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Reported Vague Symptoms and At-Risk Status: the Case of Polyvinyl Chloride Workers in Louisville

ROBERTA G. SANDS, PhD, MSW
RICHARD A. GREENBERG, PhD

Dr. Sands is an Associate Professor, College of Social Work, Ohio State University. Dr. Greenberg is Professor of Epidemiology and Biostatistics, Department of Community Health, University of Louisville School of Medicine, Louisville, KY.

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Tearsheet requests to Dr. Sands at the College of Social Work, Ohio State University, 1947 College Rd., Columbus, OH 43210.

Synopsis

This study concerns the frequency of visits to the dispensary by workers with vague symptoms of physical illness at a polyvinyl chloride plant in Louisville, KY, where an outbreak of hepatic angiosarcoma occurred. The illness behavior of three cohorts of workers at three levels of risk—workers removed from the chemical plant to a pallet plant (PP) because their screening results indicated liver abnormalities; workers who had some positive test results (TP); and workers whose test results were negative (TN)—was studied before (time 1) and after (time 2) the angiosarcoma crisis. It was predicted that, during time 2, the groups' visits to the dispensary would increase in relation to their levels of risk (PP>TP>TN). Although there was an overall increase in the percentage of visits because of vague symptoms during time 2, the only cohort with different behavior was the group of TP workers: they reduced *their use of the dispensary.*

These results are similar to those in a previous study in which all symptoms of illness were included. It is speculated that social and individual factors, as well as the labeling phenomenon, explain the results. Health care providers are encouraged to follow up with workers at risk who seem to avoid monitoring their health.

THE PRESENTATION OF COMPLAINTS of physical distress at a medical service is related to many factors besides physical illness. Illness behavior, "any activity, undertaken by a person who feels ill, to define the state of his health and to discover a suitable remedy," (*1*) is known to be associated with social class, ethnicity, education, sex, and age (*2-6*). Situational variables, such as the attitudes of the family and physician, influence a person's desire to seek alleviation from discomfort or to remain sick (*7*). Distress and the "inclination to adopt the sick role" increase the frequency of illness behavior (*8,9*).

Parsons developed the concept of the sick role

as a legitimate social status that carries with it exemptions and obligations (*10*). The sick person is exempt from ordinary social role responsibilities and from blame for being ill. Nevertheless, the person is obligated to try to get well and to seek out and cooperate with competent helpers. This concept has received some empirical support (*11*). Moreover, it has been applied to diverse populations such as the chronically ill, the aging, and alcoholics (*12–14*). Few efforts have been made to look at the sick role in relation to individuals whose status as sick persons is marginal.

Medical screening examinations have identified segments of populations who are considered at risk of contracting serious diseases. Those persons whose results are positive are usually advised to monitor their health practices and to continue to participate in the screening programs. Frequently they are not exempt from social role obligations or from blame for being at risk. Thus, these persons at risk occupy a "quasi sick role" that is not legitimized, does not involve "rights" or "exemptions," and is not reinforced by medical practitioners or the social environment (*15*). Their at-risk status, then, is ambiguous and uncertain.

Ambiguity and uncertainty affect illness behavior. Subjects in the study of Banks and Keller of symptom experience and health action were less inclined to seek medical care when the symptoms were familiar (*16*). On the other hand, Apple's respondents were more likely to see a doctor for ambiguous symptoms than for recognizable health problems (*17*). Suls and Mullen found that undesirable, uncontrollable life events and uncertainty about control over life events in a 3-month period had a significant relationship to days of illness during the subsequent month (*18*). The study lent support to the idea that uncertainty about negative life experiences increases illness behavior.

With the equivocal findings reported in these studies, it appears that more research on ambiguous or vague symptoms in relation to illness behavior is needed. The study we report looks at the relationship between the frequency of vague symptoms reported at a dispensary and the status of being at risk. The subjects of this research are three groups of industrial workers who occupy three levels of health risk.

