Current Topics in Care

American Journal of Alzheimer's Disease & Other Dementias®
Volume 21 Number 5
October/November 2006 304-311
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10.1177/1533317506292283
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Assessing Perceived Change in the Well-being of Family Caregivers: Psychometric Properties of the Perceived Change Index and Response Patterns

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The purpose of this study was to evaluate the psychometric properties of the Perceived Change Index (PCI), a 13-item scale that measures caregiver appraisals of self-improvement or decline in distinct areas of well-being, and to examine demographic differences in responses. The scale was administered to 255 caregivers participating at the Philadelphia site of the National Institute of Aging–funded Resources for Enhancing Alzheimer's Caregiver Health initiative. Principal axis analysis with one half of the sample was used to evaluate factor structure. Evidence of convergent and divergent validity was examined using the second half of the sample. Differential response patterns by caregiver characteristics were also examined using regression analysis. Using one half of the sample, 3 underlying factors were found (affect, $\alpha = .85$; somatic, $\alpha = .80$; management, $\alpha = .76$), accounting for 63% of the variance. The overall index was internally consistent (Cronbach's $\alpha = .90$). Using the second half of the sample, Pearson correlational analyses of the overall index and its subscales revealed that perceived improvement was significantly associated with fewer depressive symptoms, higher scores on perceived positive aspects of caregiving, and more participation in social activities. As expected, it was not associated with the care recipient's Mini-Mental Status Examination scores or functional status. Perceived improvement scores for specific areas of well-being were associated with being African American, male, and a spouse. The PCI is a brief, easily administered, and valid self-report measure that can serve as an indicator of caregiver appraisal of well-being in research and clinical practice.

Keywords: Alzheimer's disease; informal caregiving; burden

The significant psychological and health consequences of providing dementia care highlight the importance of assessing the well-being of family caregivers. Whereas previous research focused on caregiver burden and depression,[1,2] other dimensions, including positive and negative components of well-being, have been neglected.

We developed a brief tool, the 13-item Perceived Change Index (PCI), to assess caregiver appraisals of improvement or deterioration in areas of well-being that are proximal to the caregiving experience. The measure uses a time comparison of 1 month in which caregivers evaluate whether specific areas of daily life are better or worse.

Although self-report of change is not customarily used in behavioral research, theories of adaptation[3,4] and other affective research have examined change in life circumstances as a determinant of emotional well-being.[5-7] Also, outcomes such as satisfaction

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The research reported in this article was supported by funds from the National Institute on Aging (U01 AG 013265). A version of this article was presented at the Gerontological Society of America meetings, November 2000.

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have been examined as a function of both the direction and velocity of changed circumstances, with higher satisfaction associated with more rapid changes.[8] Self-ratings of health have also been shown to vary with changes in symptoms and mood from the previous to present day,[9] suggesting that change in circumstances may influence well-being and should be examined. The caregiving experience for a person with a neurodegenerative disease such as dementia typically entails considerable change in circumstances from day to day and across the disease trajectory. Therefore, for dementia caregivers in particular, the effect of changing circumstances on well-being is especially important to consider.

Ascertaining self-appraisals of change in status also has a strong precedent in pharmacological trials in which clinical impressions of behavioral change are routinely obtained, particularly for cognitive enhancement drugs. For example, caregiver appraisal of patient improvements was a primary outcome of donepezil trials, a drug to treat cognitive deficits.[10] Moreover, research suggests that caregiver ratings of symptom improvement or worsening are valid and reliable.[11] A randomized trial on the psychological benefits of exercise found that whereas intervention participants rated improvements in health-related areas, standard measures did not detect differences.[12] A housing relocation study likewise found that participant ratings of change in well-being was the strongest indicator of housing impact.[13]

This article presents the underlying factor structure of the PCI, preliminary convergent and discriminant evidence, and whether scores differ by caregiver and care recipient characteristics for which well-being previous research has shown to vary.[14-16]

