CHRONIC PAIN SCREENING QUESTIONNAIRES FOR GENERAL POPULATION SURVEYS: A REVIEW

Kathleen M. Danchik and Thomas F. Drury, National Center for Health Statistics K.M. Danchik, NCHS, 3700 East West Highway, Hyattsville, MD 20782

INTRODUCTION

During the past decade, a variety of efforts have been made to review the state of the art of pain measurement. However, most of these reviews have considered pain assessment either in the context of laboratory experiments, in the contexts of clinical diagnostic efforts and therapeutic outcomes, or in the context of drug efficacy trials (1). Little has yet been done to codify where things stand from the perspective of questionnaire methods in general population surveys of chronic pain. This paper clarifies the extent to which suitable questionnaires have been developed for screening general population samples for chronic pain, and identifies issues which need to be resolved to advance this type of survey measurement.

After a description of the context in which this review of chronic pain screening questionnaires was approached, the objectives and scope of the review will be outlined, the major results to date will be summarized, and a number of major conceptual, methodological, measurement, and questionnaire design research issues which need to be better studied by survey researchers working in close collaboration with experts in the clinical management and scientific study of chronic pain will be highlighted. Since measurement and questionnaire design issues are quite familiar to survey researchers, the issues section will place more emphasis on the conceptual and underlying methodological questions which arise from the complexity of chronic pain.

CONTEXT OF THE REVIEW

Chronic pain is a major public health problem (2). But systematic and comprehensive epidemiologic data on the magnitude, scope and impact of the problem do not exist. In response to this need for national data on chronic pain, National Center for Health Statistics (NCHS) staff in the Division of Epidemiology and Health Promotion have been evaluating the feasibility of using the National Health Interview Survey (NHIS) and the National Health and Nutrition Examination Survey (NHANES) to address these data needs.

OBJECTIVES OF THE REVIEW

To utilize either of these data systems effectively requires that the sample be screened for chronic pain. Since only limited efforts have been made in past NHIS and NHANES surveys to ask directly about pain, and since neither of these survey programs have ever included a comprehensive set of screening questions dealing with chronic pain (3), a review of the literature was carried out with a twofold purpose: (a) to locate questionnaires which had been used in population-based surveys to screen for chronic pain, and (b) to evaluate of adapting existing suitability survey the questionnaires in whole or in part for use in the NHIS or NHANES.

SCOPE OF THE REVIEW

For purposes of this review. the phrase "chronic pain screening questionnaires for general population surveys" was delimited as follows:

o "<u>Chronic pain</u>" was defined as (a) pain that persists beyond the normal healing time for an acute injury or disease; or (b) pain related to a chronic disease; or (c) pain that emerges and persists or recurs episodically for months or years (4).

o A "<u>Screening Questionnaire</u>" was defined as a standard set of questions, explicitly designed to achieve one or more of the following survey objectives: (a) to identify persons with one or more chronic pain problems, (b) to identify persons with specific types of chronic pain syndromes, or (c) to classify persons with chronic pain problems into homogeneous subclasses. For the most part, the review was limited to questionnaires which had actually been used in studies of well-defined populations. The only exception to this was the inclusion of the limited number of pain assessment protocols designed for use in clinical settings to identify homogeneous subclasses of patients.

o The "General Population" was limited to civilian, noninstitutionalized adults. Screening instruments for children were not included for two reasons: (a) the whole area of pain assessment for children is specialized, and (b) legal constraints limit access to children for direct interviewing.

PRELIMINARY FINDINGS FROM THE REVIEW

The analysis and evaluation of the questionnaires identified by this review of chronic pain screening questionnaires is still in progress, however, several important findings have emerged.

1) Nineteen different questionnaires which met the review criteria were located. Compared to other areas of pain measurement, however, relatively little has been done to develop chronic pain screening instruments of known reliability and validity for use in population-based surveys.

2) The questionnaires identified are of several different types: Some screening instruments, such as the Nuprin Pain Questionnaire and the McMaster University Pain Study, attempt to deal with pain and persistent pain in a fairly comprehensive way. (See Table I for questionnaire references.) Others, such as the Migraine Headache Prevalence Survey Screening Questionnaire, the Vermont Low . Back Pain Questionnaire, and the Rose Angina Questionnaire, focus on specific chronic pain syndromes. Still others focus on a specific syndrome but also include questions dealing with a broader range of chronic pain problems. The Group Health Cooperative Survey of Common Health Problems, with emphasis on orofacial pain, is an excellent example of this type of questionnaire. Other questionnaires, such as the University of Pittsburgh Multiaxial Assessment of Pain, currently being developed, are designed to be used as a package to identify homogeneous subclasses of persons with chronic pain. Another type of questionnaire includes items which deal with pain complaints as a way of dealing with one dimension of an individual's general health status. The physical complaints items used in the Social Security Administration's 1978 Survey of Disability and Work and the pain items included in the Nottingham Health Profile are examples of this last type of questionnaire.

