Recalling Pain and Other Symptoms

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> If you come to think about it, physical pain has many singularities. Of all human experiences it is, as long as it lasts, the most absorbing; and it is the only human experience which, when it comes to an end, automatically confers a real if not perhaps a very high kind of happiness. It is also the only experience this side of death which is by its nature solitary. But the oddest thing about it is that despite its intensity, despite its unequaled power over mind and body, when it is over *you cannot really remember it at all.*
>
> (Peter Fleming, *My Aunt's Rhinoceros and Other Reflections*. New York: Simon and Schuster, 1956. [emphasis added])

THE RECALL OF SYMPTOMS IS AN IMPORTANT ingredient in various health status surveys—such as the National Health Interview Survey—and asking for reports of symptoms is often used as a device to aid in the recall of specific illnesses or injuries (e.g., see the discussion in Jabine et al. 1984; Fienberg, Loftus, and Tanur 1985). If you were to ask people to compile a list of symptoms that might be of use in this regard, *pain* would invariably

Milbank Memorial Fund Quarterly/*Health and Society*, Vol. 63, No. 3, 1985

be on the list. Yet, among symptoms pain may be as elusive as any. What is pain? Is pain always associated in some way with illness and injury? Is pain a sensation? Are there objective ways to measure the extent of pain being experienced by an individual? Are pain experiences comparable across individuals? Such questions are not easily answered.

In this paper we explore some of the dimensions of the recall of pain and other symptoms and point to research problems currently being pursued by various investigators. Our examples are drawn from several sources: testimony in lawsuits, a British study on medical problems with feet, National Center for Health Statistics (NCHS) research on medical recollection, and an NCHS-sponsored survey—the National Ambulatory Medical Care Survey (NAMCS)—which focuses in part on symptoms and pain. This diversity of examples highlights the similarity of issues affecting the accuracy of recall and reporting of symptoms in everyday life, in histories collected by health care providers, and in survey interviews.

There has been much research on the neural and neurochemical mechanisms of pain perception (e.g., see Terman et al. 1984) and there is an extensive bibliography on pain and its relief in the pharmacological literature. Yet, the understanding of mechanisms for the recall of pain and the cognitive aspects of memory for pain and other symptoms have eluded investigators. Because of the importance of these issues to health survey work we believe that this area presents some of the most exciting prospects for fruitful collaboration of cognitive psychologists, biomedical researchers, and survey researchers—fruitful in the sense of providing useful insights and progress toward solutions.

Two Legal Examples

James J. Hannan died of a heart attack in Kentucky in March 1979. At the time of his death, Mr. Hannan was insured under a $500,000 life insurance policy issued by the All American Life Insurance Company, obtained in March of 1978, just a year before his death. After Mr. Hannan's death, the life insurance company refused to pay the death benefit on the grounds that in applying for the insurance, Mr. Hannan had omitted certain pertinent medical information from his application. In declining to pay the claim, the Life Claims supervisor for All American wrote, "In reviewing the pertinent medical information

developed during a routine investigation of this claim, it is now apparent that the insured's full health history had not been disclosed on his application which he dated and signed on January 12, 1978." Specifically, Mr. Hannan failed to mention that he had complained of chest pains within the previous five years. The insurance company discovered several doctors to whom he had complained of chest pains in 1972 and 1973; in 1977 he reported a pain that was brought on by exertion and relieved by rest. A lawsuit was filed in the United States District Court for the Western District of Kentucky (*Louisville Trust Bank v. All American Life* 1980).

Did Mr. Hannan willfully fail to mention chest pains in order to obtain the insurance, or did he fail to mention the pains for some other reason? Mr. Hannan, in fact, acknowledged freely a heart attack he suffered in 1969, and admitted to chest pains when these were clearly related to that heart attack. But he was not always questioned about chest pains in a way that related them to the heart attack. For example, he answered "no" to the question, "During the past five years, have you had dizziness, shortness of breath, pain or pressure in the chest?" How is a patient to answer this compound question if the answer is *mostly* "no?" Is it possible that he interpreted this question about pain as a question about pain in connection with breathing? In short, could the wording of the question have been responsible for the lack of acknowledgment that the insurance company took to be deliberate?

