relationship had no correlation with either subscale of satisfaction. However, the duration of the relationship did; the longer the caregiver and care receiver had known each other, the more positive was the care receiver's evaluation of the instrumental aspects of caregiving.

Thirteen items measured the mutuality expressed by the caregiver and by the care receiver. Six of these items measured the affective sharing between the dyads: for example, "We love each other very much." Two items measured the amount of sharing and confiding expressed toward the other, and five items measured

the amount of affective expression perceived to be received from the other. The interview schedules for both the caregiver and care receiver contained comparable items. The two 13-item scales for both the caregiver and care receiver were significantly and logically related to satisfaction with the affective aspects of caregiving (r=.33 and .45 respective, p<.05).

Discussion

The results of this study must be considered within the context of the limitations imposed by the sample used for these analyses: (a) the sample size was small (n = 38); (b) the sample was not representative of the general population receiving informal care in the community (e.g., approximately one third of the subjects had Parkinson's disease); and (c) nearly 20% of the care receivers were eliminated from the sample due to a lack of cognitive ability and/or physical frailty.

Further limitations are imposed by the tendency of this frail, vulnerable population to respond in a socially desirable manner. Acquiescence is not surprising when respondents are asked to evaluate the persons upon whom they are dependent. Socially desirable response sets usually result in a restricted range of responses in the positive direction which limit the instrument's reliability and usefulness for making correlations with other caregiver variables.

Reliability. The alpha reliability coefficients for the total scale and two subscales of the satisfaction measure appear to substantiate their internal consistency. The inter-item correlations provide further evidence of homogeneity. However, this homogeneity extends across subscales as well as within, making it unclear whether the two subscales are measuring different dimensions of satisfaction as intended (i.e., instrumental and affective). Studies measuring patient satisfaction with formal care providers have also found it difficult to distinguish between these two dimensions (Ware, Davies-Avery & Stewart, 1977). There may be several reasons for this ambiguity. The operational definitions of these dimensions may not be clearly distinct. The items themselves may not be worded clearly to allow the respondents to make a differentiation between the dimensions. Socially desirable response sets may preclude the respondents' ability to make this distinction (i.e., a reluctance to be critical of the caregiver in either dimension). Finally, it may be that the instrumental dimension has an affective component that cannot be distinguished from the affective dimension.

Validity. Despite the above limitations, some conclusions can be drawn regarding the construct validity of this instrument. The correlations with the caregiver variables are, for the most part,

interesting and logical. For example, the indicator of potential abuse was negatively correlated with both instrumental and affective aspects of care. The direction and magnitude of this correlation suggests that potential abuse and dissatisfaction with care are related, and may be interactive with each other.

Also interesting is the negative correlation between both subscales of satisfaction and the variable of learning caregiving by trial and error. When considered with the positive correlations of the affective subscale with the amount learned from health professionals regarding community services and the overall preparedness scale, the relationships appear to provide evidence that the quality of caregiving is impacted by how well the caregivers perceive they have learned their role and the extent learned regarding available community services. Further, the important role of the health care professional is underscored with this finding.

Finally, a significant correlation was found between the affective aspects of care and the caregiver variable measuring the positive aspects of caregiving in relation to the negative. While this relationship appears logical, it is puzzling that the two caregiver measures of caregiver role strain due to worry and associated with direct care do not show a similar correlation with satisfaction. There is also no significant correlation with the

measure of caregiver role strain due to stress in the caregiving relationship. It could be assumed that some dimensions of caregiver role strain are indications of how willing the caregiver is to expend energy and effort on the care tasks, in which case the strain incurred is a result of this conscientious care. The care receiver would then be satisfied in the presence of caregiver role strain and not dissatisfied.

Only two care receiver variables were significantly correlated with satisfaction: care receiver age with the instrumental aspects, and subjective health compared to one year ago with the affective aspects. The latter correlation would appear to reflect indirectly on the quality of care received; assuming the care receiver perceived his or her health improvement or decline as an outcome of care. However, the instrumental aspects of care in this case would also be expected to show a significant relationship with this variable, which it does not.

The correlation of age with the instrumental dimension of satisfaction is also intriguing, but difficult to explain. The Dyadic Relationship variable duration of the relationship is also correlated with the instrumental aspects of care. It is likely that the older care receivers, who have had longer relationships with the caregiver are spousal dyads. These would be life-long, intimate relationships where instrumental needs are more likely to

be recognized and met. However, the status of the relationship distinguishing between spousal and child/parent relationships did not prove to be significantly correlated with satisfaction.

Lastly, the significant correlations of the caregiver and care receiver mutuality scales with the affective dimension of satisfaction are logical and appear to provide direct evidence of the validity of this subscale. However, it is possible that the mutuality scales are subject also to socially desirable response sets, which would be reflected in these correlations. Therefore, although low scores on this scale may correctly indicate some degree of dissatisfaction with caregiving, the higher scores may be measuring something other than the two dimensions of satisfaction.

Conclusions

Overall, evidence of internal consistency reliability and construct validity are presented with the results of this study. The affective dimension appears a more consistent measure of satisfaction with caregiving, correlating significantly with twice as many caregiving constructs, and having greater internal consistency, and a higher alpha coefficient that the instrumental subscale. This is consistent with findings from patient satisfaction research where the emotional support received from formal care providers was found to be more predictive of patient

satisfaction than the content or technical quality of care (Ben-Sira, 1976). Yet the higher alpha coefficient of the total scale provides a rationale for the combination of the two subscales into one scale.

Given the lack of previous research in the area of care receiver satisfaction, the results of this study are considered preliminary, and have provided the basis for modifications and refinement of the instrument. Specifically, recent changes in the instrument include: (a) a response option of "almost always" has been added, creating a 5-point response range with the intent of spreading the responses and increasing the variability; (b) a large-type version was created to be self-administered when possible, allowing the care receiver privacy while responding with the intent of decreasing the tendency of social desirability; (c) the importance of performing tasks related to social needs has been recognized by researchers (Knipscheer, 1985; Lipman & Longino, 1980) thus, an item was added to the total scale to measure this dimension of caregiving; and (d) an item has also been added to the instrument asking the care receiver to compare the care from the caregiver with care given in similar situations.

This modified Satisfaction with Caregiving scale (see Figure 2) is presently being utilized to collect data on 158 caregiving dyads in the longitudinal study, Effects of Organized

Family Caregiver Relief. These data will provide further opportunity to establish the internal consistency reliability and construct validity of this scale.

