Appendix 18 Chronic Illness Resources Survey: Self Management

A Social–Ecologic Approach to Assessing Support for Disease Self-Management: The Chronic Illness Resources Survey

Russell E. Glasgow,[1,3] Lisa A. Strycker,[2] Deborah J. Toobert,[2] and Elizabeth Eakin[1]

Accepted for publication: May 1, 2000

We report on the development and validation of an instrument to assess support and resources for chronic illness management (the Chronic Illness Resources Survey; CIRS). The 64-item full instrument and the 29-item Brief CIRS are based on a social–ecologic model, designed to apply across chronic diseases, and assess support and resources at each of seven levels (e.g., family and friends, physician and health care team, neighborhood/community). A prospective evaluation with 123 patients having heart disease, arthritis, diabetes, and/or COPD revealed that the overall instrument, as well as subscales and the brief instrument, had acceptable internal consistency, moderate to high test–retest reliability, good construct validity, and moderate concurrent and prospective criterion validity. We discuss potential uses of the CIRS for assessment, feedback, tailoring intervention, and evaluation and make recommendations for future research.

KEY WORDS: chronic illness; social support; self-management; assessment; social ecology.

INTRODUCTION

Chronic diseases presently afflict more than 100 million Americans. The health care cost associated with treating these diseases is staggering, and

[1]AMC Cancer Research Center.
[2]Oregon Research Institute.
[3]To whom correspondence should be addressed at 11716 98th Place SW, Vashon, Washington 98070. Fax: (206) 567-5916. e-mail: russkpf@earthlink.net.

0160-7715/00/1200-0559$18.00/0 © 2000 Plenum Publishing Corporation

almost certain to increase given current patterns and demographic projections [Brownson *et al.*, 1998; U.S. Department of Health and Human Services (USDHHS), 1990]. Despite general agreement that self-management is required for control of chronic disease and for prevention of disease complications, it is sobering that across chronic diseases, patients generally do not adhere well to self-management regimen recommendations (Glasgow and Eakin, 1998; Gochman, 1997; Sherbourne *et al.*, 1992). Both barriers and adherence appear to be more problematic for "lifestyle" behaviors such as eating patterns, exercise, and smoking than for medication adherence (Brown, 1990; Glasgow, 1994; Roter *et al.*, 1998; Rubin *et al.*, 1991).

There is abundant evidence that higher levels of social support are related to better long-term self-management and better health outcomes (see reviews by Kaplan and Toshima, 1990; Uchino *et al.*, 1996). Researchers have utilized a variety of definitions and measures of social support ranging from social network contacts to received (Barrera *et al.*, 1981) and perceived (Cohen and Hoberman, 1983) support and need for and satisfaction with support (Sarason *et al.*, 1983). Support has been assessed from a variety of sources, including spouses, family, friends and neighbors, and co-workers and supervisors (e.g., Coppotelli and Orleans, 1985; Dignam *et al.*, 1986; Kahn, 1994; Lichtenstein *et al.*, 1986). Most, but not all, studies have reported significant relationships between support and health (see reviews by House *et al.*, 1988; Uchino *et al.*, 1996). Similarly, a variety of health outcomes has been related to support. Relationships have been reported among support and immunity (Cohen *et al.*, 1997), health status and health behaviors (Coppotelli and Orleans, 1985; Glasgow and Toobert, 1988), mortality (House *et al.*, 1988), and quality of life (Glasgow *et al.*, 1997a).

While much has been learned, existing research on support and health outcomes also has several limitations (Vaux, 1997). For example, most studies have (1) used only a single measure of support or a single support source (e.g., spouse or co-workers), (2) failed to relate support measures to conceptual models, (3) used a limited range of health outcomes, and/or (4) failed to analyze results appropriately to control or adjust for potential confounding covariates (such as demographics and social desirability response bias).