Background

In 1974, following a series of experiments performed elsewhere on rats, Doctors Creech and Johnson discovered hepatic angiosarcoma among polyvinyl chloride workers at a chemical plant in Louisville, KY. This discovery precipitated a crisis not only locally, where there was a great deal of media coverage, but in similar plants in other States and countries where additional cases were identified. The seven cases that were initially identified in Louisville represented one-third of the known cases in the world at that time. In response to what appeared to be the beginning of an epidemic, the company, in cooperation with the University of Louisville, instituted a medical screening program. Within a year, by which time two additional cases were diagnosed locally, the University of Louisville received a contract from the National Cancer Institute (No. N01-CN-55212) to develop further a program of cancer control detection and prevention.

The following is a substudy of previous research on illness behavior among industrial workers employed in the chemical plant in which the cases of angiosarcoma, a cancer of the liver, were identified (*19*). Employees, as well as retired workers, of this plant participated in a mass screening program in which they were offered physical examinations, special laboratory tests, and (in selected cases) radiological and radioisotopic examinations and organ function studies. Medical findings were supplemented with data on employees' medical history, work assignments, and chemical exposure levels.

As a result of testing, two at-risk groups were identified. The first were those whose screening tests indicated possible liver abnormalities (for example, portal fibrosis, fatty metamorphosis, enlarged spleens). Many of these workers had further tests, including needle or tissue biopsies, and were removed from continued exposure to chemicals and either reassigned to another section of the plant or put on a medical furlough. Subsequently, the company created a wood pallet plant at a separate work site about a half-mile from the main plant and staffed it with the high-risk workers who were recalled to work. The second group were workers who had some positive (abnormal) test results, but these abnormalities were not necessarily related to liver damage or to vinyl chloride exposure. These findings were maintained after repeated examinations or laboratory tests. Workers with positive test results were advised to consult with the company or university physician and to continue followup with the medical surveillance program.

The previous study (*19*) concerned the frequency of dispensary use by three groups of workers: the

Table 1. Frequency of visits to the dispensary because of vague symptoms before (time 1) and after (time 2) the angiosarcoma crisis in Louisville

Category	Time 1		Time 2	
	Number	Percent	Number	Percent
Pallet plant workers [1]	137	45	147	38
Chemical plant workers with some positive test results	61	20	68	18
Chemical plant workers whose tests were negative	105	35	172	44
Total visits because of vague symptoms	303	100	387	100
Percent visits because of vague symptoms	...	30	...	45
Total visits, all symptoms	1,019	...	865	...

[1] These workers had been moved from the chemical plant to the company's pallet plant when screening results indicated they had liver abnormalities.

pallet plant workers (PP), workers who had some positive test results (TP), and workers whose test results were negative (TN). Visits to the plant dispensary before and after the angiosarcoma crisis were documented. Although it was expected that the frequency of illness behavior would be highest for the PP group during the postcrisis period, no significant differences were found. Consequently, it was suggested that the dispensary nurses who had complained about the PP workers overusing the dispensary—those complaints prompted the previous study as well as this one—had unfairly accused the PP workers.

Among the three groups of workers studied, the PP workers were at highest risk. Continued exposure to vinyl chloride in the regular workplace was considered dangerous for them, so they were permitted to work in another environment. The medical status of the PP workers was marginal and uncertain: they might develop angiosarcoma and enter the sick role legitimately, they might become defined as normal, or they might remain in the no man's land of being at risk. Being at risk is not an acknowledged status. Thus, it could be said that the PP workers occupied a quasi sick role that was not reinforced or legitimized. Nevertheless, these workers were at risk of developing a life-threatening disease, a prospect that would appear to be stressful. Although the previous study found that stress was not expressed by an increase in the use of the dispensary for illnesses and injuries, that study did not look at the types of illnesses and injuries for which the subjects sought medical attention. Moreover, the previous study did not specifically address the nurses' complaints concerning PP workers using the dispensary with unusually high frequency for what the nurses described as "pettiness" and "obvious malingering." This study will be focused on dispensary use in relation to vague complaints.