A valid, reliable instrument measuring care receiver satisfaction can be useful both for research purposes and for direct application by clinicians. Levels of satisfaction/dissatisfaction can be used along with other measures as indicators of the types and intensities of intervention needed in a caregiving situation, or to evaluate the outcome of specific interventions. Assessing satisfaction over time allows a longitudinal picture of the dyadic relationship, and suggest at what time interventions should be made. In-home supports, for example, might be found necessary in many situations to augment family caregiving and prevent caregiver role strain, premature institutionalization, and elder abuse. Finally, with decreasing resources and increasing reliance upon the family as caregivers to our elderly population, the development of adequate tools for measuring variables related to family caregiving, provide a means for documenting the effects of family caregiving. Documentation, in turn, provides a rationale for implementing policy changes necessary to optimize the family caregiving role.

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APPENDIX A

Tables

Table 1

Item Analysis For Instrumental and Affective Subscales

Subscale/Item	Corrected Item-Total Correlation	
	With Respective Subscale Score	With Total Score
Total Scale[a]		
Instrumental[b]		
Skillful	.47	.58
Thorough	.35	.36
Promptly	.55	.59
Appropriate	.62	.71
Dependable	.60	.69
Affective[c]		
Patiently	.59	.72
Interest	.73	.67
Devotion	.79	.72
Time	.75	.78
Concern	.52	.53

[a]Alpha coefficient = .88; Mean inter-item correlation = .47

[b]Alpha coefficient = .72; Mean inter-item correlation = .39

[c]Alpha coefficient = .84; Mean inter-item correlation = .56

Table 2

Correlation Matrix of Single Items and Global Item

Items	1	2	3	4	5	6	7	8	9	10
Global	.16	.22	.48	.29	.56	.38	.44	.49	.56	.45
1. Skillful		.23	.41	.43	.34	.63	.47	.46	.39	.34
2. Thorough			.26	.33	.31	.28	.27	.29	.36	.14
3. Promptly				.46	.51	.43	.45	.41	.59	.40
4. Appropriate					.60	.73	.40	.55	.66	.35
5. Dependable						.61	.36	.53	.62	.60
6. Patiently							.47	.58	.60	.34
7. Interest								.72	.72	.54
8. Devotion									.72	.55
9. Enough Time										.38
10. Concern										

Note. Correlations $\geq .28$ are significant at $p < .05$.

Table 3

Correlation Coefficients for Items Within and Outside Subscales

	Item Correlations			
	Within Subscale		Outside Subscale	
Subscale/Item	Range	Mean	Range	Mean
Instrumental[a]				
Skillful	.23 to .43	.35	.34 to .63	.46
Thorough	.23 to .33	.28	.14 to .36	.27
Promptly	.26 to .51	.41	.40 to .59	.46
Appropriate	.33 to .60	.46	.35 to .73	.54
Dependable	.31 to .60	.44	.36 to .62	.54
Affective[b]				
Patiently	.34 to .60	.50	.28 to .73	.54
Interest	.47 to .72	.61	.27 to .47	.39
Devotion	.55 to .72	.64	.29 to .55	.45
Time	.38 to .72	.61	.36 to .66	.52
Concern	.34 to .55	.45	.14 to .60	.37

[a]Instrumental Subscale: Range = .23 to .60; $\bar{r}$ = .39.

[b]Affective Subscale: Range = .34 to .72; $\bar{r}$ = .56.

Table 4

Frequencies of Scores For Total Scale and Instrumental and Affective Subscales

Scores	Total	Instrumental	Affective
2.81 - 3.00	17	17	18
2.61 - 2.80	4	2	6
2.41 - 2.60	8	3	3
2.21 - 2.40	2	7	2
2.01 - 2.20	2	4	2
1.81 - 2.00	3	2	4
1.61 - 1.80	-	1	1
1.41 - 1.60	-	-	1
1.21 - 1.40	1	-	-
1.01 - 1.20	-	1	-
M	2.65	2.62	2.68
Md	2.78	2.75	2.88
SD	.41	.44	.42

Note. 0.00 = No; 1.00 = Sometimes; 2.00 = Most of the Time; 3.00 = Always.

Table 5

Correlation Matrix of Total Scale, Subscales and Global Item

Scales/Subscales	Instrum.	Affect.	Global
Total Scale	.95**	.94**	.54**
Instrumental		.79**	.45*
Affective			.57**

*p<.005

**p<.001

Table 6

Correlations of Caregiver Variables With the Instrumental and Affective Subscales of Satisfaction With Caregiving

Variable	Alpha Coeff.[a]	Instrumental r	Affective r
Age		.26	.19
Gender		.02	.07
Subjective Health		-.03	.06
Mobility		-.02	-.15
No. Health Prob.	.73	.10	.22
Education		-.18	.05
Income Category		-.23	-.23
Income Adequacy		-.04	.06
Nature of Role	.81	.13	.19
Strain/Direct Care	.90	.00	.19
Strain/Worry	.78	-.14	-.06
Strain/Stress	.70	.02	.02
Duration		-.06	-.04
Positive>Negative		.25	.34*
Potential Abuse		-.40*	-.39*
Trial & Error		-.29*	-.35*
Comm. Serv./Prof.		.20	.29*
Total Preparedness	.72	.21	.34*

*p<.05

[a]For multi-item scales only.

Table 7

Correlations of Care Receiver Variables With the Instrumental and Affective Subscales of Satisfaction With Caregiving

Variable	Alpha Coeff.[a]	Instrumental r	Affective r
CR Age		.28*	.24
Gender		-.03	-.13
Health/Others		.07	.20
Health/1 Year Ago		.15	.34*
Mobility		.08	.15
Education		.01	.08
Income Category		-.13	.03
Income Adequacy		-.04	.16
Total Care Needs	.91	-.07	-.06

*p<.05

[a]For multi-item scales only.

Table 8

Correlations of Dyadic Relationship Variables With the Instrumental and Affective Subscales of Satisfaction With Caregiving

Variable	Alpha Coeff.[a]	Instrumental r	Affective r
Status/Rel.		.03	.01
Duration/Rel.		.32*	.18
CR Mutuality	.87	.24	.45*
CG Mutuality	.92	.23	.33*

*p<.05

[a]For multi-item scales only.