It is also possible that Mr. Hannan simply forgot that he had had chest pains. One might be tempted to think that something important, like chest pains, could not easily be forgotten. Yet, this is simply not so. People can forget about highly important events in their lives when as little time as a year has elapsed. In one study of people who were known to have been involved in a motor-vehicle accident during the 12-month period preceding the interview, 14 percent failed to report the accident at all. While most people reported the accident if asked within 3 months, close to 30 percent failed to report if asked after a 9 to 12-month delay. In another study of people who were known to have been hospitalized during the 12-month period preceding the interview, close to 20 percent failed to report the hospitalization if asked after a 40-week delay. (See Loftus 1982 for more details about these studies.) Thus, even important events in one's life can apparently be forgotten rather quickly.

Mr. Hannan's forgotten symptoms occurred in the past. His experience tells us nothing about the question of whether someone could fail to remember symptoms he had recently experienced. However, the experiences of another patient in a different location, William Labbe, do. Mr. Labbe died in 1983 of acute respiratory failure. He had been an active jogger, and also played basketball occasionally. A year earlier he had seen a doctor for high blood pressure and was treated with a drug called Inderal. Only after the patient's death did the doctor learn that his patient had had a history of mild asthma which had required aerosol medication. The aerosol medication package contained a warning that, for individuals with hypertension, the medication should only be used upon the advice of a physician. Moreover, the drug Inderal was contraindicated for patients with asthma. The doctor claimed that he always asked new patients about breathing problems and the use of any medications and that the patient must not have reported these to him. A lawsuit was filed in the state of Washington (*Labbe v. Mangan and Lucas* 1983). The plaintiffs contended that a man with a history of asthma, who was currently using aerosol medication, would not fail to report this to a doctor who had asked specifically about it. During his deposition in February 1984, a year and a half after his initial appointment with Mr. Labbe, the doctor was asked: "Q: You say you would have asked him, based upon what you feel was your practice at the time. . . . Did you ask him that? A: I'm sure I did. Q: Do you have a memory of that? A: I haven't the exact memory, but that was my practice."

Did the doctor remember to follow his usual practice of questioning this time? Could Labbe have forgotten about his chronic asthma? Did Labbe interpret the question differently from the way the doctor intended to ask it? Perhaps Labbe thought the doctor was asking about breathing problems at the moment, rather than breathing problems in the recent past. Perhaps Labbe did not classify as "medication" his aerosol inhaler, which he purchased without a prescription.

These cases make salient the importance of memory for symptoms that people experience. Not only must symptoms be correctly recalled so that physicians can have the necessary information to treat their patients properly, but occasionally the extent to which the ordinary person can and does accurately recall such information can be important in resolving issues of dispute in a fair and equitable way. Once we understand something about the mechanism by which patients do

recall and report their symptoms, we will be in a better position to devise ways of enhancing the accuracy and completeness of reports, both to health care providers and to survey interviewers.

Studies of Medical Recollection

In much of the following material we compare medical records with survey responses. Such comparisons are often important and informative; their results are often characterized as survey underreporting (when events in medical records are not mentioned by survey respondents) or as survey overreporting (when events mentioned by survey respondents do not appear in medical records). But the reader should bear in mind that medical records are by no means infallible. First, such records can be no better than the reports—usually from patients themselves—upon which they are based. Being aware of this, many health care providers develop systematic forms—not unlike survey questionnaires—to guide their interviewing for the elicitation of histories. Some go so far as to solicit copies of records from previous providers. Second, the recording by health care providers of reported events is often both rich and discursive, but it usually lacks the systemization developed for coding schemes to record events and conditions reported in well-designed surveys, where careful studies are often made of the reliability of such coding (see, e.g., Jabine 1985). Thus, discrepancies found between survey reports and medical records, while important in highlighting areas in which reporting and/or recording can be improved, should not automatically be attributed to survey deficiencies.

