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ABSTRACT

Most studies of stress and coping processes among patients with serious illnesses have focused on acute illness states. Far less research has involved systematic examination of the types and frequency of illness-related stresses experienced by individuals living with chronic illness. To compare the nature and degree of illness-related stress posed by four chronic diseases, reports of illness stress were obtained from 170 middle-aged and elderly outpatients faced with a diagnosis of cancer, rheumatoid arthritis, diabetes mellitus, or hypertension. The results revealed that the two most frequently named stresses were demands imposed by the treatment regimen and restrictions imposed on the patient's lifestyle. Other important concerns reported were coping with pain and disease-related symptoms, limited mobility, and problems with social relationships caused by the illness. The results indicated that although a set of stresses common to chronic disease could be empirically identified, important illness-to-illness differences existed in the type and intensity of stress reported. Cancer patients expressed fears of death, uncertainty about future health, interpersonal relationship problems, and disease-related symptoms; diabetics felt stressed by treatment demands, and arthritics were concerned with physical limitations. While these findings conform to objective clinical features of each diagnosis, they also emphasize the importance of attending to patients' subjective illness experiences in providing comprehensive medical care. (Author/NRB)

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Perceived Stress in Chronic Illness:
A Comparative Analysis of Four Diseases

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Abstract

This research systematically compares the nature and degree of illness-related stress posed by four chronic diseases. Reports of illness stress were obtained from 170 middle-aged and elderly outpatients faced with a diagnosis of cancer, rheumatoid arthritis, diabetes mellitus or hypertension. Results indicate that although a set of stresses common to chronic disease could be empirically identified, important illness-to-illness differences exist in the type and intensity of stress reported. While these findings conform to objective clinical features of each diagnosis, they also emphasize the importance of attending to patients' subjective illness experience in providing comprehensive medical care. Clinical implications are discussed.

Introduction

Most studies of stress and coping processes among patients faced with serious illness have focused on acute illness states, involving diagnosis or hospitalization or on the end stages of life-threatening illness (Moos, 1982; Kubler-Ross, 1969). Far less research has involved systematic examination of the types and frequency of illness-related stresses experienced by individuals living with chronic illness. As the prevalence of chronic illness is expected to increase in the future, in part because of the increased longevity of the population (Califano, 1979), greater attention is being paid to psychological "quality of life" issues for those faced with chronic illness. And, as individuals react to both the nature of the physical impairment and to its psychological and social meanings, we expect patients with different diagnoses to differ in their perceptions of illness-related stress. For mental health professionals, knowledge of these differences is vital if we are to understand the ways in which individuals cope with their illness and design effective psychosocial interventions.

A Conceptual Framework of Illness Stress

Investigators seeking to understand patients' successes and failures in coping with illness have focused on illness-related crises, problems or "adaptive tasks" to conceptualize illness stress and its effects on adaptation (Moos, 1982). At least four typologies describing such tasks have emerged from the rich anecdotal literature on adaptation to physical illness as well as more systematic empirical investigations of individual illnesses. Figure 1 summarizes these

typologies and provides a framework for comparison.

Insert Figure 1 about here

Moos and Tsu's typology (1977) delineates the adaptive tasks presented by acute illness, emphasizing the early stages of illness such as hospitalization. In contrast, Visotsky and his colleagues (1961) based their categorization on observations of patients coping with a chronic disability, polio. Mages and Mendelsohn (1979) adopted a developmental perspective, indentifying the tasks relevant to particular stages of one illness, cancer. Cohen and Lazarus' (1979) schema integrates a transactional framework and emphasizes perceived threats and chal'enges across both acute and chronic illnesses. Despite differences in the illnesses studied, all four typologies cite in common the tasks of contending with the physical manifestations of the illness, emotional distress, potential disruptions in social relations, threats to one's self-concept and uncertainty about the future, if not certainty about its brevity.