Little empirical research has been conducted on illness behavior in relation to vague symptoms. Such symptoms have been described in terms of psychiatric constructs—psychosomatic illness, psychophysiological disorders, conversion hysteria. The third edition of the Diagnostic and Statistical Manual of Medical Disorders (DSM-III) includes them under categories of certain somatoform disorders (for example, hypochondriasis), psychological factors affecting physical conditions, factitious disorders, and malingering, which is not a mental disorder (*20*).

Another approach is to look at the presentation of vague symptoms as a strategy to deal with an undesired situation. Shuval, Antonovsky, and Davies describe the power of the physician in Israel to legitimize the sick role and thus permit some individuals to cope with failure by becoming sick (*21*). Sickness can allow one to become passive and dependent, live in an institution, obtain better housing, and receive social welfare benefits. Field's research on medical services in Soviet Russia shows how the label of sickness is sought by malingerers who wish to avoid responsibility (*22*). Waitzkin discusses the way in which the sick role meets institutional as well as individual needs. The sick role enables the individual to deviate from role requirements and acquire nurture and attention. On the institutional level, the sick role allows organizations to maintain stability, control deviance, and provide an escape route for undesirable behavior (*23a*).

Objectives

The question of this research was whether PP workers, who occupied a high risk but marginal status, were malingering. The question was raised of the researchers by dispensary nurses who perceived high risk workers as using the plant's medical clinic with unusual frequency ("Overt complaints in excess of the institutionally appropriate range of sick role behavior are considered 'malingering' " (*23b*)). Vague complaints of physical illness that are in excess of those expressed by control groups would lend support to the argument.

The objectives of this research were these:

1. To determine whether there is a relationship between vulnerability to illness and the frequency in which vague complaints of illness are presented at a dispensary.
2. To determine whether there is a difference in the frequency in the presentation of vague symptoms among the three groups over time.

It was predicted that the frequency of visiting the dispensary because of vague symptoms in the period following the angiosarcoma crisis (time 2) would be relative to risk status (PP>TP>TN). We authors assumed that vague symptoms are more sensitive to social contingencies (for example, isolation imposed by placement in the pallet plant, the desire to be relieved of work) than are the specific complaints of illness and injury that were studied previously.

Method

The sample consisted of three matched groups of 24 industrial workers who participated in the medical screening program from 1975 to 1977. Workers in the TN and TP groups (who served as controls for PP workers) were matched as closely as possible with each PP worker according to four criteria: age (within 5 years), sex (all male), building at the main plant where the controls worked and the PP workers previously had worked (type of exposure), and status (hourly or salaried). The PP group originally consisted of 29 men. Five cases were excluded because two PP workers were on leave during the first period and one during the second year and because no matches could be found that satisfied all the above criteria for two other cases.

Dispensary records of men in all three groups were examined for two periods of 1 year each. Time 1 was the year preceding a change in the status of PP workers (medical furlough or reassignment of PP workers). The furlough-reassignment period was excluded because workers were aware that they had been exposed to the carcinogen and because the medical furloughs created inequity among the three groups in access to the dispensary. Time 2 corresponded with each PP worker's first year in the pallet plant. Each matched triplet used the period determined by the PP worker's history. (The relationship between vinyl chloride exposure and angiosarcoma was not known in the plant until the end of time 1.)