Several large-scale studies have been conducted to compare the information reported by people with that found in preexisting medical records. In one study, over 15,000 chronic conditions recorded in the medical records and/or reported in interviews were examined (National Center for Health Statistics 1967). Some conditions were found to be reported with a fair degree of accuracy and completeness, including diabetes, vascular lesions of the central nervous system, heart conditions, diseases of the gallbladder, and absence of fingers and toes. Some conditions were severely underreported, including neoplasms, mental illness, menstrual disorders, and skin diseases. Given that these were conditions which may cause embarrassment or dismay and denial on the part of the respondent, their underreporting was not unexpected.

The study also showed that respondents often failed to report conditions which had little impact on their lives (National Center for Health Statistics 1965). Finally, some conditions were overreported, including hay fever, asthma, tuberculosis, migraine headaches, hypertension, hemorrhoids, rheumatic fever, sinusitis, bronchitis, and visual/hearing/speech impairments. Such overreporting was presumably caused by people reporting conditions of long duration (or even conditions that they had many years ago but which had recently been quiescent) and which were thus not noted in current medical records.

Also of interest in this study was the finding that the percentage of underreporting of conditions was about the same for men and women; however, the women had a greater tendency to overreport conditions. For persons over 65 years old, the accuracy and completeness of reporting was substantially higher among women than among men. Finally, the amount of education of the respondent was unrelated to reporting errors.

How do these results relate to Mr. Labbe whose doctor claimed that he had not told him about having asthma? Thirty-one percent of the asthma conditions that appeared in the medical records were not reported in the interview; 51 percent of the asthma conditions that were reported in the interview were not reported in the medical records. Thus, the overreporting of asthma exceeds the underreporting. Despite this, a fairly sizable percentage of patients who are known to have had asthma failed to report it during a presumably important interview. Although we cannot be sure that Mr. Labbe was like these individuals, if he had been he would not have been a rare case.

The data on recall described above, provided from analyses of government surveys, constitute only a first step toward what needs to be done truly to understand the ability of people to report fully their medical histories and conditions, i.e., with a reasonable degree of accuracy and completeness. One problem with these data is that they are old; society has changed and what people consider to be important or embarrasing or memorable may have changed. Further, problems with using previous data concern the accuracy of records that were kept then versus now. Specific studies designed to examine the accuracy of recollection could go a long way toward alleviating these and other problems with the prior research. As we shall point out below, one area in which some specific studies have already emerged is the area of recollection of pain.

Pain as the Presenting Symptom in Medical Diagnosis

The National Ambulatory Medical Care Survey (NAMCS) is a sample survey of office-based care that has been conducted annually from 1973 through 1981 by NCHS. The target universe of NAMCS is composed of office visits made by ambulatory patients to nonfederal and noninstitutional physicians who are principally engaged in office-based, patient-care practice in the contiguous United States. As such, NAMCS provides a useful but limited perspective on the reporting of pain and other symptoms—for example, it gives no information on the symptoms that are not reported to a physician.

Like other NCHS surveys, NAMCS uses a multistage probability sample design. In the present design there is step-wise sampling of areas called primary sampling units, physicians' practices within primary sampling units, and patient visits within physicians' practices. The physician sample (5,805 for the combined years 1980 and 1981) was selected from master files maintained by the American Medical Association and the American Osteopathic Association. Those members of the sample who proved to be in scope participated at a rate of 77.3 percent. Responding physicians completed visit records for a systematic random sample of their office visits made during a randomly assigned weekly reporting period. During 1980 and 1981 responding physicians completed a 2-year total of 89,447 patient record forms. The National Opinion Research Center, under contract to the NCHS, was responsible for the field operations of the survey.

For each office visit the physicians were asked to give the "patient's complaint(s), symptom(s), or other reason(s) for *this* visit (in patient's own words)." Of all such office visits 6.1 percent were new-pain visits as distinguished by the following characteristics:

- The visit was unreferred;
- Pain was the chief symptom presented by the patient;
- The physician had not previously seen the patient for the condition associated with the pain.