Methods

Sample and Recruitment

The PCI was evaluated with 255 caregivers participating at the Philadelphia site of the National Institutes of Health Resources for Enhancing Alzheimer's Caregiver Health (REACH) initiative. Individuals were eligible for study participation if they were the primary caregiver, at least 21 years old, caregiving for at least 6 months, and providing at least 4 hours of daily care. Caregivers were not eligible if they did not live with the care recipient, were undergoing chemotherapy or radiation for cancer, had more than 3 hospitalizations in the past year, or they planned nursing home placement within the study time frame. Care recipients had to have a Mini-Mental State Examination (MMSE)[17] score less than 24 or documented dementia diagnosis and deficits in at least 1 activity of daily living[18] or in 2 instrumental activities of daily living.[13]

Caregivers were recruited from community agencies and media announcements.[19] Individuals who contacted the research team were screened by telephone for eligibility and willingness to participate. Of the 413 persons who contacted the research team, 290 (70%) were eligible for study participation. Of these 290, 255 (88%) were willing to participate.

Procedures

Trained interviewers obtained signed informed consent approved by the Institutional Review Board and conducted a baseline interview consisting of the REACH measures described elsewhere[20] and the PCI, a measure specific to the Philadelphia site. The PCI was administered following the REACH measures so that all participants were asked these questions at the same point in the interview. The core measures took about 3 hours to administer, whereas the PCI took about 10 minutes.

Measures

PCI

Content for the PCI was drawn from a literature review and reflected areas amenable to change, evidence of being a concern to caregivers, and that potentially decline as a consequence of caregiving, which could affect health. Caregivers rated 13 items on a 5-point Likert-type scale (1 = *became much worse*, 2 = *became somewhat worse*, 3 = *stayed the same*, 4 = *improved somewhat*, 5 = *improved a lot over the past month*). Negatively valenced items were reverse coded, with higher scores indicating improvement. A total score was computed by averaging the responses across all items.

Measures of Convergence

The 20-item Center for Epidemiological Scale of Depression (CES-D) assesses occurrence of symptoms within the past week (0 = *rarely to never*, 3 = *frequently*).[21] Scores represent the sum of caregivers' responses, with higher scores indicating more depressive symptoms (Cronbach's $\alpha = .71$).

We used the REACH 9-item Positive Aspects of Caregiving (PAC) Scale to measure the extent to which caregivers appraise positive benefits ("Caregiving made me feel good about myself").[20] Caregivers rated each item using a 5-point Likert-type format (1 = *disagree a lot*, 5 = *agree a lot*). Scores represent the summed responses, with higher scores indicating more positive experiences (Cronbach's α = .88).

We used the REACH 6-item Social Activities Index to assess caregiver satisfaction with activities over the past month (0 = *not at all*, 2 = *a lot*). Scores represent the sum of responses, with higher scores indicating greater satisfaction (Cronbach's α = .86).

Measures of Divergence

To assess divergent validity, we used the care recipient's MMSE score of cognitive functioning (Cronbach's α = .93).[17] We also assessed functional dependence by counting the number of activities (bathing, eating, dressing upper body, dressing lower body, toileting, grooming, and getting in and out of bed) for which help was needed (Cronbach's α = .91).[18]

Predictions

We anticipated that PCI scores would be inversely related to CES-D scores such that caregivers with fewer depressive symptoms would report higher PCI scores; conversely, higher depressive scores would be associated with lower PCI scores. We reasoned that the CES-D, as an indictor of depressive symptoms, would be associated with PCI scores since declines in the areas represented are symptomatic of depression. We also predicted that caregivers with high PAC and social activity scores would report higher PCI scores. We reasoned that caregivers who reported more benefits from caregiving and who were socially engaged would perceive their everyday functioning as staying the same or improving.

Conversely, we expected caregiver appraisals of improvement or decline to be independent of care recipient illness characteristics. We reasoned that it is the caregiver's appraisal of the care situation rather than patient characteristics that affects well-being.