Another concern is that several of the scales for assessing support for coping with a chronic illness are target behavior or disease specific (e.g., Sallis *et al.*, 1987; Glasgow and Toobert, 1988). While there is nothing inherently wrong with this approach (Mischel, 1968), it limits the opportunity for drawing generalizations across behaviors and diseases. Also, many adults, especially over age 60, have not just a single disease, but multiple chronic illnesses (Brownson *et al.*, 1998). Finally, some of the best validated support scales are time-consuming to administer or score, limiting their use in applied settings.

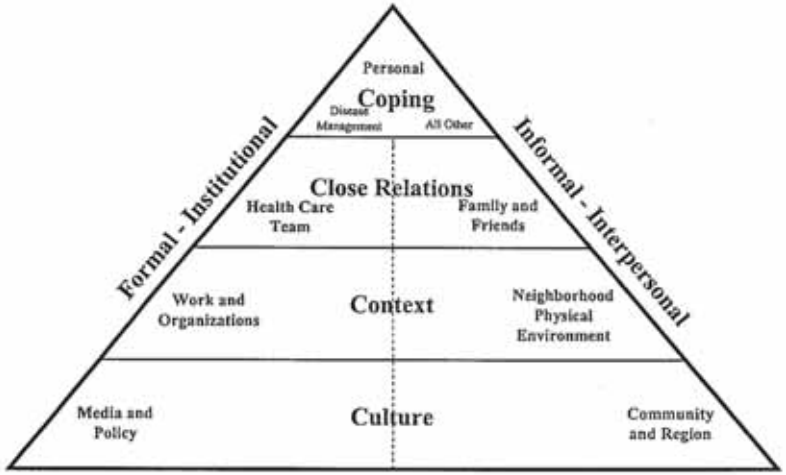

Fig. 1. Pyramid of social–environmental support.

To address several of these issues, our research group has developed a multilevel "pyramid" model of social–environmental support related to disease self-management (Glasgow and Eakin, 1998; Glasgow *et al.*, 1999). As shown in Fig. 1, this model includes support from family and friends, as well as support received from health care resources. These are the two most common types of support on which research has been conducted. Chronically ill patients, however, are also influenced by more distal sources of support (and barriers), including workplace, media, public policy, and other neighborhood and community factors. Although not as thoroughly researched, or as intuitively obvious, we feel that including more distal factors as part of a comprehensive model is beneficial for conceptual, measurement, and intervention purposes. Space limitations preclude detailed discussion, but such a multilevel social–ecologic model (Auslander and Corn, 1996; Green and Kreuter, 1991; Stokols, 1996) has a number of advantages for understanding context and for generating both possibilities for support resources and hypotheses for future research (see Glasgow, 1995; Glasgow and Eakin, 1998). Among other advantages, such a multilevel approach permits study of the comparative and combined influences of different levels of support and of the effects of both "passive" interventions, including policies and environmental factors (Auslander and Corn, 1996; Brownson *et al.*, 1995; Glasgow *et al.*, 1999; Stokols, 1992), and more active support behaviors.

Such a perspective should also apply across a variety of different chronic conditions. As stated by the Institute for the Future (1998, p. 148) in a report on the future of health care in America prepared for The Robert Wood Johnson Foundation, "Recognizing shared determinants of health rather than only those unique to specific diseases will enrich and modify our understanding of how internal and external factors interact to produce health or lead to illness and disease."

The purpose of this article is to describe the conceptual background, development, and preliminary validation of a new self-report instrument of perceived support, the Chronic Illness Resources Survey (CIRS). We report on the reliability, norms, and construct and predictive validity of both the original survey and a brief version of the instrument. Our goal was to develop an instrument having the following qualities: (1) reasonably brief and capable of self-administration; (2) applicable across a variety of different chronic illnesses; (3) ability to assess reliably support resources at several different levels, including more distal workplace, community, and media/public policy influences not usually considered; (4) compatible with a social–ecologic and systems theoretical perspective; and (5) useful for both prediction and designing personalized intervention and self-management support programs. The remainder of this paper describes our experience, results, and conclusions on the extent to which these objectives were achieved.