The data-collecting instrument used accounted for each visit or telephone call by each worker in each group in the two periods. Data were gathered on the date of visit, treatment, record category (occupational injury, nonoccupational illness, visit for screening tests, and so forth). Diagnoses were coded according to a master code of some 100 medical conditions. For this study only diagnoses coded in vague categories were used. These included vague or general references to problems with vision, hearing, speech; muscular-skeletal or nervous system problems; allergic, endrocrine, metabolic, nutritional, and skin problems; heart and circulatory problems; respiratory or breathing difficulties; digestive system problems; genitourinary conditions; as well as "nerves," substance abuse, family and job difficulties, weight problems, exertion, lack of exercise, age, general symptoms (shortness of breath, chest pains, fatigue, headaches, and so forth), no diagnosis, and diagnosis unknown. Excluded from consideration were the recorded categories pertaining to telephone calls, visits for information on routine tests, and visits for taking and getting information about screening tests. (Note: dispensary records did not include information on workers' visits to private doctors. Nevertheless, a psychosocial survey of pallet plant workers and a random sample of main plant workers performed in 1976 found that there was no difference between the two groups in the frequency of their use of private physicians and emergency rooms. Anecdotal information collected by staff of the psychosocial rehabilitation unit of the vinyl chloride project confirms that many workers felt that the company was responsible for their medical care.)

As in the previous study, the analysis was based upon rank ordering of frequencies of employees' visits to the dispensary. Accordingly, the number of visits for each matched triplet (for example, worker #5 PP, TP, and TN) for each period was placed in order of frequency with the highest given a 3, the middle a 2, and the lowest a 1. In case of ties, the mean between remaining ranks was given to both (for example, 2.5). Rank order tests were used because the number of dispensary visits cannot be approximated by a normal or Poisson distribution. The Wilcoxon matched-pairs, signed-rank test was used to test for a change in frequency of visits between periods within groups, and the Friedman two-way analysis of variance was used to test for an interaction and for differences between groups at each period (*24*). To compare the frequency of visits to the dispensary

Table 2. Frequency and ranking of visits to the dispensary because of vague symptoms before (time 1) and after (time 2) the angiosarcoma crisis in Louisville

Worker code number	Time 1 [1]						Time 2 [2]					
	Pallet plant workers		Workers with negative test results		Workers with some positive test results		Pallet plant workers		Workers with negative test results		Workers with some positive test results	
	Number	Rank	Number	Rank	Number	Rank	Number	Rank	Number	Rank	Number	Rank
1	1	2.5	1	2.5	0	1.0	1	3.0	0	1.5	0	1.5
2	4	1.5	4	1.5	5	3.0	3	1.0	7	2.0	13	3.0
3	16	3.0	3	1.0	7	2.0	13	2.0	19	3.0	6	1.0
4	0	1.0	1	2.0	3	3.0	7	3.0	6	2.0	1	1.0
5	3	3.0	0	1.0	1	2.0	7	3.0	0	1.0	3	2.0
6	1	1.0	4	3.0	2	2.0	2	1.5	3	3.0	2	1.5
7	14	3.0	2	1.0	8	2.0	9	3.0	0	1.0	8	2.0
8	24	3.0	0	1.0	4	2.0	7	3.0	2	2.0	0	1.0
9	7	2.0	17	3.0	4	1.0	14	2.0	25	3.0	3	1.0
10	12	3.0	5	1.0	9	2.0	13	3.0	9	2.0	7	1.0
11	9	3.0	1	1.5	1	1.5	2	3.0	1	1.5	1	1.5
12	3	2.0	4	3.0	0	1.0	1	2.0	0	1.0	2	3.0
13	5	3.0	1	1.0	3	2.0	3	1.0	15	3.0	4	2.0
14	6	3.0	2	2.0	0	1.0	4	2.5	4	2.5	1	1.0
15	2	1.0	4	2.0	5	3.0	1	2.0	11	3.0	0	1.0
16	4	2.0	9	3.0	1	1.0	1	2.0	2	3.0	0	1.0
17	1	2.5	0	1.0	1	2.5	1	2.0	1	2.0	1	2.0
18	0	2.0	0	2.0	0	2.0	1	1.5	3	3.0	1	1.5
19	5	3.0	0	1.5	0	1.5	13	3.0	1	1.0	6	2.0
20	9	3.0	0	1.5	0	1.5	16	2.0	23	3.0	1	1.0
21	0	1.0	4	3.0	2	2.0	0	1.5	4	3.0	0	1.5
22	3	2.0	25	3.0	1	1.0	6	3.0	5	2.0	3	1.0
23	4	2.0	6	3.0	3	1.0	13	3.0	7	2.0	3	1.0
24	4	2.0	12	3.0	1	1.0	9	2.0	24	3.0	5	1.0
Rank sum		54.5		47.5		42.0		55.0		53.5		35.5

[1] $\chi^2_2 = 3.27$, $P = 0.195$.
[2] $\chi^2_2 = 9.81$, $P = 0.007$.