Data Analysis

We examined distributions of individual PCI items and then split the Philadelphia REACH sample (N = 255) between the first 127 subjects (forming sample 1) and the remaining 128 subjects (forming sample 2). To examine factor structure, we submitted sample 1 data to exploratory principal axis factor analysis, rotated to a varimax solution.[22,23] According to Weiss,[24,25] principal axis factoring, though similar to principle components factor analysis, uses a reduced correlation matrix with R^2 as an estimate of common variance, thus excluding unique and error variance. Cronbach's α was used to assess internal consistency of the overall index and subscales.

Using sample 2, we examined the interrelationships of convergent and discriminant indicators and PCI with Pearson product–moment correlation coefficients.[26] We examined differential appraisals by race (white, nonwhite), gender, relationship (spouse, nonspouse), education, age, years caregiving, and income with hierarchical multiple regression analyses for mean overall PCI and subscale scores as dependent variables using the entire sample (N = 255).

Results

Sample Characteristics

The total sample (N = 255) consisted primarily of women and nonspouses. Caregivers had at least 12 years of education, were 61 years of age, had a median annual income of $15 000 to $20 000, and provided care on average for 4 years. Whites and African Americans each constituted 48% of the sample. Care recipients were primarily women and 81 years of age on average.

In a comparison of the 2 study samples (Table 1) using χ^2 and Wilcoxon rank-sum tests, 1 difference between samples was found: there were more spouse caregivers in sample 1 (n = 57) than in sample 2 (n = 42), $\chi^2(1) = 3.91$, $P = .048$.

Principal Axis Factor Analysis

Ratings from sample 1 were submitted to principal axis factoring (using R^2 as an estimate of common variance) rotated to a varimax solution. This yielded 3 factors with eigenvalues greater than 1.00 and factor loadings ranging from 0.35 to 0.81, with all items retained in the final scale (Table 2). The first factor consists of 4 items referred to as somatic well-being (Cronbach's α = .79). The second factor of 5 items refers to affect (Cronbach's α = .87). The third factor of 4 items refers to ability to manage (Cronbach's α = .75). Two items loaded on all 3 factors: being

Table 1. Background Characteristics of Study Samples

	Sample 1 (n = 127)			Sample 2 (n = 128)		
Variable	$\bar{x}$	SD	%	$\bar{x}$	SD	%
Caregiver						
Gender						
Male			28.3			22.7
Female			71.7			77.3
Race						
White			48.0			48.4
African American			49.6			46.1
Other			2.4			5.5
Relationship to care recipient						
Spouse			44.9			32.8
Nonspouse			55.1			67.2
Age, y	61.85	14.79		60.27	13.82	
Education, y	11.87	2.62		12.59	2.59	
Years of caregiving	4.27	3.82		4.23	3.73	
Income[a]	3.54	2.54		3.73	2.39	
Care recipient						
Gender						
Male			37.0			30.5
Female			63.0			69.5
Age, y	79.84	8.10		81.61	7.77	

a. Income category = $15 000 to $19 999 per year.

Table 2. Rotated Factor Matrix of the Perceived Change Index: Sample 1 (n = 127) Cronbach's α = .90

In the Past Month, for Each Item, Please Tell Me If You Have Felt Things Have Become Much Worse, Become Somewhat Worse, Stayed The Same, Improved Somewhat, or Improved a Lot	Factor		
	1 Somatic (α = .79)	2 Affect (α = .87)	3 Management (α = .75)
Feeling rested	0.813	0.202	0.122
Ability to sleep through the night	0.623	0.225	0.220
Ability to have time for yourself	0.594	0.196	0.080
Your energy level	0.571	0.393	0.183
Feeling overwhelmed	0.567	0.352	0.387
Feeling upset	0.265	0.714	0.288
Feeling calm or relaxed	0.334	0.699	0.331
Things have been going your way	0.272	0.500	0.293
Feelings of being angry	0.222	0.444	0.183
Ability to understand the care recipient's behavior	0.028	0.157	0.726
Sense of control over the care recipient's problems	0.220	0.333	0.650
Ability to manage day-to-day caregiving	0.406	0.287	0.640
Ability to handle new caregiving problems	0.166	0.262	0.406

overwhelmed and being calm or relaxed. We included these on the Affect subscale given our conceptual intent. The 3 factors accounted for 63% of the variance, and the overall PCI scale was internally consistent (Cronbach's α = .90).