METHODS

Research Design and Subjects

A prospective validation study was conducted to evaluate an instrument to assess multiple levels of support for self-management of chronic diseases and predicting medium-range (4-month) disease self-management and quality of life. Recruited from newspaper advertisements and a managed care organization list were a total of 123 individuals between 40 and 88 years of age (M = 63 years, SD = 12 years) having arthritis, diabetes, chronic obstructive pulmonary disease (e.g., bronchitis, asthma), heart disease, or a combination of these chronic illnesses. This sample size was determined a priori by calculating the number of subjects (120) required to detect a correlation of $r = .35$ with 90% power, using a two-tailed α of .01. The sample included 15 participants having arthritis only, 16 having diabetes only, 19 having lung disease only, 10 having heart disease only, and 63 having a combination of two or more of these diseases.

Patient characteristics are presented in Table I. As can be seen, on average patients were older, had been diagnosed for almost 10 years, and represented a range of income and education levels. Patients were screened by telephone, and those meeting eligibility criteria were invited to attend small group sessions to complete paper-and-pencil surveys at baseline and 4 months. A randomly selected subset of patients also completed 1-week or 1-month retests of selected instruments or a support resources self-

Table I. Characteristics of Study Participants ($N = 123$)

Variable	Mean or % (SD)
Demographics	
Age	63 (12) (range = 40 to 88)
% female	62%
Race	
% Caucasian	94%
% Native American	4%
% Hispanic	2%
Education	
% high school graduate or less	31%
% some college	42%
% college graduate or more	27%
Employment	
% work full- or part-time	22%
% homemakers	8%
% retired	54%
% other	16%
% live alone	27%
% married	58%
Household income	
Less than $10,000	22%
$10,000 to $29,999	47%
$30,000 or $49,999	21%
$50,000 or more	10%
Disease/medical history	
Chronic disease	
% having arthritis	50%
% having diabetes	39%
% having lung disease	43%
% having heart disease	38%
Years diagnosed	
Arthritis	12 (11)
Diabetes	10 (9)
Lung disease	13 (16)
Heart disease	8 (6)
Number of comorbid diseases (of 10)	2.9 (1.6) (range = 1 to 8)
Insurance	
% having no insurance	7%
% having private insurance	11%
% having managed care/HMO insurance	48%
% having Medicare	54%
% smoke cigarettes	13%
SF-12 Mental Health Scale score	46 (9)
SF-12 Physical Functioning Scale score	36 (10)

monitoring task. American Psychological Association ethical principles were followed, the project was approved by the local institutional review board, and patients were paid a total of $45 or $70 for their participation, depending on the number of assessments and surveys completed.

Measures

Participants completed the 64-item Chronic Illness Resources Survey (CIRS). This instrument was comprised of items devised by our research team to reflect support influences discussed in the literature and our clinical experience (see the Appendix). The CIRS items were based on experience using a previous shorter version, titled the "Chronic Illness Support Scale," with diabetes patients (McKay *et al.*, 1999) and formative evaluation interactions with patients similar to those in the present study. Items were a mixture of general, especially emotional, support and resources for specific self-management tasks, such as diet, exercise, and medication taking, common to all chronic diseases. In selecting items, an effort was made to include informational, emotional, instrumental, and tangible support resources (House, 1985). The survey was segmented to reflect eight distinct levels of psychosocial environmental support—physician and health care team, family and friends, personal actions, neighborhood, community, media and policy, community organizations, and workplace—based upon our Pyramid of Social-Environmental Support model (Glasgow *et al.*, 1999; Glasgow and Eakin, 1998).