While the conceptual work on adaptive tasks suggests that there are stressors common to most physical illnesses, research on individual illnesses (Follick, Smith, & Turk, 1984; Kames, Naliboff, Heinrich, & Schag, 1984; Meyerowitz, Heinrich, & Schag, 1983; Schag, Heinrich, & Ganz, 1983). suggest strong differences in the nature and intensity of stressors faced by patients with different diagnoses. These studies, by and large, have focused on single illnesses, precluding comparisons among different diagnoses. As illnesses which vary in their level of

treatment requirements, life-threat, or degree of disability may have very different impacts on subsequent adjustment and emotional well-being (Felton, Revenson, & Hinrichsen, 1984), we felt it important to empirically determine whether there are meaningful variations in patients' perceptions of their illness. Such variations may be prerequisites for understanding what coping strategies and what psychosocial interventions will effectively improve patient care.

Method

Procedure and Sample

The data are part of a study of adaptation to chronic illness designed to allow comparisons among individuals faced with hypertension, diabetes mellitus, rheumatoid arthritis, and systemic blood cancers. (Three cancer diagnoses were included in the study: chronic lymphocytic leukemia, multiple myeloma, and lymphoma. These three groups did not differ on any study variable and were treated as a single group in data analyses.) In selecting the illnesses, those which ran too rapid a course for study or were localized in a specific body site were excluded from consideration. As the proportion of the population with one or more chronic illnesses increases steadily with age, the sample was drawn from non-hospitalized patients aged 40 and older who had a primary diagnosis of one of these illnesses. Referrals to the research project were made by private physicians, specialty clinics in hospitals, and a hypertensive screening agency, all located within a metropolitan area. Respondents were contacted initially through their physician; 170 patients (58%) agreed to participate. Primary reasons given for nonparticipation were lack of time or

inconvenience. Respondents were interviewed in their homes or in university offices by trained psychology and social work students using a structured interview format.

The sample was composed of 67 men and 103 women aged 41 to 89 (mean age: 61 + 8.6 years). At the time of the interview, patients had been diagnosed an average of 65 months (s.d.=91 months): this wide range was evident in each illness group and no illness to illness differences in time since diagnosis were found. Although the diagnostic groups had been selected with the same research criteria and were similar in age, race (86% white) and marital status (64% married), a few demographic differences were present. The arthritis and hypertension groups contained a greater proportion of women and had slightly lower income levels than the diabetes or cancer groups. Therefore, analyses of illness to illness differences were undertaken both with and without statistical controls for these factors in order to account for their possible confounding effects.

Measurement of Illness Stress

To assess perceptions of the stresses of chronic illness, respondents were asked an open-ended question: "Being ill often means having to deal with different problems connected with the illness. What are the things you have had to deal with since you learned of your illness?" Respondents were prompted to report as many stresses as they had experienced, and each stress was recorded separately. These responses were then content-analyzed to yield variables for each respondent indexing the types of illness stress experienced and the total number of stresses reported.

A 10-category coding scheme for type of stress was developed on a 25 percent sample of the responses, with equal numbers of cases drawn from each illness group. Another 25 interviews were then independently scored by three raters to obtain interrater reliability for the coding scheme. Percent agreement was 100% for the total number of stresses and 92% for the types of stress reported, indicating high interrater reliability. Each protocol was coded for up to five illness stresses and for the total number of illness stresses reported (which exceed five in a few cases).

Results

The mean number of illness stresses reported was 2.08 ± 1.5 , with two-thirds of the sample reporting two or more. As shown in the first column of Table 1, the two most frequently named stresses were demands imposed by the treatment regimen, such as taking daily medication, and restrictions imposed on one's lifestyle, such as being unable to perform previous social roles. Coping with pain and disease-related symptoms, limited mobility, and problems with social relationships caused by the illness were also important concerns. Fears of dying or future disability, acceptance of the fact that one has a serious illness, strong emotional reactions to being ill, such as anger or depression, and dissatisfaction with the quality of health care received were reported to a lesser degree.