NOTE: Frequencies per matched triplet of workers were ranked from 1 to 3.

of the three groups of workers for the two periods, the analysis was performed as a sequence of these rank-order tests.

Results

Table 1 presents total frequencies of visits by group over time. During time 1 the workers in the three groups made a total of 303 visits for vague symptoms. This figure represents approximately 30 percent of all visits (1,019) that were made during that precrisis period. During this time the PP workers had the highest percentage of visits. For the second period there was an increase in the frequency (387) and percentage (45 percent) of visits for vague symptoms as compared with time 1. Curiously, those workers whose test results were negative had the largest increase in dispensary visits. Nevertheless, there was a decline in the total frequency of visits for all symptoms (865) from time 1. Although these frequencies present a picture of trends, they need to be subjected to statistical tests for clarification of their significance.

Table 2 gives the frequencies and rankings of dispensary visits for vague symptoms for times 1 and 2. With respect to time 1, the Friedman two-way analysis of variance is not significant.

In the case of time 2, the Friedman two-way analysis of variance is significant ($P < 0.01$). Using multiple comparison procedures (*25*), the TP group is shown to have fewer visits ($P < 0.05$) than either the PP or TP group.

Table 3 gives the difference in frequencies (time 2 minus time 1). There is no evidence of any interaction between time and group. The Wilcoxon matched-pairs, signed-rank test was then applied to the difference within each group separately. For the PP group, 11 men had more visits, 10 had fewer visits, and 3 had the same number that they had in the previous period. For the TN population, 15 men had more visits, 6 had fewer visits, and 3 had the same number ($P < 0.05$, signed-rank test). For the TP population, 10 had more visits, 9 had fewer visits, and 5 had the same number. The difference shown by the TN population, although just significant at the 5 percent level, is not considered meaningful because of the

lack of interaction and the number of comparisons made. We note, however, the striking similarity between these results and those reported in our previous paper.

Discussion and Conclusions

When one looks at the proportion of visits that were made for vague symptoms in relation to total visits, the high percentage of visits that were made for vague symptoms becomes evident. Before the angiosarcoma crisis, 30 percent of the visits were because of vague symptoms. This figure increased to 45 percent following the crisis. Interestingly, the frequency of visits for all reasons declined in the wake of the crisis (time 2), yet proportionately more workers responded by going to the dispensary more frequently for vague symptoms than previously. Moreover, after the crisis the workers who tested negatively (who were healthy) increased their rate of dispensary use.

During time 1, the differences in rank sums among the three groups were not significant. In the period before the crisis, then, the three groups were on a par.

Curiously, the group with positive test results (TP) had significantly fewer visits than the other two groups during time 2. Apparently these workers, who had some threatening test results but were not removed from their worksites, reacted to the positive findings by a *lowered* frequency of visits to the dispensary for vague symptoms as compared with the other groups.

When we looked at the relationship between time and group, we did not arrive at any significant findings. There was one within-group difference that occurred among workers whose test results were normal (TN). This group experienced an increase in visits. Although we are doubtful whether this result is statistically meaningful, it is striking that we found the same trend in the same direction in the previous study of visits for illnesses and injuries.

Overall, our findings on visits for vague symptoms are similar to our findings in the previous study. We did not find that the workers at highest risk (PP workers) increased their visits because of vague conditions. These workers did not appear to be seeking legitimization of their quasi sick role. They did not appear to be malingering. On the contrary, they were conducting themselves in the same way they had before the vinyl chloride threat.