Convergent and Divergent Validity

Table 3 shows sample 2 means and standard deviations for indicators. As anticipated, mean PCI and subscale scores were significantly associated with

Table 3. Means and Standard Deviations for Predictor Variables for Sample 2 (n = 128)

Caregiver Factor	$\bar{x}$	SD	Theoretical Range
Social activity participation	4.70	3.31	1.00-1.00
Positive aspects of caregiving	33.88	9.05	9.00-45.00
CES-D	14.64	12.18	0.00-54.00
Mini-Mental State Examination	12.89	7.34	0.00-27.00
ADL functional independence	4.41	1.86	1.00-7.00

Table 4. Intercorrelation Matrix of Predictor and Criterion Variables With Sample 2 (n = 128)

	Perceived Change	Affect	Somatic Symptoms	Manage Caregiving
Social activities participation	0.43*	0.39*	0.45*	0.25*
Positive aspects of caregiving	0.41*	0.41*	0.32*	0.30*
CES-D	–0.48*	–0.47*	–0.42*	–0.31*
MMSE	0.01	–0.05	0.04	0.07
ADL functional independence	0.07	0.05	0.08	0.05

*$P < .001$.

each convergent variable but not with indicators of divergence (Table 4).

Response Patterns by Caregiver Characteristics

Using the total sample (N = 255), we examined responses to each PCI item. Figure 1 shows that over the past month, caregivers reported becoming somewhat worse on somatic items ($\bar{x}$ = 2.62, SD = 0.68), staying the same for affective items ($\bar{x}$ = 2.87, SD = 0.68), and staying the same or improving for managing caregiver tasks ($\bar{x}$ = 3.07, SD = 0.64). Caregivers reported the most deterioration in energy level ($\bar{x}$ = 2.56, SD = 0.89) and greatest improvement in understanding care recipient behaviors ($\bar{x}$ = 3.16, SD = 0.92).

Next, we examined whether perceived changes varied by caregiver characteristics. Table 5 reports the means and standard deviations for the total PCI and each subscale by caregiver characteristics. Multiple regression analysis revealed that, taken together, caregiver demographic characteristics were significantly associated with total PCI scores, $R^2 = 0.08$, $F(7, 247) = 3.25$, $P = .030$, with caregiver race ($t = 4.03$, $P = .001$) and gender ($t = –2.00$, $P = .047$) making the strongest independent contributions to the overall regression model (see Table 6). That is, nonwhite caregivers, most of whom were African American and male, reported more overall average improvements over the previous month than white caregivers or women did.

A similar pattern was observed for somatic symptoms. Although the regression model examining the relationship among the set of caregiver characteristics and perceived change in somatic symptoms was not significant, $R^2 = 0.05$, $F(7, 247) = 1.88$, $P = .074$, nonwhite caregivers and men reported greater average improvement in somatic symptoms than did white or female caregivers.

The multiple regression model testing the association between caregiver characteristics and perceived change in affect was statistically significant, $R^2 = 0.07$, $F(7, 247) = 2.80$, $P = .008$. We found that nonwhites reported greater improvement in affect ($t = 4.41$, $P = .001$).

The multiple regression model examining the association between caregiver characteristics and perceived change in ability to manage caregiving also was statistically significant, $R^2 = 0.09$, $F(7, 247) = 3.34$, $P = .002$, with race ($t = 3.29$, $P = .001$) and relationship to care recipient ($t = –2.13$, $P = .034$) making the strongest independent contributions. Nonwhites and spouses reported greater average ability to manage caregiving day to day.