Insert Table 1 about here

There were few significant correlations among the different illness

stresses (average intercorrelation=.09). Restrictions on lifestyle were related to limited mobility ($r = .27, p < .001$) and pain ($r = .24, p < .001$). Pain was understandably related to disease-related symptoms ($r = .27, p < .001$); health care complaints were related to emotional reactions to the illness ($r = .27, p < .01$). Reports of treatment demands were negatively related to pain ($r = -.17, p < .05$), limited mobility ($r = -.28, p < .001$), and restricted lifestyle ($r = -.33, p < .001$). These intercorrelations appear to reflect the illness to illness differences in stress reports described in the next section.

Diagnostic Differences in Illness Stress

Despite the common themes reported by patients with different diagnoses, the nature and intensity of illness stress experienced varied substantially from one illness to another. Table 1 presents the results of the analyses of variance and corresponding post-hoc comparisons. Statistically controlling for the number of illness stresses reported had no net effect on the results for type of stress.

Cancer and arthritis patients reported a greater degree of illness-imposed stress overall, followed by diabetics and then hypertensives, $F(3,166)=12.79, p < .001$. Cancer patients expressed fears of death and uncertainty about future health and functioning, problems with its negative impact on interpersonal relationships, and disease-related symptoms more often than patients with other illnesses. While cancer patients also experienced higher levels of pain and restrictions on daily functioning than diabetics or hypertensives, closer analyses reveal that for the most part, these two stresses seemed to be limited to cancer patients undergoing

chemotherapy or radiation treatment.

Treatment demands were named most frequently as problems by diabetics, with hypertensives also reporting a fairly high level. Predominant concerns for rheumatoid arthritis patients centered around limitations on daily physical functioning, including a greater degree of limited mobility and a greater degree of restricted activity than all other patients. This may well be due to the chronic and persistent pain reported to a significantly higher degree by this group of patients.

These findings are substantiated by other variables assessing perceptions of illness stress. Cancer patients appraised their illness and its consequences as being more serious than patients with other diagnoses, $F(3,164)=3.10$, $p < .03$, Duncan comparison, $p < .05$. Furthermore, hypertension and diabetes patients demonstrated a more internal health locus of control (Wallston, Wallston, Kaplan & Maides, 1978) than did cancer or arthritis patients $F(3,164)=11.30$, $p < .001$, Duncan comparison, $p < .05$.

The few differences in gender and income distributions across illness groups did not account for the diagnosis-to-diagnosis differences in illness stress reports. Only differences in symptom reports became nonsignificant when income was partialled, and no changes occurred when gender was used as a covariate. In addition, the fact that the hypertensive and rheumatoid arthritis groups had comparable male-to-female ratios and income levels, yet were significantly different in their reports of disease-related symptoms, limitations on mobility, treatment demands and in intensity of

stress makes it extremely unlikely that these demographic factors account for the illness-to-illness differences.

Given the heterogeneity among respondents in length of illness as well as stage theories of adaptation to illness (e.g., Mages & Mendelsohn, 1979) we also examined the variable of time elapsed since diagnosis in relation to illness stress. When the 29 percent of the sample diagnosed within the past year were compared with those who had been ill for more than a year on the intensity and types of stress experienced only one significant difference emerged: more recently diagnosed patients reported a greater degree of illness stress overall, $t(168) = -2.40, p < .02$. Including length of illness as a covariate in the analyses presented in Table 1 produced no decreases in either magnitude nor statistical significance of the effects. Thus, the progression of time does not appear to have played any role in respondents' descriptive accounts of the stresses of their illness.

Discussion

Clearly, patients who have been coping with a chronic illness for some time are faced with multiple illness-related stresses. Although the stresses reported by this group of patients do not exhaust all possible types, most of the broad adaptive tasks identified in the literature are represented. It should be noted that stresses in the hospital environment and strains on financial resources were reported by less than two percent of respondents and thus excluded from data analyses. The low incidence of these problems may be a result of sampling factors or of the chronic nature of the illnesses selected for study. Had the sample been newly-diagnosed or homebound it is likely

that the intensity of stress reported would be heightened. Such potentially important sources of stress must be addressed in future research.

