An Exploration of the Dimensions of Illness Behavior

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Illness behavior is typically studied from the perspective of medical care practitioners. Problems for which people seek medical care are often deemed to be the universe of such ailments whereas actually they represent a small percentage of total illness experienced. This paper describes the rest of the iceberg of health problems. By using a health diary, all problems recorded by 107 participants over a three-week period were analyzed. A total of 348 problems (3.25 per person) were recorded with less than six percent of the problems receiving professional medical care. Stated differently, individuals were experiencing at least one health problem on approximately half of all study days. Health beliefs regarding selected problems were also obtained, along with non-orthodox practitioner (eg, chiropractors and naturopaths) utilization patterns.

Sick role and illness behavior have been extensively studied in recent years.[1,2] These studies, however, have been restricted to the clinical arena. Research has focused neither on the process of becoming ill nor on the process of seeking care. Since the landmark paper by White in 1961[3] describing the large percentages of symptoms and illnesses for which people do *not* seek medical care, more attention but still little research has been devoted to illness behavior occurring outside of biomedical institutions. Only between 10 and 30 percent of health problems are estimated to receive professional medical attention,[4] the majority of problems being handled by self- or home treatment, lay consultation, or by consultation with a non-orthodox health practitioner.
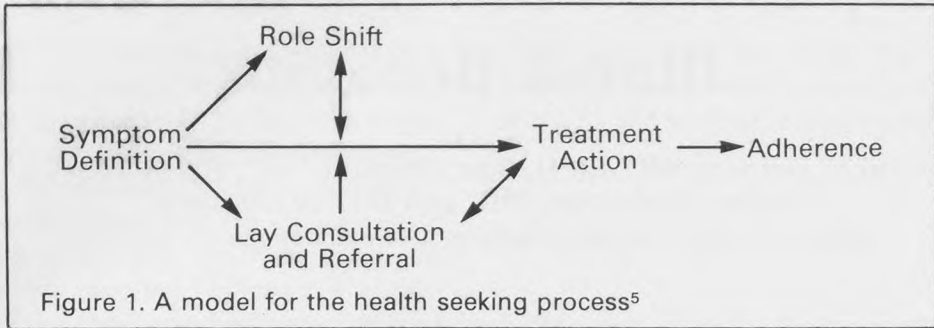
How do people make choices about health

care? Chrisman has developed a model[5] which schematically represents the health seeking process (Figure 1). This model demonstrates how cultural and social forces influence an eventual contact with a care providing system. It also forces a recognition of the fact that medical care, as provided by physicians, is neither central to nor a necessary part of the health care seeking process. Physicians generally engage in a small portion of the treatment actions and encourage adherence (compliance) to that treatment, often ignoring the self-care, lay consultation, and sick role behaviors of their patients. Cultural, social, and personal factors can, and usually do, identify an acceptable (and affordable) source of care outside of the medical arena. An understanding of this concept on the part of the physician can serve to strengthen the patient-physician relationship, help the clinician gain clinical insight into why the patient came to the physician at a particular time, and perhaps help patients make more appropriate future choices about when to seek professional care.

Perceived severity, cost of treatment, understanding of the illness, faith in the care provider, and activity limitation have all been shown to

Role Shift

Symptom Definition → Treatment Action → Adherence

Lay Consultation and Referral

Figure 1. A model for the health seeking process[5]

predict whether or not a person will seek medical care.[6,7] Each of these factors in turn can be influenced by the person's cultural and social (class) backgrounds. In order for the physician to provide optimal care, he or she must have access to the patient's reason for seeking medical care. In this context, the physician must distinguish between disease (abnormality in the structure of body organs and systems) and illness (the patient's perception and definition of sickness).[8]

The purpose of the present study was to assess the volume of health problems which people experience, treatment actions taken for these problems, and the meanings attached to them. A comprehensive picture of illness episodes was obtained through a health diary containing all injuries, stresses, and illnesses. The meanings which people attributed to the episodes were ascertained via the patient explanatory model.[9] This instrument, developed by Kleinman, is a clinically practical one for obtaining the *patient's* view of the illness process, prognosis, and desired treatment. Treatment actions were examined as they occurred in four separate but often overlapping areas: self-care, home or family care, care received from unorthodox health practitioners, and orthodox medical care. A treatment action of particular interest to the authors was the use of nonorthodox, "alternative" health practitioners such as chiropractors, naturopaths, and herbalists. The utilization of such practitioners concurrently with the services of orthodox practitioners is a sensitive topic to most physicians and one that is often ignored.