APPENDIX B

Figures

Figure 1

****

Satisfaction with Caregiving

****

We know that older persons, for a variety of reasons, may be satisfied with some aspects of the care they receive from family members or friends, and not satisfied with other aspects of this care. We are interested in how you feel regarding the care you receive from your (RELATIONSHIP OF CAREGIVER), and ask that you respond to the following questions as honestly as possible. We really want to know how you feel, personally. Please remember that your answers will be known only to our research team.

A. Do you feel that the care you receive from your (RELATIONSHIP OF CAREGIVER) is skillful and competent?

No.....0
Yes.....Would you say that this is true:
Sometimes.....1
Most of the time.....2
Always.....3

B. Do you feel that your needs are taken care of thoroughly?

No.....0
Yes.....Would you say that this is true:
Sometimes.....1
Most of the time.....2
Always.....3

C. Do you feel that care is given to you patiently?

No.....0
Yes.....Would you say that this is true:
Sometimes.....1
Most of the time.....2
Always.....3

D. Do you feel that interest is expressed in the care you need?

No.....0
Yes.....Would you say that this is true:
Sometimes.....1
Most of the time.....2
Always.....3

E. Do you feel that your needs are taken care of promptly?

No.....0
Yes.....Would you say that this is true:
Sometimes.....1
Most of the time.....2
Always.....3

****

Satisfaction with Caregiving (cont.)

****

F. Do you feel that care is given to you with devotion and affection?

No.....0
Yes.....Would you say that this is true:
Sometimes.....1
Most of the time.....2
Always.....3

G. Do you feel that the care you receive is appropriate for what you need?

No.....0
Yes.....Would you say that this is true:
Sometimes.....1
Most of the time.....2
Always.....3

H. Do you feel that your needs are taken care of dependably?

No.....0
Yes.....Would you say that this is true:
Sometimes.....1
Most of the time.....2
Always.....3

I. Do you feel enough time is allowed for your care?

No.....0
Yes.....Would you say that this is true:
Sometimes.....1
Most of the time.....2
Always.....3

J. Do you feel that consideration and concern are shown for your comfort?

No.....0
Yes.....Would you say that this is true:
Sometimes.....1
Most of the time.....2
Always.....3

K. On a scale of one to ten, how satisfied are you with the care you receive from your (RELATIONSHIP OF CAREGIVER)?--with ten being very satisfied and one being very dissatisfied?

1.....2.....3.....4.....5.....6.....7.....8.....9.....10
Very Dissatisfied ... Very Satisfied

Figure 2

****

SATISFACTION WITH CARE RECEIVED FROM
FAMILY MEMBERS & FRIENDS

****

We know that people, for a variety of reasons, may be satisfied with some aspects of the care they receive from family members or friends, and less satisfied with other aspects of this care. I would like to ask you some questions about how you feel regarding the care you receive from your (_____).

1. Do you feel that the care you receive from your (_____) is skillful and competent?

No..... 0
Yes.....Would you say that this is true:
Sometimes..... 1
Most of the time..... 2
Nearly Always..... 3
Always..... 4

2. Do you feel that your needs are taken care of thoroughly?

No..... 0
Yes.....Would you say that this is true:
Sometimes..... 1
Most of the time..... 2
Nearly Always..... 3
Always..... 4

3. Do you feel that care is given to you patiently?

No..... 0
Yes.....Would you say that this is true:
Sometimes..... 1
Most of the time..... 2
Nearly Always..... 3
Always..... 4

4. Do you feel that your (_____) expresses interest in the care you need?

No..... 0
Yes.....Would you say that this is true:
Sometimes..... 1
Most of the time..... 2
Nearly Always..... 3
Always..... 4

****

SATISFACTION WITH CARE RECEIVED FROM
FAMILY MEMBERS & FRIENDS (CONT.)

****

5. Do you feel that your needs are taken care of promptly?

No..... 0
Yes.....Would you say that this is true:
Sometimes..... 1
Most of the time..... 2
Nearly Always..... 3
Always..... 4

6. Do you feel that care is given to you with devotion and affection?

No..... 0
Yes.....Would you say that this is true:
Sometimes..... 1
Most of the time..... 2
Nearly Always..... 3
Always..... 4

7. Do you feel that the care you receive from your (_____) is appropriate for what you need?

No..... 0
Yes.....Would you say that this is true:
Sometimes..... 1
Most of the time..... 2
Nearly Always..... 3
Always..... 4

8. Do you feel that your needs are taken care of dependably?

No..... 0
Yes.....Would you say that this is true:
Sometimes..... 1
Most of the time..... 2
Nearly Always..... 3
Always..... 4

9. Do you feel that enough time is allowed for your care?

No..... 0
Yes.....Would you say that this is true:
Sometimes..... 1
Most of the time..... 2
Nearly Always..... 3
Always..... 4

****

SATISFACTION WITH CARE RECEIVED FROM
FAMILY MEMBERS & FRIENDS (CONT.)

****

10. Do you feel that consideration and concern are shown for your comfort?

No..... 0
Yes.....Would you say that this is true:
Sometimes..... 1
Most of the time..... 2
Nearly Always..... 3
Always..... 4

11. Do you feel that the care you receive from your (_____) includes consideration of social activities that are important to you, such as, seeing friends, going out, playing cards, writing letters, etc.?

No..... 0
Yes.....Would you say that this is true:
Sometimes..... 1
Most of the time..... 2
Nearly Always..... 3
Always..... 4

12. On a scale of one to ten, how satisfied are you with the care you receive from your (_____)? With ten being <u>very satisfied</u>, and one being <u>very dissatisfied</u>.

1.....2.....3.....4.....5.....6.....7.....8.....9.....10
Very Dissatisfied — Very Satisfied

13. Now I would like you to compare the care you receive from your (_____) with the care you think (_____) usually give (_____) in your situation. Would you say the care you receive from your (_____) is:

Much better than 4
Better than 3
About the same as 2
Not as good as 1
(Don't know) 8
(Blank/refused) 9

the care other (_____) give their (_____).

APPENDIX C

Selected Measures From Caregiver Interview Schedule

CAREGIVER INTERVIEW

****

LIVING SITUATION

****

I just want to check that I understand correctly your relationship to (CARE RECEIVER: USE SURNAME). He/she is your _____, is that right?
(CIRCLE APPROPRIATE RESPONSE)

Wife	1
Husband	2
Mother	3
Father	4
Mother-in-law	5
Father-in-law	6
Sister or brother	7
Grandparent	8
Other - relative	9
Friend or companion with whom you live	10
Other - non relative	11

Approximately how many years have you and (CARE RECEIVER) known each other?