Discussion

This article reports the psychometric properties of PCI, a simple-to-administer, brief, 13-item self-report measure of perceived change in well-being with 3 robust subscales. Initial psychometric analyses suggest that

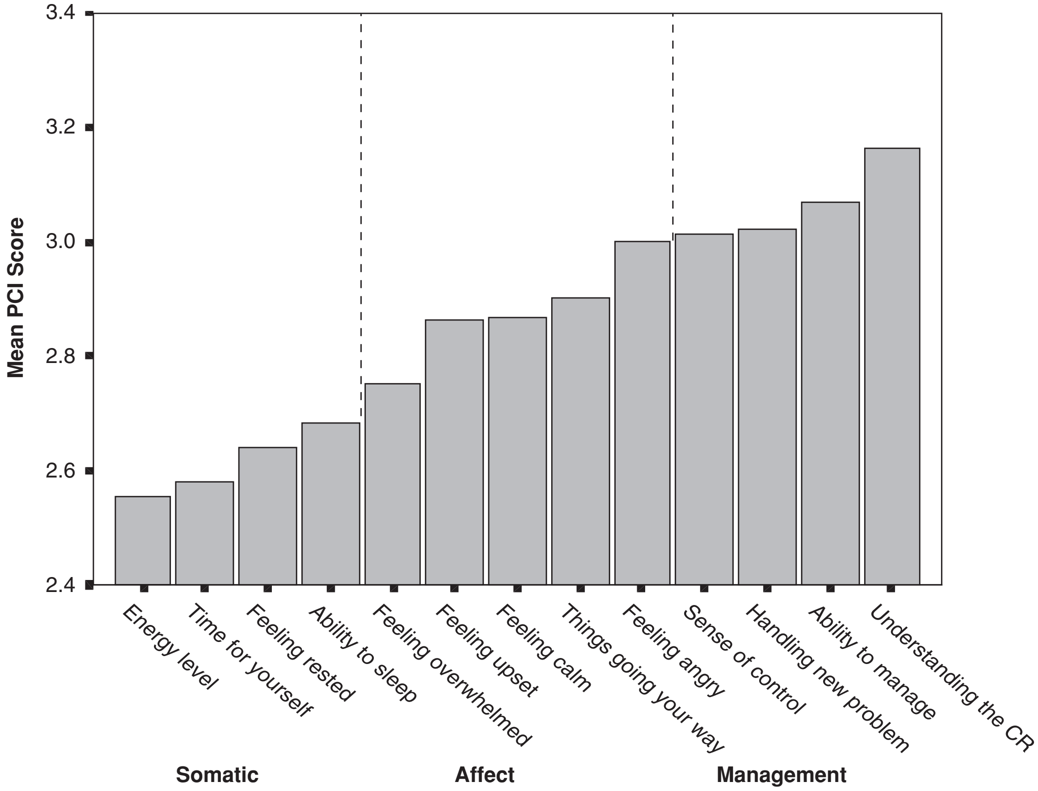

Figure 1. Mean Perceived Change Index (PCI) item responses at baseline (N = 255).

Table 5. Means, Standard Deviations, and Mean Total Scores of Predictor and Criterion Variables (N = 255)

	Perceived Change			Affect			Somatic Symptoms			Manage Caregiving		
Caregiver Characteristic	$\bar{x}$	SD	Total	$\bar{x}$	SD	Total	$\bar{x}$	SD	Total	$\bar{x}$	SD	Total
Race												
White	2.71	0.50	35.13	2.69	0.65	13.45	2.50	0.65	9.99	2.92	0.50	11.69
Nonwhite	3.00	0.59	38.92	3.04	0.66	15.22	2.72	0.69	10.89	3.20	0.72	12.81
Gender												
Male	2.95	0.55	38.23	2.94	0.61	14.68	2.78	0.62	11.06	3.12	0.65	12.49
Female	2.82	0.57	36.71	2.85	0.70	14.26	2.56	0.69	10.25	3.05	0.63	12.20
Relationship to care recipient												
Spouse	2.84	0.57	36.90	2.84	0.66	14.17	2.61	0.65	10.40	3.08	0.67	12.32
Nonspouse	2.86	0.57	37.23	2.90	0.70	14.49	2.62	0.70	10.49	3.06	0.62	12.24

the total and subscales (Affect, Somatic, and Ability to Manage) are valid and internally consistent. Items reflect modifiable dimensions that may fluctuate in response to caregiving demands.