Zola[4] suggests several areas of research that, if pursued, would add to our understanding of the decision to seek medical care. Among his suggested topics are: the utilization of "other medical" practitioners (eg, chiropractors), self-treatment, and subjective lay appraisal. These three topics are addressed in the present study.

Methods

Background and Sampling

This study was designed as both an educational and a research experience for family practice residents. The present paper describes the research findings; the educational aspects will be presented in a future report.

Subjects volunteering to participate in the study are members of Group Health Cooperative of Puget Sound, a large prepaid health insurance plan serving a population of about 300,000. The cooperative offers a comprehensive plan including outpatient care and prescription drugs which are free at the point of delivery. Since essentially all medical care is covered, the vast majority of utilizations would be expected to take place within the cooperative.

Study participants were sampled from patient panels of 4 second and third year residents. The sample was limited to adults living in Seattle. Participating physicians were further asked to exclude those whom they felt were unlikely to follow through with a demanding study effort. Volunteers were solicited by mail, and any household members living with the participants were invited to take part in the study.

Design

The design included two home interviews and a three-week health diary completed by each participant. The first interview served to gather the following information: demographic data, ethnicity, presence of health care workers in the family, prevalence of chronic medical conditions, perceived illness status, exercise habits, and finally utilization patterns of non-orthodox practitioners. The first interview also included an explanation of the health diary and how to keep it. The diary was kept by each individual older than 15 years for the

Table 1. Population Characteristics				
Age Group (years)	Number of Persons	**Demographics**		
		Sex	Education (Adults)	Race
0-15	31 ⎱ ⎰	8 Female 23 Male		
16-30	15 ⎫	<High School = 0	100 Caucasian
31-45	49 ⎬	43 Female	High School =11 Some College = 9	7 Black
46	12 ⎭	33 Male	College =19 Post-Graduate =37	

Health Status
Chronic or recurrent health problems   Yes—45%   No—55%
Regular aerobic exercise in adults   Yes—63%   No—37%
Perceived health *at first interview*   "Not sick at all"   —67%

three weeks following the first interview; children's diaries were kept by a parent. Each participant was telephoned by the interviewer midway through the diary period and asked if there were any questions about or problems with the diary. Four pieces of information were obtained for each of the listed problems; the *participant's* name for the problem, its severity, its duration, and the treatment given. A second home interview took place at the end of the diary period and served two functions. First, all problem episodes were reviewed for completeness of recording. Secondly, participants were asked to judge which were the most and least significant problems during the three-week period. Explanatory models were then elicited on each of these problems.

Interviewers were the family practice residents (R.A., H.M.) involved in the study. Although their patients were among the participants, neither resident interviewed his/her own patients. Residents tried to assume the role of a *lay interviewer* in order to minimize the artifact created by a physician being directly involved in this type of study, although participants were aware that the interviewers were physicians.

Analysis

A coding manual was constructed prior to the data gathering phase. Upon completion of second interviews, all data were coded by the residents

and prepared for keypunching and computer analysis.

Explanatory model data were subjected to content analysis under the direction of one of the authors (A.K.). Information contained in the explanatory models was not collected as quantitative data but rather used to furnish an in-depth view of how individuals perceived the meaning of their own illness.

Other than a content analysis of explanatory models, data analysis fell into three categories: a demographic description of the population, a description of non-orthodox practitioner use, and an analysis of the reported problems as the dependent variable and numerous other factors (gender, number of chronic conditions, age, perceived health status) as independent variables.
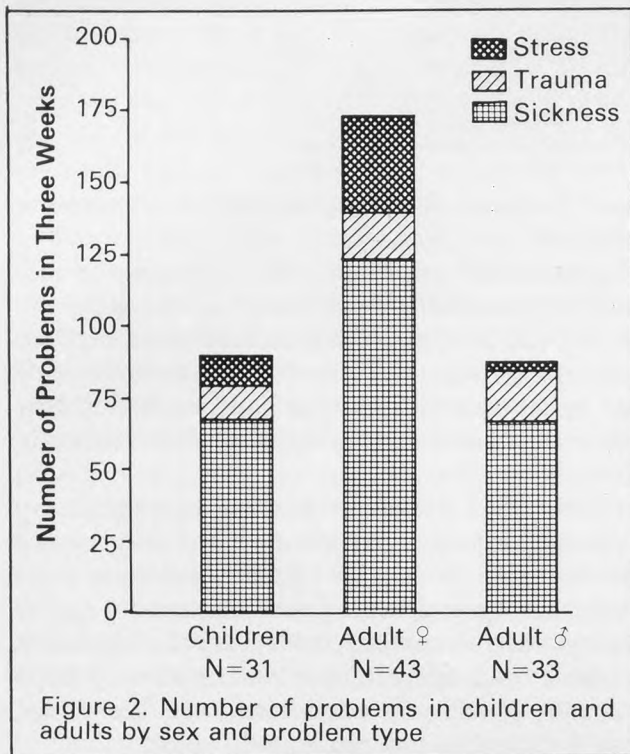
Results