Confronted with a new-pain symptom, the office-based practitioner tends to intensify the diagnostic effort required to find its cause. Thus, at virtually every new-pain visit reported in NAMCS, one or more

diagnostic procedures was ordered or provided (National Center for Health Statistics 1984).

A very high percentage of doctor-office visits involves clearly identifiable purposes—e.g., an early NAMCS feasibility survey had 24.8 percent of all visits for medical and surgical aftercare and 30.3 percent for prenatal care (National Center for Health Statistics 1974). Thus, the 6.1 percent for new-pain visits represents a substantial proportion of visits in which the doctor is required to exercise primarily diagnostic judgment.

The Physiology and Measurement of Pain

When we think back to a painful fall or to a time when we accidentally touched a burning object, it seems hard to really recreate the pain. This common subjective experience has probably been more responsible than anything else for the widespread belief that pain cannot accurately be recalled:

> Though familiar to us all, pain is mercifully difficult to remember once it has passed (if it were not, it has been observed, every family would have but one child). (*Time Magazine*, June 11, 1984, 58–59).

> Let a sufferer try to describe a pain in the head to a doctor and language runs at once dry. (Virginia Woolf as cited in Beecher 1957, 61).

From a physiological perspective, the primary modalities of cutaneous sensation are usually taken to include touch, pressure, hot, and cold. Within these sensations the physiologist thinks in terms of events occurring on the skin that can be classified in terms of their effects on the sensory nervous system. Pressure and hot and cold can be measured objectively from this perspective, either by various instruments or by detectors of the sensory nervous system, although whether these measurements relate to individuals' subjective assessments of the sensations that they experience is a matter of dispute. Most investigators who study pain argue that pain cannot be measured objectively (e.g., see the discussion in Beecher 1957), although many have tried to do so, even in terms of thresholds and tolerances on instruments such

as the pressure algometer (e.g., Mersky and Spear 1964). The view that measurement of pain involves elicitation of subjective responses did not stop Beecher and others from attempting quantitative work on the effectiveness of drugs in altering pathological pain. In fact, Beecher (1957) begins his exhaustive review by quoting the famous Kelvin dictum (see Merton, Sills, and Stigler 1984):

> I often say that when you can measure what you are speaking about, and express it in numbers, you know something about it; but when you cannot measure it, when you cannot express it in numbers, your knowledge is of a meagre and unsatisfactory kind: it may be the beginning of knowledge, but you have scarcely, in your thoughts, advanced to the stage of *science*, whatever the matter may be. (William Thompson, Lord Kelvin).

Yet Beecher and many subsequent researchers who have attempted to measure pain did not presume that measurement implied a complete understanding of pain.

Any explanation of pain must be able to account for all of this sensation's unusual characteristics. So, for example, sometimes people continue to experience pain after its original cause has disappeared (e.g., sufferers of neuralgia, an infection of the peripheral nervous system, may complain of pain after the infection has cleared up). Another unusual characteristic is that sometimes people experience referred pain—the sensation of pain in one location in the absence of any direct stimulation from that site. An example comes from people suffering from angina pectoris, who report pain extending from the chest to the forearm, although the pain is thought to originate in the heart (Barlow and Mollon 1982). There are naturally occurring examples of pain that are not associated with any injury or illness as well as the reverse (Wall 1977)—e.g., phantom limb pain in amputees and placebo effects in medical trials. There are short-lived acute pain (often easily tied to a specific event such as childbirth or surgery) and persistent or recurrent chronic pain (which includes various forms of arthritis, back pain, and headaches). If one is to provide relief for these or any other forms of pain, one must take into account their sources. Pathological pain responds reliably to morphine, for example, whereas experimentally induced pain does not (Beecher 1957; Smith et al. 1966).

The Recall of Pain

Given this somewhat disorderly state of knowledge about what pain is and how and when we can measure it, we should not be too surprised to find conflicting information on the memory for pain. For example, Linton and Melin (1982) report that chronic-pain patients remember having significantly more pain than they reported at the time the pain was actually occurring. On the other hand, Hunter, Philips, and Rachman (1979) found that neurosurgical patients' recall of acute pain was "surprisingly accurate" up to 5 days after an experience of acute pain.