In each segment, six to nine questions probed the amount of support received from that resource [e.g., "Has your doctor or other health care advisor listened carefully to what you had to say about your illness?" "Have the grocery store(s) where you shop had a good supply of fresh fruit and vegetables?"] on a 5-point Likert scale (1 = "not at all" to 5 = "a great deal"). A final question in each section measured the perceived importance of that resource for managing illness—a dimension that was added to address feedback obtained from focus groups. This importance question also was included for clinical purposes, allowing interventionists to help patients develop plans for enhancing resources in domains that patients feel are important but in which they have low levels of support. The importance ratings were not included in the subscales but analyzed separately.

Participants also completed a demographic/medical history background questionnaire and other instruments to evaluate the construct and predictive validity of the CIRS. To test the convergent validity of the CIRS personal, family and friends, physician/health care team, neighborhood, and worksite constructs, respectively, the Self-Efficacy for Exercise and Eating Behaviors scales (Sallis *et al.*, 1988), the Social Support for Eating Habits and Exercise Survey (Sallis *et al.*, 1987), the Medical Satisfaction Questionnaire (Glasgow *et al.*, 1996), the Campbell Community Survey (Campbell, 1995), and the Take Heart company and co-worker support survey (Glasgow *et al.*, 1997b) were administered. Measures to test criterion validity included the Kristal Fat and Fiber Behavior Questionnaire (FFB; Kristal *et al.*, 1990), the Physical Activity Scale for the Elderly (PASE; Washburn *et al.*, 1993), the Illness Intrusiveness scale (Devins, 1994), the Medical Outcomes Study (MOS) SF-12 Mental Health and Physical Functioning scales (Ware *et al.*, 1995), and the MOS Illness Management scale (Sherbourne *et al.*, 1992).

The Social Support for Eating Habits and Exercise Survey (Sallis *et al.*, 1987), the Interpersonal Support Evaluation Checklist (ISEL; Cohen *et al.*, 1985), and the Social Network Index (Cohen *et al.*, 1997), all widely used measures of different types of social support, were included to compare their criterion validity with that of the CIRS.

Finally, participants completed an abbreviated version of the Balanced Inventory of Desirable Responding (BIDR; Paulhus, 1984) to measure possible response bias due to socially desirable responding. The BIDR measures two constructs: self-deceptive positivity (the tendency to give self-reports that are highly desirable but honestly held) and impression management (the conscious tendency to give highly desirable self-reports).

Analyses

Prior to analyses, the data set was screened for out-of-range values and scales were created according to algorithms for the established instruments. Seven CIRS subscales were created by computing means of subscale items (physician and health care team, family and friends, personal actions, combined neighborhood/community, media and policy, community organizations, and workplace) and the total CIRS support scale score was computed as the mean of all the subscale values. In addition, a Support × Importance scale was formed for each level and overall by multiplying support level and importance ratings. Descriptive analyses were then conducted to assess distributional characteristics of the raw and composite variables (e.g., kurtosis, skewness), to ensure that normality assumptions of the planned analyses were met. Descriptive statistics were computed (e.g., means, standard deviations) to characterize the amount of support reported across different levels, and across different diseases, ages, and genders. Reliability coefficients (Cronbach's α) and test–retest Pearson product–moment correlation coefficients were computed for all CIRS subscales.

Based on a randomly selected subset of 36 participants who self-monitored support actions received over a 1-month period, correlations were also computed to document relationships between self-monitored

support received at the different levels, as measured by the daily support resources recording task, and perceived support, as measured by corresponding summary scores from the CIRS.

The CIRS was tested as a concurrent and 4-month prospective predictor of reported self-management and quality of life criterion variables using correlational analyses. Parallel analyses were conducted to compare the strength of relations between these outcomes and (a) the CIRS, (b) the less comprehensive Social Support for Eating Habits and Exercise Survey (Sallis *et al.*, 1987), and (c) the more global Interpersonal Support Evaluation Checklist (Cohen *et al.*, 1985). The Social Network Index (Cohen *et al.*, 1997) also was used, but administered only at 4 months, which permitted 4-month concurrent analyses but precluded prospective analyses with this measure.