The Population

Out of 240 sampled households, 44 (18 percent), containing 107 individuals, participated in the study. Characteristics of this population are shown in Table 1. Perceived health status was also assessed by incorporating a question taken verbatim from the Sickness Impact Profile.[10] The Sickness Impact Profile had previously been given to a random sample of persons within the cooperative. People in the present study generally considered themselves either "not sick at all" or

Table 2. Alternative Practitioner Utilization by 107 Individuals		
	Ever Utilized	In Past Year
Podiatrist	3	1
Chiropractor	9	3
Religious Healer	2	2
Health Food Store	3	3
Chinese Medicine, Herbalist	1	1
Naturopath	4	2
Pharmacist	9	5
Specialty Clinic	6	3
Total	37	20

Figure 2. Number of problems in children and adults by sex and problem type

ers either "ever" or in the past year. Results are shown in Table 2. Nineteen percent of persons in the study had visited such a practitioner during the past year, and 35 percent had done so at some time in the past. Seventy-six percent of these visits were said to have resulted in improved health status. During the study period itself, two persons visited a chiropractor and one a Chinese medicine practitioner. Persons with chronic conditions had utilized non-orthodox practitioners significantly more often (χ^2 =5.2, P= <.05) than had those without chronic conditions. A final, somewhat surprising finding was the fact that persons with and without orthodox medical workers in the immediate family were no different in their utilization patterns of non-orthodox practitioners.

"very mildly sick" at the time of the first interview. The numerical mean of responses to this question in the diary study group was identical to that previously obtained in the Group Health Cooperative random sample. A final characteristic of the study subjects is that 45 percent stated they had a health care worker (eg, nurse physician) either as a first-degree blood relative or as a spouse.

Alternative Practitioner Utilization

Participants were queried as to whether they had utilized the services of alternative practition-

Health Diary Results

The 107 participants recorded 348 problems during the three-week diary period. These problems are summarized by age, sex, and problem type in Figure 2. A somewhat different perspective is obtained by tabulating the data according to the number of total study days occupied by problems (Table 3). Less than half of all study days were problem free, with participants averaging more than one problem per week. Children, adult females, and adult males averaged 3.26, 3.74, and 2.57 problems, respectively, for the three-week period. The difference between adult males and females is significant (t = 1.8, P < .05). Persons claiming to be aerobic exercisers reported fewer mean problems (3.45) than non-exercisers (4.3) (t = 1.64, not significant). Further analysis revealed strong correlations between the number of re-

Table 3. Days During the Study Period With and Without Recorded Problems Tabulated by Family Member and Problem Type

	Calender Days			
	Children <15 Years Old (N=31)	Women (N=43)	Men (N=33)	Total
Total Study Days*	651	903	693	2,241
No-Problem Days	323 (49.6)**	449 (49.7)	392 (56.6)	1,164 (51.8)
Days with Any Problem	328 (50.4)	454 (50.3)	301 (43.4)	1,083 (48.2)
Days with Sickness†	300 (46.1)	397 (44.0)	258 (37.2)	955 (42.0)
Stress Related Problem Days†	3 (0.4)	63 (7.0)	32 (4.6)	98 (4.4)
Trauma or Injury Days†	29 (4.4)	26 (2.9)	43 (6.2)	83 (3.7)

*Calculated by multiplying the number of subjects by the 21-day period
**Percentages are calculated vertically (eg, women recorded no problems on 49.7 percent of the study days
†Since more than one problem could occur on any given study day, the sum of sickness, stress, and trauma days is greater than the number of days with "any problem"

Table 4. Diagnostic Categories of Problems Comparing Results in the Present Study, the 1977 National Ambulatory Medical Care Survey,[11] and Another Diary Study Performed by Alpert[12]

Problem Type	Present Study	NAMCS (1976)	Alpert Study
Respiratory	25*	14	43
Gastrointestinal	12	3	9
Accident or Injury	15	7	14
Skin Problems	4	6	8
Emotional/Psychologic	12	4	6
Headache	8	2**	5

*Values are given as a percent of total problems
**This value was extracted from NAMCS reported symptoms, not physician diagnosis

ported chronic conditions and the number of problems entered in the diary (r = .24, P = .008, N = 99), and between the perceived severity of a problem and its duration (r = .28, P < .001, N = 325).