3) Although some of the questionnaires which screen for specific chronic pain syndromes, such as the Rose Angina Questionnaire, have been used in the NHANES survey, the questionnaires which address chronic pain in general are not completely suited for use in the NHIS or the NHANES. They fail to explicitly and systematically address a number of important issues, beginning with assumptions about the conceptualization of pain and of chronic pain.

UNDERLYING ASSUMPTIONS ABOUT PAIN

At first glance it might appear that the underlying conceptualization of a chronic pain screening instrument for use in a general population survey would be fairly straightforward. Pain is certainly a subjective experience, and questioning is ideally suited for eliciting information about a person's subjective states. The major conceptual problem would therefore seem to consist in defining pain, and delimiting the meaning of chronic pain. But it is not as easy as it first appears.

The recently published International Association for the Study of Pain (IASP) <u>Classification of Chronic Pain</u> (5) defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage." But not everyone in the field of pain study would accept this definition unreservedly. Pain experts with a behavioral focus quickly point to the phenomenon of operant pain behavior which may persist in the absence of actual or potential tissue damage in response to reinforcements from the social environment (6). As with many other concepts in the survey research field, pain may be defined either subjectively or behaviorally.

Regardless of how the definition of pain is approached, there is generally broad agreement among pain experts that chronic pain needs to be distinguished from acute pain (7), but there is less agreement over how best to conceptualize these differences. Chronic pain has been broadly conceived as pain which persists beyond the normal time for healing of an acute injury or illness. For some conditions the normal time for healing may be less than a month (even as few as 4-5 days); for other conditions, six or more months. The IASP <u>Classification of Chronic Pain</u>, recognizing that a spectrum of time is involved here, opted to distinguish pain as chronic if it persisted for three months or more.

Chronic pain has also been thought of as pain associated with a chronic disease, or as pain which emerges and recurs episodically for months or years. This latter type of episodic pain has been referred to as "recurrent pain". But how <u>recurrent</u> pain has to be before it is considered <u>chronic</u> pain has never been definitively argued in the literature.

A further broad conceptual issue which needs to be considered in the design of a chronic pain screening instrument for a general population survey is the distinction which is usually made between chronic pain and cancer pain (8). Cancer pain has both acute and chronic aspects to it, associated with cancer treatments and with tumor progression. But cancer pain is generally considered a special case because of the extreme nature of many of the behavioral, emotional and physiological aspects of the pain associated with it.

CASE DEFINITION ISSUES

These broad conceptual issues are strategic in that they have major implications for case definition. But, irrespective of how one approaches the broad conceptualization of pain and of chronic pain, there are important alternatives which arise in the definition of the type of case which a screening instrument is supposed to identify.

Perhaps the most fundamental option in case definition which needs to be considered is the extent to which the screening instrument will be designed to identify persons with one or more chronic pain problems, or persons with specific chronic pain syndromes, or homogeneous subclasses of persons with chronic pain. Concern with homogeneity in the definition of a case usually emerges in surveys designed to identify or analyze risk factors for chronic pain, or strategic variations in the management of chronic pain. Surveys designed to describe the spectrum of chronic pain problems in the general population are usually more concerned with measuring chronic pain in the context of a heterogeneous population.

Cross-sectional surveys of the general population are ideally suited to produce estimates of the prevalence of chronic pain problems, but whether the screening instrument is going to be designed to produce estimates of point prevalence, period prevalence, or lifetime prevalence needs to be carefully considered. If the survey objective is also concerned with estimating "at risk" cases, then we have still additional things to consider, as we also do if the objective is to identify "incident" cases.

In surveys designed for application, it may also be important to be able to distinguish the extent of the problem from the number of persons who have the problem. Estimates of treatment needs, for example, need information on the full spectrum and number of chronic pain problems. The development of health care marketing strategies and health service delivery programs to address those needs requires information on the number, sociodemographic composition and territorial distribution of persons with these problems. If the survey objectives also call for identifying patterns of pain problems, then the screening instrument has to be designed with these kinds of further cross-classfications of the data in mind.

It is also important to realize that the choices that need to made in defining a case will usually take place in the context of intended data uses. For this reason it is useful to distinguish case definitions which attempt to address broad social enlightenment functions, those which attempt to provide intelligence for program planning and evaluation, and those which attempt to provide information that will constitute feedback for operational programs (9). In most instances, the level of social organization at which the data are to be used will tend to favor one set of conceptual decisions in case definition over others.