_____ years

This project focuses on people like you who are what we refer to as "caregivers" to a family member or friend. About how many years have you been a caregiver for CARE RECEIVER)?

_____ years

****

CAREGIVER HEALTH

****

I am going to read to you six statements about health. After I have read them all, tell me which one fits you best. (READ ALL STATEMENTS TO THE CAREGIVER BEFORE OBTAINING HIS/HER RESPONSE - CIRCLE ONLY ONE ANSWER.)

a. I must stay in bed all or most of the time 1
b. I must stay in the house all or most of the time 2
c. I need the help of another person in getting around inside or outside the house 3
d. I need the help of some special aid, such as a cane or wheelchair, in getting around inside or outside the house 4
e. I do not need the help of another person or aid but have trouble getting around freely 5
f. I am not limited in any of these ways . 6

Compared to other persons your age, would you say that your health is: (READ CHOICES)

Excellent 4
Good 3
Fair 2
Poor 1

How does your health now compare to your health one year ago? Is your health now: (READ CHOICES)

Much better 5
A little better 4
About the same 3
A little worse 2
Much worse 1

****

CAREGIVER HEALTH (cont.)

****

I am going to read you a list of problems that some caregivers have. we want you to tell us if you have any of these problems.

Do you have problems with your:

Do you have a problem with:

		NO	YES. (If YES, ask:) How much does this problem get in the way of your taking care of (CARE REC)? Would you say (READ CHOICES):			
			Not at all	A little	Some	A lot
A	Hearing or ears	0	1	2	3	4
B	Eyes	0	1	2	3	4
C	Back	0	1	2	3	4
D	Hands	0	1	2	3	4
E	Feet or legs	0	1	2	3	4
F	Lungs or breathing	0	1	2	3	4
G	Bladder or bowel control	0	1	2	3	4
H	Teeth or dentures	0	1	2	3	4
I	Memory	0	1	2	3	4
J	Speech or talking	0	1	2	3	4
K	Heart	0	1	2	3	4
L	Arthritis	0	1	2	3	4
M	Overweight	0	1	2	3	4
N	High blood pressure	0	1	2	3	4
O	Diabetes	0	1	2	3	4
P	Headaches	0	1	2	3	4
Q	Pain	0	1	2	3	4
R	Other	0	1	2	3	4

_____

Specify other

****

NATURE OF THE CAREGIVING ROLE/CAREGIVER ROLE STRAIN

****

The next set of questions is very long. However, the information from this section is very important to us because we want to have a really good idea of what you do to take care of (CARE RECEIVER).

Family members and friends provide many different kinds of help for older people. I am going to read you a list of types of help which are often given to older people. Some of these types of help will not apply to your situation and some might. I would like to know whether you, or someone else, give this help to (CARE RECEIVER). For example, you may receive help from another relative, friends, neighbors, or someone whose job it is to do this kind of work.
(ASK THE FOLLOWING QUESTIONS FOR EACH TYPE OF HELP. IF THE RESPONDENT ANSWERS NO TO THE FIRST AND THIRD QUESTIONS, SKIP TO THE NEXT TYPE OF HELP.)

1) Do you (READ TYPE OF HELP FROM LIST) for (CARE RECEIVER)?
(RECORD ANSWER IN COLUMN 1 BELOW)

2) (IF YES) How hard is it for you to do that? Would you say it is not very hard, a little hard, pretty hard or very hard?
(RECORD ANSWER IN COLUMN 2 BELOW)

3) Does someone else help out in this way? (IF YES) Who helps out?
(RECORD ANSWER IN COLUMN 3 BELOW; MARK ALL APPROPRIATE)

4) Do you have to arrange for this help or do they just do it on their own?
(RECORD ANSWER IN COLUMN 4 BELOW)

5) (IF YES) How hard is it for you to arrange to have someone else do this?
(RECORD ANSWER IN COLUMN 5 BELOW)

1. Do you (READ TYPE OF HELP FROM LIST) for (CARE RECEIVER)

2. (IF YES) How hard is it for you to do that? (READ OPTIONS)

3. Does anyone else help out in this way? Who helps out? (READ CHOICES)

4. Do you have to arrange for this help or do they just do it on their own?

5. (IF YES) How hard is it for you to arrange to have someone else do this? (READ CHOICES)

TYPE OF HELP	Column 1 DO YOU DO?		Column 2 HOW HARD TO DO?				Column 3 DOES ANYONE ELSE HELP?				Column 4 ARRANGE HELP FROM OTHERS?		Column 5 HOW HARD TO ARRANGE?			
Do you _____for	NO 0	YES 1	EASY 1	NOT TOO HARD 2	PRETTY HARD 3	VERY HARD 4	ANOTHER RELATIVE OR	FRIEND FR	NEIGH-BORS N	SOMEONE WHOSE JOB IT IS J	NO 0	YES 1	EASY 1	NOT TOO HARD 2	PRETTY HARD 3	VERY HARD 4
A. Change bandages or dressings...	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
B. Help (CARE REC.) when he/she wants to use the telephone.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
C. Watch (CARE REC.) and make sure he/she is safe...	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
D. Assist(CARE REC.) with walking.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
E. Protect(CARE REC.) from falls.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
F. Do the laundry...	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4

1. Do you (READ TYPE OF HELP FROM LIST) for (CARE RECEIVER)

2. (IF YES) How hard is it for you to do that? (READ OPTIONS)

3. Does anyone else help out in this way? Who helps out? (READ CHOICES)

4. Do you have to arrange for this help or do they just do it on their own?

5. (IF YES) How hard is it for you to arrange to have someone else do this? (READ CHOICES)