Problems are displayed by diagnostic category and compared to similar categories recorded in the National Ambulatory Medical Care Survey[11] and in a diary study involving low income urban families[12] (Table 4). Treatment actions are shown in Table 5.

Office and emergency room visits numbered 18 during the three weeks, equivalent to an annual visit rate of 3.06 for the study group, a rate comparable to the 2.7 national average.[11]

Explanatory Model Analysis

Explanatory models were obtained for the most significant and least significant problems in each

Table 5. Treatment Actions Taken for Problem Episodes (Percent)		
Self- or Family Care		92.3
No active treatment (watch and wait)	24.7	
Home Remedy	28.9	
Proprietary or prescription medicine		
(without medical consultation)	38.7	
Care at Home After Professional Telephone Advice		2.3
Office, Emergency Room, or Hospital Care		5.4

Table 6. Explanatory Model Questions Asked with Reference to the Most and Least Significant Problems in Each Household
Regarding this problem...
1. How did you decide that this was a health related problem?
2. What do you think caused it?
3. What did you think might happen if you did nothing about it?
4. How would you describe the effect of this problem on (a) your body, (b) your usual activity?
5. Where did you go for help and why?
6. Why did you choose this particular treatment?
7. How effective do you think the treatment was?

household. The explanatory model questions are listed in Table 6.

These questions resulted in a wealth of information about 86 individual problems. Several types of models were recognized after discussion of each episode by the four physician authors of the study. Forty-one models were considered to use biomedical explanations which seemed "complete" in that they seemed factually correct and relatively thorough (for a non-physician interviewee). An example of such a model was a "cold" which was said to be "caused by viruses, microscopic creatures that invade the tissues in the air passages, irritating these tissues and causing them to swell and produce secretions." Twenty-seven models were considered biomedical but "incomplete" based mainly on a lack of factual knowledge compared to the more "complete" models. Thirteen models used biomedical terminology but the factual content of these models was clearly wrong. An example of this type of model was revealed in a boy with eczema who said that his "skin itched because of allergies which caused a build-up of chemicals and pollens under the surface of (his) skin until (he) scratched them away." A number of these factually incorrect

models incorporated what were considered to be secular folk beliefs. Examples of this were cold exposure causing upper respiratory tract illness, diarrhea being a purgation of toxin or organisms from the system, and headaches being caused by excessive sugar consumption.

Discussion

Clear communication between practitioners and patients is essential to quality medical care. Health seeking behavior research has begun to explore the variety of ways that individuals first decide that certain bodily events constitute illness and then choose a course of action. *Health diaries* help focus on the whole range of health concerns and problems experienced by a patient, not merely those which are brought to the attention of the medical care system. *Explanatory models* help clarify beliefs and expectations so that practitioners and patients can negotiate a care plan which is both medically sound and acceptable to the patient. This study utilized both these tools.

The results can be divided into three parts: alternative practitioner use, problem frequencies

and health care sought, and explanatory models.

Given this specific population, the pattern of alternative practitioner use is of interest, particularly in this prepaid system where it represents an additional cost to the patient. Familiarity with traditional medicine, as represented by health care workers in the family, did not affect this use. It neither seems to have discouraged use of non-orthodox practitioners on the grounds that they are "quacks" nor encouraged their use in rejection of "the system." The results confirm that many people use neither traditional nor alternative practitioners exclusively, but rather combine the two types of care. One determinant of alternative practitioner use which emerged from the study was chronicity of the condition for which care was being sought, a finding alluded to by other authors but rarely substantiated by quantitative data. A hint of some other determinants can be seen in the explanatory model of one person who had sought care from naturopaths and a Chinese medicine practitioner for an "imbalance in his system." In view of traditional medical practitioners whom he had consulted earlier, he had no "disease," yet he was taking medications and considered the condition to be his most significant health problem. It was clear that his system of health beliefs encompassed more than traditional medicine; it defined a range of "illnesses," some of which mandated treatment by a Western medical practitioner, some by an alternative practitioner, and some by both. The findings of this study emphasize the need for physicians to learn about and take into account their patients' use of alternative practitioners in negotiating a plan of care.