While a substantial number of people reported only a few problems, almost everyone was currently experiencing some degree of illness-related stress. More importantly, most of these health-related problems had emotional overtones, even though emotional reactions to the illness were overtly reported by only 10 percent of the sample. For example, physical limitations often were described with sorrowful reference to the past. "I had always been very active, involved in many organizations," said one arthritis sufferer. "Now I can't even do most of the things around the house that a wife does. At the beginning it was extremely difficult to adjust to these things. Now--it gets easier each day, but it still upsets me a great deal." Thus, the strong relationship between health and emotional well-being, particularly among older people, is reflected patients' descriptions of the stresses of their illness.

It has been suggested that some of the adaptive tasks of illness overlap with the developmental tasks of aging. While some of the stresses reported here may characterize normal aging, it is unlikely that this is the case in the current study for two reasons. First, respondents were specifically instructed to describe the stresses which they had experienced as a direct result of having their illness. Second, no age differences were found in illness stress reports, confirming our earlier notion of "illness as equalizer".

Respondents' reports of illness stress are highly compatible with

clinical portraits of their diagnoses. The existential plight of cancer patients, noted in the clinical (Weisman & Worden, 1976) and popular literatures (Sontag, 1979) emerged in this sample's frequent reports of fears of death and struggles in accepting the meaning of their illness. As one patient stated, "To put it simply, lymphoma is cancer. Cancer is life-threatening. That's something I'll always have to deal with." The salience of disruptions in interpersonal relationships for cancer patients noted by other research (Dunkel-Schetter & Wortman, 1982) was also confirmed.

At the same time, some stresses which are presumed to be problematic in a particular diagnosis may prove less stressful in the eyes of patients with that diagnosis than common medical knowledge suggests. Diabetics, for example, frequently experience "secondary" complications which, among the patients in this sample, included retinopathy, neuropathy, and in males, impotence. The incidence of reports of these conditions or their manifestations (e.g., failing vision, pain in limbs) was far lower, however, than rheumatoid arthritics' reports of pain or cancer patients' reports of treatment-related symptoms. Rather, we found problems in maintaining the medical treatment regimen to be the primary stresses reported by diabetics. It is also interesting that uncertainty of disease progression was infrequently reported by rheumatoid arthritis patients, since uncertainty has been described as one of the psychological hallmarks of that disease (Weiner, 1977).

Our empirical documentation of illness-to-illness difference in illness stress reports also sheds light on the psychological processes

that govern people's perceptions of stress. Leventhal and his colleagues (H. Leventhal, Meyer, & Nerenz, 1980) have developed a cognitive model of illness representation, in which patients use both concrete symptoms and abstract knowledge to categorize and understand their illness. Patients' interpretations of symptoms may be idiosyncratic and discrepant with medical knowledge, and they may be ultimately affects adherence to medical treatment (E. Leventhal, 1984).

Similar processes may be operating in patients' definitions of the stresses of their illnesses. For example, hypertensives and diabetics reported more treatment demands than did rheumatoid arthritis or cancer patients, the patients who reported the greatest degree of stress. It may be that the hassles of getting to the doctor's office and of taking daily medication loom larger to those not contending with the more taxing stresses of severe pain or marked disability. If people do use an internal hierarchical ranking of stress, as our data suggest, then the types of stress which patients report may be informative of the intensity of stress they are experiencing.

These data provide clues for tailoring psychosocial interventions which minimize the emotional distress of chronic illness and maximize the quality of the patient's life. When resources are scarce, psychosocial interventions might best be targeted at those problem areas which are subjectively most critical to patients. Support groups and other interventions aimed at bolstering the social support of ill people, for example, might be most cost-effective when aimed at cancer patients, since such people commonly experience these stresses. Interventions with arthritis patients might focus more strongly on

concrete ways to compensate for lack of mobility or on teaching cognitive coping strategies to minimize pain. With hypertension or diabetes patients, attention might be more strongly focused on the psychological factors inhibiting adherence to prescribed treatment with the goal of teaching coping techniques which will increase adherence without creating additional emotional distress.