How are we to reconcile these differing sets of results? The differences between these two studies are substantial. The Hunter, Philips, and Rachman study asked about acute pain associated with a very specific event, while the Linton and Melin study asked about chronic pain. The Hunter, Philips, and Rachman study used short recall intervals, while the Linton and Melin study queried patients after much longer intervals. Based simply on these two studies, one might hypothesize that memory for pain is accurate if it refers to an acute event and is recalled after a short interval, while memory for pain is less accurate if it refers to a chronic event and is recalled after a long interval.

It is also possible that the patients in the two studies differed in other ways that could have been responsible for the different conclusions. Perhaps the patients in one study were in less pain when they recalled their earlier pain. Psychological and emotional factors can alter the *experience* of pain, magnifying or inhibiting it. In one study, people who were anxious reported more discomfort from a painful stimulus than did people who felt relaxed (Mersky 1973). In another study, Eich et al. (1984) showed that memory for the intensity of prior physical pain depends critically on the intensity of present pain. When their present pain intensity was high, patients with chronic migraine headaches remembered earlier painful experiences as being more intense than their pain diaries indicated. When their present pain intensity was low, however, patients remembered prior pain as being less severe than it actually was. So it would be reasonable to propose that such factors as current level of anxiety as well as current pain state could influence the memory of pain. Research involving rigorous experimental tests is still needed to provide further confirmation of these hypotheses.

What other factors may influence the accurate recall of pain? Indeed, is it pain that people recall or is it really the events such as injuries and severe illnesses? If the latter is true, e.g., a kidney stone attack may be used to recall the pain rather than the other way around, is there any reason to pursue the use of pain as a symptom to diagnose, classify, or recall unspecified illnesses? These are all research questions that cut across the domains of cognitive psychology, physiology, medicine, and survey research.

To understand some of the elusive aspects of the recall of pain, we may need to recast our very thinking of pain as sensation. For example, Wall (1977) suggests that we need to begin thinking about pain as being in a class of *feelings* that include hunger, thirst, and suffocation, and that this would "shift the discussion of the phenomenon of pain away from the stimulus to a realm of reactions." Yet others suggest that, to understand the problems associated with the memory for pain, we would do well to examine what has been learned regarding the memory for taste, which is quite different from the cutaneous sensations discussed earlier and has been studied from different perspectives.

Trouble with Feet

The reasons for underreporting of conditions tend to be complex, and often vary depending on the nature of the condition. This is well illustrated in a British study described in Clarke (1969) and carried out by the Institute of Community Studies, London. A random sample of 1,500 registered voters from 12 constituencies in England and Wales was selected, and 82 percent of the sample was interviewed to learn of their perceptions of and attitudes toward their own foot problems. Clarke (1969) reports that 62 percent of those interviewed reported some kind of trouble with their feet in the four weeks preceding the interview. The general question regarding foot trouble was followed by a list of specific conditions. Only 25 percent said that they had trouble in response to the general question, and the remaining 37 percent responded "yes" to at least one specific condition (e.g., "not trouble, just a corn, that's all, but it was painful in the past four weeks"). Just under 50 percent of those reporting foot trouble at the interview said that they had suffered pain or discomfort from their feet during the past four weeks. Of these, 75 percent said "yes"

in response to the following general pain question: "Have your feet been painful or caused you any discomfort during the past four weeks?" The remaining 25 percent reported pain when asked in more detail about specific conditions that they had previously mentioned. Several of those who reported trouble, but did not report pain said that the reason they experienced no pain was that they had altered their behavior in order to avoid it. (The questionnaire did not seem to allow for "pain but no trouble.")

A randomly selected 50 percent of the respondents were then asked if they would be willing to undergo examination by a trained chiropodist, and 50 percent of those asked actually had their feet examined. Of those who were examined, 72 percent had reported foot problems; of all those who were not examined, only 58 percent had reported problems. The comparison of diagnoses of foot problems by the chiropodist with interview reports is given in table 1. (The figures in parentheses have been proportionally adjusted to add to totals for the entire sample at the interview.)