TYPE OF HELP	Column 1 DO YOU DO?		Column 2 HOW HARD TO DO?				Column 3 DOES ANYONE ELSE HELP?				Column 4 ARRANGE HELP FROM OTHERS?		Column 5 HOW HARD TO ARRANGE?			
Do you _____for	NO 0	YES 1	EASY 1	NOT TOO HARD 2	PRETTY HARD 3	VERY HARD 4	ANOTHER RELATIVE OR	FRIEND FR	NEIGH-BORS N	SOMEONE WHOSE JOB IT IS J	NO 0	YES 1	EASY 1	NOT TOO HARD 2	PRETTY HARD 3	VERY HARD 4
G. Give(CARE REC.) medications or shots.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
H. Make major decisions about health care.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
I. Have to handle (CARE REC.)'s paranoia or suspiciousness	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
J. Do shopping and errands.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
K. Accompany (CARE REC.) as he/she does shopping and errands.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
L. Sit and spend time with (CARE REC.)	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4

1. Do you (READ TYPE OF HELP FROM LIST) for (CARE RECEIVER)

2. (IF YES) How hard is it for you to do that? (READ OPTIONS)

3. Does anyone else help out in this way? Who helps out? (READ CHOICES)

4. Do you have to arrange for this help or do they just do it on their own?

5. (IF YES) How hard is it for you to arrange to have someone else do this? (READ CHOICES)

TYPE OF HELP	Column 1 DO YOU DO?		Column 2 HOW HARD TO DO?				Column 3 DOES ANYONE ELSE HELP?				Column 4 ARRANGE HELP FROM OTHERS?		Column 5 HOW HARD TO ARRANGE?			
Do you _____for	NO 0	YES 1	EASY 1	NOT TOO HARD 2	PRETTY HARD 3	VERY HARD 4	ANOTHER RELATIVE OR	FRIEND FR	NEIGH-BORS N	SOMEONE WHOSE JOB IT IS J	NO 0	YES 1	EASY 1	NOT TOO HARD 2	PRETTY HARD 3	VERY HARD 4
M. Iron and/or mend clothes.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
N. Assist with bathing or washing.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
O. Have to handle (CARE REC.)'s behavior problems.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
P. Clean up when (CARE REC.) soils him/herself.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
Q. Assist with hair care and shampooing.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
R. Prepare or help prepare meals....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4

1. Do you (READ TYPE OF HELP FROM LIST) for (CARE RECEIVER)

2. (IF YES) How hard is it for you to do that? (READ OPTIONS)

3. Does anyone else help out in this way? Who helps out? (READ CHOICES)

4. Do you have to arrange for this help or do they just do it on their own?

5. (IF YES) How hard is it for you to arrange to have someone else do this? (READ CHOICES)

TYPE OF HELP	Column 1 DO YOU DO?		Column 2 HOW HARD TO DO?				Column 3 DOES ANYONE ELSE HELP?				Column 4 ARRANGE HELP FROM OTHERS?		Column 5 HOW HARD TO ARRANGE?			
Do you _____for	NO 0	YES 1	EASY 1	NOT TOO HARD 2	PRETTY HARD 3	VERY HARD 4	ANOTHER RELATIVE OR	FRIEND FR	NEIGH-BORS N	SOMEONE WHOSE JOB IT IS J	NO 0	YES 1	EASY 1	NOT TOO HARD 2	PRETTY HARD 3	VERY HARD 4
S. Sit down and eat with (CARE REC.).....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
T. Have to listen and answer repetitive questions that (CARE REC.) asks.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
U. Have to watch (CARE REC.) in case he/she wanders off.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
V. Have to get up at night to help (CARE REC.).....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
W. Take care of (CARE REC.)'s dentures.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
X. Have to remind (CARE REC.) who he/she is and where he/she is..	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4

1. Do you (READ TYPE OF HELP FROM LIST) for (CARE RECEIVER)

2. (IF YES) How hard is it for you to do that? (READ OPTIONS)

3. Does anyone else help out in this way? Who helps out? (READ CHOICES)

4. Do you have to arrange for this help or do they just do it on their own?

5. (IF YES) How hard is it for you to arrange to have someone else do this? (READ CHOICES)

TYPE OF HELP	Column 1 DO YOU DO?		Column 2 HOW HARD TO DO?				Column 3 DOES ANYONE ELSE HELP?				Column 4 ARRANGE HELP FROM OTHERS?		Column 5 HOW HARD TO ARRANGE?			
Do you _____for	NO 0	YES 1	EASY 1	NOT TOO HARD 2	PRETTY HARD 3	VERY HARD 4	ANOTHER RELATIVE OR	FRIEND FR	NEIGH-BORS N	SOMEONE WHOSE JOB IT IS J	NO 0	YES 1	EASY 1	NOT TOO HARD 2	PRETTY HARD 3	VERY HARD 4
Y. Help to get legal matters attended to.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
Z. Arrange for (CARE REC.) to visit friends....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
AA. Transport to medical appointments....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
BB. Assist with dressing and undressing.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
CC. Check in on (CARE REC.) to make sure he/she is ok.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
DD. Assist with banking and financial matters.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4

1. Do you (READ TYPE OF HELP FROM LIST) for (CARE RECEIVER)

2. (IF YES) How hard is it for you to do that? (READ OPTIONS)

3. Does anyone else help out in this way? Who helps out? (READ CHOICES)

4. Do you have to arrange for this help or do they just do it on their own?

5. (IF YES) How hard is it for you to arrange to have someone else do this? (READ CHOICES)

TYPE OF HELP	Column 1 DO YOU DO?		Column 2 HOW HARD TO DO?				Column 3 DOES ANYONE ELSE HELP?				Column 4 ARRANGE HELP FROM OTHERS?		Column 5 HOW HARD TO ARRANGE?			
Do you _____for	NO 0	YES 1	EASY 1	NOT TOO HARD 2	PRETTY HARD 3	VERY HARD 4	ANOTHER RELATIVE OR	FRIEND FR	NEIGH-BORS N	SOMEONE WHOSE JOB IT IS J	NO 0	YES 1	EASY 1	NOT TOO HARD 2	PRETTY HARD 3	VERY HARD 4
EE. Contact health and social service agencies to see if their services are appropriate for (CARE REC.).....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
FF. Get someone from a health or social service agency to come to help (CARE REC.)	0	1	1	2	3	4	0	1	OR	FR	N	J	1	2	3	4
GG. Make sure that services from agencies continue to come.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
HH. Read to him/her..	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
II. Check (CARE REC.)'s skin and apply lotions.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
JJ. Assist with writing checks and paying bills.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4

1. Do you (READ TYPE OF HELP FROM LIST) for (CARE RECEIVER)

2. (IF YES) How hard is it for you to do that? (READ OPTIONS)