Most importantly, what needs to guide comprehensive care is the adoption of an "insider's perspective" (Shontz, 1982). In this research we allowed patients to become "expert witnesses", informing us of what illness-related stresses they encountered and found both individual and illness-related variation. In practice, as in research, it will be helpful to chart adaptation to chronic illness in context of the specific stresses faced and the patient's subjective experience. Diagnosis alone does not alert us to the salience of particular psychosocial tasks confronting each patient.

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Figure 1

Four Typologies of the Adaptive Tasks of Illness

Cohen and Lazarus (1979)	Nages and Mendelsohn (1979)	Moos and Tsu (1977)	Visotsky et al. (1961)
SERIOUS ILLNESS	CANCER	ACUTE ILLNESS	LONG-TERM DISABILITY (poliomyelitis)
Accepting and recognizing the demands of the illness	To be able to recognize and deal with the realities of the situation To put fears of disease progression out of mind, but to continue medical treatment		
Dealing with the physical manifestations of the illness	Threats to bodily integrity and comfort from the illness, diagnostic procedures or treatment, including •Bodily injury or disability •Permanent physical changes •Physical pain and discomfort •Incapacitation	To accept one's helplessness and dependency To mourn the loss of or compensate for lost parts or function	Dealing with pain and incapacitation Enhancing prospects of physical recovery and bodily functions
Coping with the hospital environment	Adjustment to the hospital setting Problems in understanding medical terminology or customs Necessity for decision-making in stressful and novel situations		Dealing with the hospital environment and special treatment procedures Developing adequate relationships with hospital staff
Dealing with emotional distress	Threats to emotional equilibrium Dealing with feelings of anger, anxiety, depression	To be able to regulate one's emotional reactions	Preserving a reasonable emotional balance Keeping distress within manageable limits
Preserving self-concept	Threats to one's self-concept or belief system Threats to customary roles	To maintain a sense of self-esteem and intactness To integrate the experience of illness with the rest of one's life	Preserving a satisfactory self-image Maintaining and/or restoring a sense of personal worth
Maintaining satisfactory interpersonal relations	Separation from family, friends, and other social supports	To communicate one's changed attitudes, needs and limitations	Preserving relationships with family and friends Maintaining and/or restoring relations with significant others
Preparing for the future	Threats to life and fears of dying Threats to one's future plans Uncertainty about the course of the illness and one's future	(for end-stage patients): To prepare to leave family and friends To provide for loved ones	Preparing for an uncertain future Generating encouragement and hope Enhancing prospects for a favorable interpersonal, social and economic situation after maximum physical recovery has been obtained

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Table 1

Differences among Illness Groups in Reports of Illness Stress

	Total Sample (N=170)	Diagnosis				F (df=3,166)	Duncan comparison
		Hyper- tension (N=39)	Diabetes (N=44)	Cancer (N=42)	Rheumatoid Arthritis (N=45)		
Treatment Demands	37.1%	51.3%	72.7%	23.8%	2.2%	21.53***	A,C < H < D
Restricted Lifestyle	32.4	2.6	4.5	35.7	82.2	46.51***	H,D < C < A
Disease-related Symptoms	18.8	7.7	18.2	33.3	16.6	3.22*	H,D,A < C
Problems with Relationships	17.6	7.7	20.5	31.0	11.1	3.97**	H,A < C
Limited Movement	15.9	2.6	0.0	7.1	51.2	26.79***	D,H,C < A
Pain	15.3	2.6	6.8	19.0	31.1	5.93***	H < C,A; D < A
Emotional Reactions	11.8	10.3	11.4	16.7	4.4	.24	
Accepting the Illness	11.2	5.1	6.8	28.6	4.4	6.51***	A,H,D < C
Fears of Dying/ Uncertainty	5.9	2.6	2.3	16.6	2.2	4.87**	A,D,H < C
Dissatisfactions With Health Care	4.1	0.0	2.3	7.2	6.7	1.34	

Note: While analyses of variance were computed using the number of stresses reported (hence the F statistics reported), the percentage of respondents in each illness group reporting one or more stresses in each category is presented in this table to illustrate group differences more clearly.

a
H = Hypertension, D = Diabetes, C = Cancer, A = Rheumatoid Arthritis

*** p < .001 **p < .01 *p < .05