Descriptive and correlational analyses were performed to evaluate construct validity (i.e., predictive, divergent, and convergent validity), variability, and temporal stability of both the overall CIRS scale and the subscales—and to guide development of a brief version of the CIRS instrument.

RESULTS

CIRS Subscales and Patient Characteristics

CIRS scale scores generally were not related to patient characteristics, with the exception of age. Age was moderately and significantly related to the total CIRS scale ($r = .35$, $p < .001$) and all subscales, with the exception of media/policy support and worksite support, with older patients reporting more support.

None of the CIRS scale scores was significantly correlated with socially desirable responding as measured by either of the two scales derived from the abbreviated version of the Balanced Inventory of Desirable Responding (self-deceptive positivity and impression management).

Presented in Table II are descriptive statistics of the subscales and total scale scores derived from the CIRS. Using the full instrument, physician and health care team support and personal support were rated highest, followed by media and policy support, family and friends support, and neighborhood/community support, with support from community organizations and worksites ranked lowest. In general, patients perceived moderate levels of support, with adequate variability, across all dimensions.

As shown in Table III, 14 of the 21 subscale intercorrelations were significant ($p < .01$). The highest correlations were found for the personal support subscale with subscales measuring support from family and friends ($r = .52$), neighborhood/community ($r = .49$), and physician and health care

Table II. Normative Data for Full and Brief CIRS at Baseline

Scale or subscale	Mean (SD)					
	Overall	CHD	Arthritis	Diabetes	COPD	Overall importance
Full CIRS						
Personal	3.1 (0.7)	3.2 (0.8)	3.0 (0.7)	3.1 (0.7)	3.0 (0.8)	4.2 (1.0)
Family and friends	2.7 (0.9)	2.8 (0.9)	2.5 (0.8)	2.7 (0.9)	2.8 (0.9)	3.7 (1.4)
Physician/health care team	3.3 (1.1)	3.3 (1.1)	3.3 (1.1)	3.2 (1.1)	3.2 (1.1)	4.2 (1.1)
Neighborhood/community	2.6 (0.6)	2.6 (0.6)	2.6 (0.6)	2.6 (0.6)	2.6 (0.5)	2.4 (1.4)
Organizations	1.8 (0.7)	1.9 (0.7)	1.9 (0.7)	1.8 (0.5)	1.8 (0.7)	2.7 (1.1)
Worksites ($N = 53$)	1.8 (0.8)	1.4 (0.4)	1.7 (0.9)	1.8 (0.7)	1.7 (0.8)	3.1 (1.4)
Media and policy	2.8 (0.7)	2.8 (0.7)	2.8 (0.7)	2.6 (0.7)	2.8 (0.8)	2.9 (1.3)
Total	2.7 (0.5)	2.7 (0.5)	2.6 (0.5)	2.6 (0.5)	2.6 (0.5)	2.9 (1.3)
Brief CIRS						
Personal	3.4 (0.9)	3.4 (1.0)	3.2 (0.9)	3.3 (0.8)	3.3 (1.0)	Same as above (only 1 item on importance per area)
Family and friends	2.4 (1.0)	2.5 (0.9)	2.3 (0.8)	2.4 (1.0)	2.3 (0.9)	
Physician/health care team	3.4 (1.2)	3.4 (1.1)	3.4 (1.1)	3.4 (1.1)	3.4 (1.2)	
Neighborhood/community	2.2 (0.8)	2.2 (0.9)	2.1 (0.7)	2.2 (0.9)	2.1 (0.8)	
Organizations	2.0 (1.0)	2.2 (1.1)	1.9 (0.9)	1.9 (0.8)	1.8 (1.0)	
Worksites ($N = 53$)	2.2 (1.1)	1.8 (0.9)	2.1 (1.2)	2.5 (0.9)	2.0 (1.0)	
Media and policy	3.4 (0.9)	3.5 (0.8)	3.4 (1.0)	3.4 (0.8)	3.5 (1.0)	
Total	2.8 (0.6)	2.8 (0.6)	2.7 (0.6)	2.7 (0.5)	2.7 (0.6)	