Using principal axis factoring and a Kaiser criterion of 0.30 or higher factor loading as a cutoff in sample 1, all 13 items were retained, and high internal consistency was obtained for the total index and each subscale. In support of its construct validity, we found that improvement for each factor and the overall index was associated with fewer depressive symptoms, more activity engagement, and greater perceived benefits from caregiving. This suggests that the overall index and subscales measure areas of caregiving that are associated with other general indicators of well-being. In contrast, and as expected, PCI total and subscale scores were not associated with care recipient functioning. This is consistent with previous research

Table 6. Multiple Regression Model of the Interrelationship of Caregiver Characteristics and Perceived Change Index, Affect, Somatic Symptoms, and Ability to Manage Caregiving (Sample 2, n = 128)

	Overall Perceived Change			Affect			Somatic Symptoms			Ability to Manage		
Characteristic	Standardized Coefficient β	*t*	*P*	Standardized Coefficient β	*t*	*P*	Standardized Coefficient β	*t*	*P*	Standardized Coefficient β	*t*	*P*
Gender	–.13	–2.00	.047	–.08	–1.21	.229	–.16	–2.44	.015	–.10	–1.51	.133
Race	.25	4.00	.001	.27	4.14	.001	.16	2.54	.012	.21	3.29	.001
Relationship	–.08	–0.90	.369	–.01	–0.16	.873	–.02	–0.24	.810	–.18	–2.13	.034
Age	–.06	–0.72	.471	–.02	–0.17	.868	–.02	–0.20	.844	–.15	–1.67	.097
Education	.06	0.79	.428	–.00	–0.05	.964	.04	0.52	.607	.12	1.80	.073
Years caregiving	–.03	0.44	.661	–.01	–0.17	.863	–.03	–0.44	.664	–.04	–0.57	.573
Income	–.04	0.54	.593	.00	–0.01	.996	–.01	–0.02	.924	–.09	–1.44	.152

showing that caregiver well-being may not change based on illness characteristics and decline. Rather, it is the caregiver's appraisal of his or her situation and coping capacity that may affect well-being.

For the total sample, the average PCI score was 2.86 (SD = 0.57), indicating that most caregivers perceived their situation as relatively stable over the previous month. Nevertheless, because the data are cross-sectional, we are unable to evaluate whether caregivers perceived staying the same at high or low levels of functioning. Caregivers reported more decline over the past month with somatic items. This is troubling given the demonstrated physiological effects of stress and the relationship between fatigue and poor health among caregivers.[27] Also of interest is that caregivers did not uniformly improve or deteriorate across all items. That is, caregivers reported improvements in some areas and perceived deterioration or stabilization in others. This underscores the importance of assessing both positive and negative affective consequences that may be experienced concurrently.[28]

As to the relationship of overall PCI scores and caregiver characteristics, we found no differences between spouse and nonspouse caregivers. Caregiver education, age, income, and years caregiving were also not significantly associated with appraisals of temporal improvement or decline. However, gender and race were associated with higher ratings such that nonwhites, most of whom were African American, reported more improvements than whites did, and men reported more improvements than women did. This finding is consistent with previous research suggesting that African Americans and men report less depressive symptoms and appraise caregiving more positively than white and female caregivers do.[14]

Given the above findings, conducting a full-scale validation study of the PCI is warranted. This measure should be compared to other caregiver burden scales and its performance examined over time to substantiate that it is detecting change over time as well as to evaluate its sensitivity to intervention effects and predictive value.

A potential limitation of self-report is the risk of response bias. Caregivers might overestimate improvement and minimize decline or the opposite. Future research should examine the effect of depression and whether self-appraisals are consistent with ratings by skilled observers.

In summary, the PCI has potential research and clinical utility. It is easy and quick to administer and feasible to use in care settings to identify and monitor fluctuations in well-being. It may help identify specific areas of deterioration for which referral or intervention can be introduced. Finally, asking individuals to rate their change in status may be effective for other populations and behavioral concerns.

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