3. Does anyone else help out in this way? Who helps out? (READ CHOICES)

4. Do you have to arrange for this help or do they just do it on their own?

5. (IF YES) How hard is it for you to arrange to have someone else do this? (READ CHOICES)

TYPE OF HELP	Column 1 DO YOU DO?		Column 2 HOW HARD TO DO?				Column 3 DOES ANYONE ELSE HELP?				Column 4 ARRANGE HELP FROM OTHERS?		Column 5 HOW HARD TO ARRANGE?			
Do you _____for	NO 0	YES 1	EASY 1	NOT TOO HARD 2	PRETTY HARD 3	VERY HARD 4	ANOTHER RELATIVE OR	FRIEND FR	NEIGH-BORS N	SOMEONE WHOSE JOB IT IS J	NO 0	YES 1	EASY 1	NOT TOO HARD 2	PRETTY HARD 3	VERY HARD 4
KK. "Fix" things and do odd jobs to maintain (CARE REC.) separate dwelling.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
LL. Transport to friends' homes, meetings and entertainment events.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
MM. Watch T.V. with him/her.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
NN. Change dirty bed linens.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
OO. Clean up after meals, do dishes.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
PP. Help (CARE REC.) to use the toilet or bedpan.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4

1. Do you (READ TYPE OF HELP FROM LIST) for (CARE RECEIVER)

2. (IF YES) How hard is it for you to do that? (READ OPTIONS)

3. Does anyone else help out in this way? Who helps out? (READ CHOICES)

4. Do you have to arrange for this help or do they just do it on their own?

5. (IF YES) How hard is it for you to arrange to have someone else do this? (READ CHOICES)

TYPE OF HELP	Column 1 DO YOU DO?		Column 2 HOW HARD TO DO?				Column 3 DOES ANYONE ELSE HELP?				Column 4 ARRANGE HELP FROM OTHERS?		Column 5 HOW HARD TO ARRANGE?			
Do you _____for	NO 0	YES 1	EASY 1	NOT TOO HARD 2	PRETTY HARD 3	VERY HARD 4	ANOTHER RELATIVE OR	FRIEND FR	NEIGH-BORS N	SOMEONE WHOSE JOB IT IS J	NO 0	YES 1	EASY 1	NOT TOO HARD 2	PRETTY HARD 3	VERY HARD 4
QQ. Assist in completing necessary forms, such as taxes, medicare, Soc. Sec. or insurance....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
RR. Hold (CARE REC.)'s hand or be physically affectionate.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4
SS. Make major financial decisions.....	0	1	1	2	3	4	OR	FR	N	J	0	1	1	2	3	4

TT. IS THERE ANYTHING THAT IS MISSING FROM THIS LIST?

_____

_____

_____

REACTIONS TO CAREGIVING

We would like to know how much you worry about each of the following. For example, how much do you worry about (READ OPTIONS), not at all, a little, some or alot?

	Not at all	A little	Some	A lot
A) (CARE REC)'S health condition..	1	2	3	4
B) Obtaining enough help for the things you can't do for (CARE REC)	1	2	3	4
C) (CARE REC)'S mood or state of mind	1	2	3	4
D) Financial problems related to (CARE REC)'S care	1	2	3	4
E) Your own ability to continue taking care of (CARE REC) because of your own health	1	2	3	4
F) How you can go on if (CARE REC) gets worse	1	2	3	4
G) Having to leave (CARE REC) alone when you go out	1	2	3	4
H) Your own future	1	2	3	4
I) Who will take care of (CARE REC) if something happens to you ...	1	2	3	4
J) Having to make the decision about whether to put (CARE REC) in a nursing home	1	2	3	4

REACTIONS TO CAREGIVING

I'm going to read you a list of things that happen in the lives of caregivers. Can you tell me how often these things happen between you and (CARE RECEIVER)?

What about (READ OPTION), how often does this happen?	Never or Rarely	Sometimes	Much of the time	Always or Nearly always
A. Stress in your relationship with (CARE RECEIVER)	1	2	3	4
B. Attempts by (CARE RECEIVER) to manipulate you.....	1	2	3	4
C. Nervousness and depression you have concerning your relationship with (CARE RECEIVER).....	1	2	3	4
D. Demands made by (CARE RECEIVER) that are over and above what s/he needs...	1	2	3	4
E. (CARE RECEIVER) being suspicious	1	2	3	4

In the balance, would you say that the positive aspects of caring for (CARE RECEIVER) outweigh the negative, that the negative aspects outweigh the positive, or that the positive and negative aspects are about equal?

Positive outweigh the negative 1
Negative outweigh positive 2
Negative and positive are about equal 3

MUTUALITY

I will read you a list of statements describing relationships. Please tell me how much each of these statements describes your relationship with (CARE RECEIVER).

	NOT AT ALL LIKE THE TWO OF YOU	A LITTLE LIKE THE TWO OF YOU	PRETTY MUCH LIKE THE TWO OF YOU	VERY MUCH LIKE THE TWO OF YOU
A.We are extremely close	1	2	3	4
B.We basically like each other	1	2	3	4
C.We love each other very much	1	2	3	4
D.We often express affection to each other	1	2	3	4
E.We are very attached to each other	1	2	3	4
F.We really get along with each other ..	1	2	3	4

How much do you share your feelings and ideas with (CARE RECEIVER)? (READ CHOICES)

Not at all	1
A little	2
Some	3
A lot	4

****

MUTUALITY (cont.)

****

How often do you confide in (CARE RECEIVER)? Would you say: (READ CHOICES)

Never or rarely	1
Sometimes	2
Much of the time	3
Always or nearly always	4

How often does (CARE RECEIVER) express feelings of appreciation for you and the things you do? Would you say: (READ CHOICES)

Never or rarely	1
Sometimes	2
Much of the time	3
Always or nearly always	4

How often does (CARE RECEIVER) express feelings of warmth toward you? Would you say: (READ CHOICES)

Never or rarely	1
Sometimes	2
Much of the time	3
Always or nearly always	4

How often does (CARE RECEIVER) give you support? Would you say: (READ CHOICES)

Never or rarely	1
Sometimes	2
Much of the time	3
Always or nearly always	4

****

MUTUALITY (cont.)