Table III. Intercorrelations Among CIRS Subscales at Baseline

	1	2	3	4	5	6
1. Personal	—	—	—	—	—	—
2. Family and friends	.52*/.38*	—	—	—	—	—
3. Physician/health care team	.34*/.40*	.23*/.15	—	—	—	—
4. Neighborhood/ community	.49*/.40*	.42*/.45*	.35*/.26	—	—	—
5. Organizations	.30*/.22	.25*/.24*	.20/.17	.48*/.34*	—	—
6. Worksites	.19/.14	.10/.20	.18/.10	.22/.24	.28/.30	—
7. Media and policy	.28*/.09	.23*/.06	.27*/.29*	.33*/.13	.40*/.13	.23/.25

Note. $N = 44$–123. The value before the slash refers to the full CIRS; the value after the slash represents results from the Brief CIRS.
*$p \leq .01$.

team ($r = .34$). Support from neighborhood/community also correlated moderately highly with organizational support ($r = .48$) and support from family and friends ($r = .42$). Other correlations were more modest, and often nonsignificant.

Importance ratings were significantly correlated with the relevant subscale summary scores ($r = .29$–$.60$, all p's $< .001$).

Internal Consistency and Temporal Stability

Because of the multiple tests conducted, for all reliability and validity analyses, only results reaching the $p < .01$ level or less are regarded as significant. Reliabilities and test–retest results for the CIRS are summarized in Table IV. The total CIRS score was internally consistent ($\alpha = .90$) and showed a good 1-month test–retest stability ($r = .83$). As would be expected, subscale results were somewhat less reliable, but still reasonable given the smaller number of items. Subscale reliabilities ranged from $\alpha = .71$ on the organizational support subscale to $\alpha = .91$ for the physician and health care team support subscale.

One-month test–retest correlations on the CIRS subscales ranged from .60 for the physician and health care team and media and policy support subscales to .91 for the personal support subscale. As would be expected, 4-month test–retest correlations were lower ($r = .71$ for the total CIRS score), with subscales ranging from $r = .42$ to .74 (all p's $< .001$).

Construct Validity

Moderate but significant correlations were found between CIRS subscales and similar established measures. The CIRS physician and health care

Table IV. Internal Consistency, Test–Retest Reliability, and Convergent Validity Results for the Full and Brief CIRS

Scale or subscale	α^a	Test–retest r^a			r with similar established measure[a]	r with self-monitoring checklist ($N = 36$)[a]
		1 week ($N = 39$)	1 month ($N = 21$)	4 months ($N = 119$)		
Personal	.73/.69	.81/.88	.91/.85	.62/.53	.43*/.48*	.45*/.40
Family and friends	.75/.50	.78/.75	.72/.64	.61/.45	.42*/.41*	.53*/.37
Physician/health care team	.91/.86	.77/.75	.60/.52	.56/.50	.42*/.43*	.14/.12
Neighborhood/community	.72/.57	.81/.76	.74/.78	.74/.68	.75*/.71*	.21/.22
Organizations	.71/.48	.70/.82	.79/.75	.69/.66	.36*/.30*	.51*/.52*
Worksites	.80/.85	.72/.86[b]	.90/—[c]	.42/.55		.50/.51
Media and policy	.75/.37	.75/.69	.60/.60	.73/.66	.60*/.60*	.31/.40
Total	.90/.79[d]	.90/.89	.83/.83	.71/.65		.58*/.61*

[a] The value before the slash refers to the full CIRS; the value after the slash presents results from the Brief CIRS.
[b] $N = 15$.
[c] $N = 5$ for the full CIRS; correlation for the Brief CIRS could not be calculated because of missing values.
[d] Computed excluding worksite items, because of the small number of workers.
*$p < .01$ (all test–retest correlations significant).