These findings suggest that people who are at high levels of risk and who are not legitimately defined as sick do not necessarily handle their vulnerability by increasing their illness behavior. During time 2, for example, the group at a medium level of risk (TP) had relatively fewer visits to the dispensary as compared with other groups. On the other hand, the group with the least to fear (TN) had an increase in vague complaints over time. The PP group, the group at the highest risk, was the most stable over time.

These findings can be interpreted in a number of ways. First, it may be that lower-middle-class male industrial workers at risk of getting cancer respond to their vulnerability as identified by screening tests by avoiding going to the dispensary (TP) or by maintaining their previous patterns of illness behavior (PP). Apparently they used the psychological defenses of denial and repression, believing that what they do not know does not hurt them.

Another explanation is that undetermined individual factors such as the "inclination to adopt the sick role" (*9*) or situational variables (*7*) are involved. Unfortunately, in this study of medical records, such factors were not examined. It is

Table 3. Frequency and ranking of visits to the dispensary because of vague symptoms before (time 1) and after (time 2) the angiosarcoma crisis in Louisville, time 2 minus time 1 [1]

Worker code number	Pallet plant workers		Workers with negative test results		Workers with some positive test results	
	Number	Rank	Number	Rank	Number	Rank
1	0	2.5	−1	1.0	0	2.5
2	−1	1.0	3	2.0	7	3.0
3	−3	1.0	16	3.0	−1	2.0
4	7	3.0	5	2.0	−2	1.0
5	4	3.0	0	1.0	2	2.0
6	1	3.0	−1	1.0	0	2.0
7	−5	1.0	−2	2.0	0	3.0
8	−17	1.0	2	3.0	−4	2.0
9	7	2.0	8	3.0	−1	1.0
10	1	2.0	4	3.0	−2	1.0
11	−7	1.0	0	2.5	0	2.5
12	−2	2.0	−4	1.0	2	3.0
13	−2	1.0	14	3.0	1	2.0
14	−2	1.0	2	3.0	1	2.0
15	−1	2.0	7	3.0	−5	1.0
16	−3	2.0	−7	1.0	−1	3.0
17	0	1.5	1	3.0	0	1.5
18	1	1.5	3	3.0	1	1.5
19	8	3.0	1	1.0	6	2.0
20	7	2.0	23	3.0	1	1.0
21	0	2.5	0	2.5	−2	1.0
22	3	3.0	−20	1.0	2	2.0
23	9	3.0	1	2.0	−3	1.0
24	5	2.0	12	3.0	4	1.0
Rank sum		47.0		53.0		44.0

[1] $\chi^2_2 = 1.75$, $P = 0.417$

NOTE: Frequencies per matched triplet of workers were ranked from 1 to 3.

recommended that future studies of this type develop procedures to elicit mechanisms of decision making and situational variables (as well as use of physicians outside the dispensary).

In our previous paper we discussed the labeling of high risk workers that was a consequence of the establishment of the pallet plant. We see this trend again in our examination of dispensary visits for vague symptoms. Clearly the pallet plant workers were not using the dispensary for vague or nonexistent disorders any more than other workers were. They were incorrectly perceived as dispensary abusers and labeled malingerers.

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Terminal Care Preferences: Hospice Placement and Severity of Disease

JAMES S. POWERS, MD
M. CANDICE BURGER, PhD

Dr. Powers is Assistant Professor of Medicine, and Dr. Burger is Research Associate, Division of General Internal Medicine, Department of Medicine, Rm. B2106, Vanderbilt University Medical Center, Nashville, TN 37232.

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Tearsheet requests to Dr. Powers.

Synopsis

National Hospice Study data for 1981–82 were used to predict the location of care for terminal cancer patients. Sites of care were conventional care in hospitals, hospital-based hospice care, and hospice care in the home. Subjects were terminal cancer patients with a prognosis of less than 6 months of life who were attended by a primary concerned person. There were 1,732 patients 18–99 years old—293 conventional care, 612 hospital-based hospice care, and 827 hospice home care patients.