TABLE 1
Problems at Examination (by percentage)

		Yes	No	Total
Problems at Interview	Yes	64% (55%)	8% (7%)	72% (62%)
	No	21 (29)	7 (9)	28 (38)
	Total	85 (84)	15 (16)	100

The results of the examination program suggest that both underreporting and overreporting occurred in the survey, but also that underreporting was far and away the more serious problem—21 percent (29 percent) of the respondents failed to report conditions detectable by the chiropodist, while only 8 percent (7 percent) reported conditions undiagnosed by the chiropodist. Notice that in this study, the chiropodist's examination was carried out *after* the survey, so *recall* of diagnosis was not at issue. But this example raises for us the troublesome question of why we should expect to find a high correspondence between subjective experience of physical problems and a physician's conclusion from an examination.

Survey Investigations of Pain and Other Symptoms

Several medical researchers have used surveys to gather information on chronic pain, especially pain associated with migraine headaches (e.g., see Ziegler, Hassanein, and Couch 1977) in which they ask questions about when the pain began. (Accurate answers to such questions would be useful, for example, in order to estimate incidence rates.) While some patients can report the year of onset of migraines, others are much less specific or are unable to remember (at least that is how they respond). Yet, the incidence rates for chronic pain and the attendant suffering are cause for public concern:

> It brings an untold burden of suffering, sending more Americans in search of a cure than any other malady. The sharp edge or the dull throb of pain, whether springing from arthritis, migraine, or from unknown causes, disables more people than either cancer or heart disease (*Time Magazine*, June 11, 1984, 58).

Even if we have trouble with the quality of the survey data used as the basis for such statements, it is staggering to be told, in the same *Time Magazine* article, that nearly one-third of the United States population has persistent or recurrent chronic pain. If the prevalence of chronic pain is so substantial, then we must devote more attention to improving the accuracy of reports on pain.

Is this pain problem unique to the United States? Ziegler has recently carried out surveys on headache pain in Mexico and China to parallel his earlier American survey, but the data have yet to be analyzed. The potential of these data for cross-cultural comparisons is tantalizing, but semantic and contextual effects for the respondents within a country must be addressed before any cross-cultural comparisons based on these—or any other—data are tackled.

Other efforts to study pain using survey questions are ongoing under the sponsorship of the National Institutes of Health, other federal government agencies, and private foundations. For example, there are several questions dealing with pain that are planned for inclusion in the National Study of Medical Care Outcomes, being planned by the Rand Corporation. The study will examine the effects of the medical care system on sick people. The responses of interest include various dimensions of patient health, functioning, satisfaction,

utilization of resources, and medical process. Possible explanatory variables include system of care (fee-for-service or prepaid group practice) and physician specialty, as well as patient characteristics.

These and other attempts to get respondents to recall pain and other symptoms may be advanced substantially by contributions from those studying the cognitive aspects of memory for pain and other sensations. As we have seen, improvement in the accuracy of recall of symptoms, especially pain, would benefit physicians and patients in diagnostic interviews, insurance companies in dealing with applicants for insurance and their beneficiaries, public health officials in the compilation of morbidity statistics, and survey practitioners in health interviews.

We are left, however, with a tantalizing question. While we have quoted several authors who assert that memory for pain is different from memory for other events or symptoms, we have not been able to establish whether such a difference really exists. Clearly, this is an empirical question that should be high on the research agenda of those studying the recall of pain.

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Acknowledgments: The preparation of this paper was supported in part by several National Science Foundation grants: No. SES-8119219 to Carnegie-Mellon University, No. SES-8119138 to the Research Foundation of the State University of New York, No. BNS-8023404 to the University of Washington, and by BNS-8011494 while the first author was a Guggenheim Fellow at the Center for Advanced Study in the Behavioral Sciences. We are grateful to T.C. Chen, F. Weinfeld, and D. Ziegler for background materials on reports of pain, and Norman Bradburn, Ann Cartwright, Mary Grace Kovar, Judith Lessler, Dorothy Rice, Monroe Sirken, and several referees for helpful comments and suggestions on an earlier draft of the paper.

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