****

How often does (CARE RECEIVER) express feelings of affection toward you? Would you say: (READ CHOICES)

Never or rarely	1
Sometimes	2
Much of the time	3
Always or nearly always	4

How often does (CARE RECEIVER) help you? Would you say: (READ CHOICES)

Never or rarely	1
Sometimes	2
Much of the time	3
Always or nearly always	4

How different does (CARE RECEIVER) seem to you now as compared to the time before you began taking care of him/her? Does he/she seem like a different person or pretty much the same as before?

A different person	1
The same as before	2

****

PREPARATION FOR CAREGIVING

****

How much have you learned by trial and error about how to care for (CARE RECEIVER)? Would you say: (READ CHOICES)

None at all	1
A little	2
Some	3
A lot	4

****

PREPARATION FOR CAREGIVING

****

There are a number of community services, such as adult day care, respite care and home care, for older persons. How much have you learned about community services for (CARE RECEIVER) from a doctor, nurse, case manager, social worker or home health aide? Would you say: (READ CHOICES)

None at all	1
A little	2
Some	3
A lot	4

Overall, how well-prepared are you to care for (CARE RECEIVER)? Would you say you are: (READ CHOICES)

Not at all prepared	1
Not too well-prepared	2
Pretty well-prepared	3
Very well-prepared	4

88. How well-prepared do you think you are to take care of (CARE RECEIVER)'s physical needs? Would you say you are: (READ CHOICES)

Not at all prepared	1
Not too well-prepared	2
Pretty well-prepared	3
Very well-prepared	4

89. How well-prepared do you think you are to take care of (CARE RECEIVER)'s emotional needs? Would you say you are: (READ CHOICES)

Not at all prepared	1
Not too well-prepared	2
Pretty well-prepared	3
Very well-prepared	4

How well prepared do you think you are for the stress of caregiving? Would you say you are: (READ CHOICES)

Not at all prepared	1
Not too well-prepared	2
Pretty well-prepared	3
Very well-prepared	4
Caregiving is not stressful	5

CAREGIVER INTERVIEW

****

PERSONAL CHARACTERISTICS

****

What is your birth date?

__ __/__ __/__ __
Month Day Year

Caregiver's gender: (RECORD WITHOUT ASKING IF OBVIOUS OR CHECK RECORDS)

Male	1
Female	2

What is the highest grade in school that you completed?

Never attended school	0
Attended grade school	1
Completed 8th grade	2
Attended high school	3
Completed high school	4
Post-high school vocational training	5
Attended college	6
Completed college	7

Which of the following four statements describes your ability to get along on your income? (READ CHOICES)

I can't make ends meet	1
I have just enough, no more	2
I have enough, with a little extra sometimes	3
I always have money left over	4

****

PERSONAL CHARACTERISTICS (cont.)

****

Here is a list of annual income categories. Which annual income category comes closest to the total amount of your household income? This includes the income of each person in the household including social security, pensions, rent from property, dividends, interest, earned income, help from relatives and any other income.

Under $3,000 per year	1
$3,000 - $5,999	2
$6,000 - $9,999	3
$10,000 - $14,999	4
$15,000 - $24,999	5
$25,000 - $34,999	6
$35,000 - $44,999	7
$45,000 and over	8
Don't know	88
Refused to answer	99

APPENDIX D

Selected Measures From Care Receiver Interview Schedule

HEALTH

I am going to read to you six statements about health. After I've read them all, tell me which one fits you best. (READ ALL STATEMENTS TO THE RESPONDENT BEFORE OBTAINING HIS/HER RESPONSE. CIRCLE ONLY ONE ANSWER.)

a. I have to stay in bed all or most of the time 1
b. I have to stay in the house all or most of the time 2
c. I need the help of another person in getting around inside or outside the house 3
d. I need the help of some special aid in getting around inside or outside the house 4
e. I do not need the help of person or aid, but have trouble getting around freely 5
f. I am not limited in any of these ways 6

Compared to other persons your age, would you say your health is: (READ CHOICES)

Excellent 4
Good 3
Fair 2
Poor 1

How does your health now compare to your health one year ago? Is your health now: (READ CHOICES)

Much better 5
A little better 4
About the same 3
A little worse 2
Much worse 1

ASSISTANCE NEEDED

I am going to read you a list of types of help which older people often need. Some of these types of help will not apply to your situation. I'd like to go through this list with you and have you tell me whether or not you usually need this kind of help.

Do you usually need someone to____?	YES, NEED HELP	NO,DO NOT NEED HELP	NOT APPLICABLE
A. Change your bandages and dressings	1	0	7
B. Help you use the telephone or make calls for you	1	0	
C. Check on you to make sure you are safe	1	0	
D. Help you with walking	1	0	7
E. Help protect you from falls	1	0	
F. Do your laundry	1	0	
G. Give you medications or shots	1	0	7
H. Arrange outside help to come in and do things for you	1	0	
I. Help you in making big decisions about your health care	1	0	
J. Do shopping and errands	1	0	
K. Go with you while you do shopping and errands	1	0	7
L. Sit and spend time with you	1	0	
M. Do your ironing and mending	1	0	
N. Help you with bathing and washing	1	0	
O. Help you with hair care and shampooing	1	0	
P. Clean up when you soil yourself	1	0	7
Q. Prepare or help prepare meals for you	1	0	
R. Sit down and eat with you	1	0	
S. Listen to you and answer your questions	1	0	
T. Be with you at night in case you need help	1	0	
U. Take care of your dentures	1	0	7
V. Help you get legal matters attended to	1	0	
W. Help you visit with friends	1	0	
X. Take you to medical appointments	1	0	

ASSISTANCE NEEDED (cont.)

Do you usually need someone to ____?	YES, NEED HELP	NO, DO NOT NEED HELP	NOT APPLICABLE
Y. Help you dress and undress	1	0	
AA. Help you with banking and financial matters	1	0	
BB. Read to you	1	0	
CC. Check your skin and apply lotions	1	0	
DD. Help you with writing checks and paying bills	1	0	
EE. Fix things and do odd jobs to maintain your dwelling	1	0	
FF. Take you to friends' homes, meetings, and entertainment events	1	0	7
GG. Watch TV with you	1	0	
HH. Change dirty bed linen for you	1	0	
II. Clean up after meals and do your dishes	1	0	
JJ. Help you in getting to the toilet, bedpan, or in maintaining other toilet functions	1	0	
KK. Help you in completing necessary forms, such as taxes, Medicare, Social Security, or insurances	1	0	
LL. Hold your hand or be physically affectionate with you	1	0	
MM. Make major financial decisions for you	1	0	
NN. Check in on you to make sure you're OK	1	0	

Is there anything that is missing from this list?