The diaries reveal a high frequency of problems and a relatively small number of symptom-free days in this largely healthy population. An excellent review of diary studies by Verbrugge[13] indicates that no such study has revealed a greater frequency of symptom episodes than the present one. Although this study was conducted during the "colds and flu" season, a pilot study in the summer yielded a similar number of problems per person per month. It seems that "good health" for most people is not the absence of problems, but the presence of ones which are in some way manageable or tolerable. Events which are classified by the individual as serious illness occur against this background of "normal" symptomatology. It is useful for the practitioner to understand how people differ in "symptom background" in order to better assess the significance of a particular symptom to a particular patient.

As recorded in Table 4, the frequency of problem types is less variable between the diary studies than between either diary study and NAMCS data. Information obtained from a health diary reveals a pattern of self-care distinctly different from care received in the physician's office. For instance, familiar ailments of minor severity such as an upper respiratory tract viral infection (URI) are comfortably treated at home. Since the NAMCS data is based on office visits, only a fraction of all upper respiratory tract infections would be captured.

Utilization of the services of health care professionals occurred in only 5.4 percent of illness episodes, a finding which verifies a contention that practitioners see only "the tip of the iceberg."[14] This is particularly impressive in a prepaid setting where no charge is made for a visit, a telephone call, or most medications. A huge amount of care is delivered by the person himself, family, and friends. Not all of this care is innocuous, such as the use of prescription drugs for problems and by persons other than those originally intended, or the misuse of over-the-counter drugs (as in the use of aspirin for stomach pain or pain associated with excessive vaginal bleeding). Factors which determine utilization were not easily identified in this study as the total number was small. However, in answering why they chose *not* to seek medical care for a given problem, participants generally indicated either that they felt the problem was self-limited, that it was amenable to self-care, that it was being watched for progression, and/or that it was "not something a doctor could do much about." A potent piece of information in care planning is why a person chose to come to the practitioner and why at a particular time; explanatory model questioning can provide this information.

The data reveal a majority of biomedically based explanatory models. This is unsurprising in this group which shares the practitioner's advanced education and which often included a health care worker in the family. What *is* surprising in this group is the number of models that, from a biomedical view, were either incomplete or wrong. Some individuals used medical terms (such as "virus") almost by rote, with further question-

ing revealing little comprehension. The mixing of folk and biomedical models can also be confusing; in the absence of strong cultural traditions, people may amalgamate secular folk and biomedical explanations in a type of "new folk belief." Blumehagen has recently elucidated such a "new folk belief" in a group of hypertensive patients who consider their problem as one of a "high tension" state as opposed to one of increased blood pressure.[15] Practitioners may support folk beliefs when couched in biomedical terms or when confronted with problems for which they have poor biomedical explanations. Hellman recently described such a phenomenon on a large scale in England[16] where patients consume tons of useless proprietary cough medicine with consent, and even support, of their physicians. Practitioners may be easily misled by the ease with which some people use biomedical terms and overestimate their understanding, with potentially harmful consequences. This would seem to be a problem especially with people such as the participants in this study who are demographically similar to the majority of physicians and in whom a shared level of knowledge may be wrongfully assumed. Explanatory model questions can, therefore, yield useful information not only from people who for social/cultural/economic reasons seem unlikely to share the practitioner's models, but from everyone.

The unique population makes the results difficult to generalize but still valuable. The people studied were largely young, white, well educated, and healthy. Their familiarity with biomedicine was enhanced by the frequent presence of health care workers in the family. Their access to medical care was facilitated by membership in a prepaid plan and relative geographic proximity to the clinic.

Some sources of bias in participants' selection and response are readily apparent, including resident identification of people likely to complete the diaries, "volunteerism," physicians as interviewers (although not of their own patients), and client and interviewer fatigue as the study progressed. It also might be alleged that the fact of keeping a diary altered the level of sensitivity to symptoms and increased the number of recorded symptoms. The diaries of children were kept by proxies which might alter the frequency from self-report. Sensitive material is unlikely to be recorded in diaries which are to be the subjects of open discussion,

thereby decreasing the number of problems recorded. The net effect of all these influences is uncertain, and yet the above limitations plague all diary studies. Despite these limitations, there is remarkable consistency between diary studies in uncovering otherwise undetected illness episodes.

As with most studies, more questions are raised than answered. The authors did concur, however, on two important areas of future study. First, considering the large, often undetected, number of health problems which people experience, can accurate predictions be made of medical care utilization? Secondly, can successful methods of day-to-day self- and family care be taught to those people presently considered "high utilizers" of the medical care system? The goal is a responsive health care system that can provide individual care to people who have both the skills to deal with many problems themselves and the ability to determine when additional help is needed.

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