MUTUALITY

I will read you a list of statements describing relationships. Please tell me how much this statement describes your relationship with (CAREGIVER).

		Not at all like the two of you	A little like the two of you	Pretty much like the two of you	Very much like the two of you
A.	We are extremely close.	1	2	3	4
B.	We basically like each other.	1	2	3	4
C.	We love each other very much.	1	2	3	4
D.	We often express affection to each other.	1	2	3	4
E.	We are very attached to each other.	1	2	3	4
F.	We really get along with each other.	1	2	3	4

How often does (CAREGIVER) express feelings of appreciation for you and the things you do? Would you say: (READ CHOICES)

Never or rarely 1
Sometimes 2
Much of the time 3
Always or nearly always 4

****

MUTUALITY (cont.)

****

How much do you share your feelings and ideas with (CAREGIVER) READ CHOICES)

Never or rarely 1
Sometimes 2
Much of the time 3
Always or nearly always 4

How often do you confide in (CAREGIVER)? Would you say (READ CHOICES).

Never or rarely 1
Sometimes 2
Much of the time 3
Always or nearly always 4

How often does (CAREGIVER)express feelings of warmth toward you? Would you say: (READ CHOICES)

Never or rarely 1
Sometimes 2
Much of the time 3
Always or nearly always 4

How often does (CAREGIVER) give you support? Would you say: (READ CHOICES)

Never or rarely 1
Sometimes 2
Much of the time 3
Always or nearly always 4

How often does (CAREGIVER) express feelings of affection toward you? Would you say: (READ CHOICES)

Never or rarely 1
Sometimes 2
Much of the time 3
Always or nearly always 4

How often does (CAREGIVER) help you? Would you say: (READ CHOICES)

Never or rarely 1
Sometimes 2
Much of the time 3
Always or nearly always 4

****

PERSONAL CHARACTERISTICS

****

What is your birth date?

__ __/ __ __/ __ __
Month Day Year

Care receiver's gender (RECORD WITHOUT ASKING, IF OBVIOUS, OR CHECK RECORDS)

Male	1
Female	2

What is the highest grade in school that you completed?

Never attended school	0
Attended grade school	1
Completed 8th grade	2
Attended high school	3
Completed high school	4
Post-high school vocational training	5
Attended college	6
Completed college	7

Which of the following four statements describes your ability to get along on your income? (READ CHOICES)

I can't make ends meet	1
I have just enough, no more	2
I have enough, with a little extra sometimes	3
I always have money left over	4

PERSONAL CHARACTERISTICS (cont.)

Here is a list of annual income categories. (HAND CARD TO RESPONDENT.) Which annual income category comes closest to the total amount of your household income? This includes the income of each person in the household including social security, pensions, rent from property, dividends, interest, earned income, help from relatives and any other income.

Under $3,000 per year	1
$3,000 - $5,999	2
$6,000 - $9,999	3
$10,000 - $14,999	4
$15,000 - $24,999	5
$25,000 - $34,999	6
$35,000 - $44,999	7
$45,000 and over	8
Don't know	88
Refused to answer	99

APPENDIX E

Consent Forms

THE OREGON HEALTH SCIENCES UNIVERSITY

INFORMED CONSENT

Investigation: The Effects of Organized Caregiver Relief Services (Pretest Phase)

Investigators: Patricia G. Archbold, RN, DNSc Phone: 503-225-8297
Barbara Stewart, Ph.D. Phone: 503-225-7796
Professors
School of Nursing
The Oregon Health Sciences University

Patricia Archbold and Barbara Stewart, Faculty Members at the School of Nursing, The Oregon Health Sciences University, and co-investigators at the Kaiser Permanente Medical Care Program Health Services Research Center, are conducting a study of caregiving to older care receivers.

If we agree to participate in the study, the following will happen.

1) The care receiver will answer questions in one interview session approximately one half hour long.
2) The caregiver will answer questions in one interview session. This interview session will require approximately one and a half to two hours. Neither the caregiver nor care receiver will have access to the interview responses of the other.

The interviews will be recorded in writing. The recordings will be handled in a manner to ensure confidentiality. Any publications from this study will include the necessary precautions to protect our identity.

Participating in the study may not benefit us directly, but may benefit other people in the future. Some of the questions may touch on painful experiences which may be upsetting to us. We may refuse to answer individual questions, or may discontinue the interview at any time without affecting our care at the Kaiser Permanente Medical Care Program or the Oregon Health Sciences University.

If we have comments or questions about participating in this policy, we should contact the investigators.

We understand that it is not the policy of the Department of Health and Human Services or any other agency funding the research project in which we are participating to compensate or provide medical treatment for human subjects in the event the research results in physical injury. The University of Oregon Health Sciences Center, as an agency of the state, is covered by the State Liability Fund. If we suffer any injury from the research project, compensation would be available only if we establish that the injury occurred through the fault of the center, its officers, or employees. If we have further questions, please call Dr. Michael Baird, M.D. at 255-8014

_____I have read what is written above and agree to be in the study.
_____I have had read to me what is written above and agree to be in the study.

Impaired Older Person	Date	Family Caregiver	Date

CRS/PABS/JH/5/16/85

THE OREGON HEALTH SCIENCES UNIVERSITY

INFORMED CONSENT

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The interviews will be recorded in writing. The recordings will be handled in a manner to ensure confidentiality. Any publications from this study will include the necessary precautions to protect our identity.

Participating in the study may not benefit us directly, but may benefit other people in the future. Some of the questions may touch on painful experiences which may be upsetting to us. We may refuse to answer individual questions, or may discontinue the interview at any time without affecting our care at the Kaiser Permanente Medical Care Program or the Oregon Health Sciences University.

If we have comments or questions about participating in this study, we should first contact the investigators. If we have further questions about this research, our rights and responsibilities as subjects, or about research-related injuries, we may contact M. R. Greenlick, Ph.D., Vice President for Research, Kaiser Foundation Hospitals at 233-5631.

_____I have read what is written above and agree to be in the study.
_____Ihave had read to me what is written above and agree to be in the study.

Impaired Older Person	Date	Family Caregiver	Date

CRS/PABS/JN/5/16/85