CASE ASCERTAINMENT ISSUES

Coupled with these alternatives in case definition are, of course, parallel considerations in case ascertainment. The development of case ascertainment procedures for a screening instrument requires operational definitions which can be used to determine "caseness." It must also distinguish a case of chronic pain from other related behavioral and psychological phenomena.

GENERAL METHODOLOGICAL ISSUES

Running through these issues of case ascertainment, case definition, and broad conceptual assumptions about pain are a whole series of underlying methodological issues which the design of chronic pain screening questionnaires for population-based surveys need to address.

1) Should we approach chronic pain screening directly and ask about pain in specific body regions, for example, or should we probe for chronic pain indirectly, approaching it by asking about the impacts of pain, or occasions in which pain-related behaviors could arise, or by asking about injuries and chronic, degenerative conditions which can give rise to pain problems?

2) What is the appropriate mix of self-report, physical examination, and observer data in a population-based study of chronic pain?

3) How far can we push cross-sectional surveys in studying chronic pain before the retrospective design falls apart?

4) How can we validate a chronic pain screening instrument in terms of sensitivity and specificity if there is no "gold" standard to serve as a benchmark to evaluate survey questions?

5) Is multi-stage screening more effective than single-stage screening?

6) What are the optimum recall periods for the assessment of subjective and behavioral aspects of chronic pain?

7) Who is the best source of information regarding chronic pain? Can information on certain aspects of chronic pain be obtained from knowledgeable proxy respondents as well as self-respondents? Is proxy data ever more reliable than self-report data?

QUESTIONNAIRE DESIGN ISSUES

A variety of questionnaire design issues also need to be considered, the most important of which is probably the need to develop a screening instrument which has homogeneous meaning across various subpopulations and across diverse types of chronic pain problems. Other issues which are familiar to survey researchers include: Addressing the efficiency of the instrument--What would be the minimum number of items needed to obtain various screening objectives? Is there an effect of context on responses to chronic pain questions? Is there an effect of the general survey content on responses to pain items? Is there an effect of survey sponsorship on recall and responses?

CONCLUDING REMARKS

Chronic pain appears to be increasing as a major public health problem in the United States. But very little data exist to document the magnitude and scope of this problem. This situation presents survey researchers with a great opportunity, for very little has been done to develop reliable and valid screening instruments for chronic pain in general population surveys. And, what has been done raises hard issues which need to be better addressed by survey methodologists and survey researchers working in close collaboration with experts in the clinical management and scientific study of chronic pain.

REFERENCES

- 1. Melzack, R. (ed.): <u>Pain Measurement and</u> Assessment. New York. Raven Press, 1983.
- 2. Bonica, J.J. and Chapman, C.R.: Chronic Pain. Current Concepts. The Upjohn Company, 1985.
- 3. National Center for Health Statistics, K.M. Danchik and T.F. Drury: An inventory of pain data available from the National Center for Health Statistics. Vital and Health Statistics, Series 1. In press.
- 4. Bonica, J.J. and Chapman, C.R.: Biology, pathophysiology, and therapy of chronic pain. In P.A. Berger and H. Keith M. Brodie (eds.): <u>American Handbook of Psychiatry Vol. 8 Biological</u> Psychiatry. New York. Basic Books, Inc., Publishers., 1986, Pp. 711-761.
- 5. International Association for the Study of Pain Subcommittee on Taxonomy: <u>Classification of</u> <u>Chronic Pain</u>. Amsterdam. Elsevier Science Publishers B.V. 1986.
- 6. Fordyce, W.E.: <u>Behavioral Methods for Chronic</u> <u>Pain and Illness</u>. <u>St. Louis.</u> C.V. Mosby Company, 1976.
- Sternbach, R.A.: Acute versus chronic pain. In P.D. Wall and R. Melzack (eds.): <u>Textbook of Pain</u>. New York. Churchill and Livingstone, 1984, pp. 173-177.
- Foley, K.M. and Sundaresan, N.: Management of cancer pain. In V.T. DeVita, Jr., S. Hellman, and S.A. Rosenberg (eds.): <u>Cancer: Principles and Practice of Oncology</u>. Philadelphia, J.B. Lippincott Company, 1985. Pp. 1940-1961.
- Biderman, A.D.: Information, intelligence, enlightened public policy: functions and organization of societal feedback. <u>Policy Sciences</u> 1, 1970, Pp. 217-230.

TABLE I. SELECTED CHRONIC PAIN SURVEY SCREENING INSTRUMENTS GROUPED BY SURVEY OBJECTIVE

IDENTIFICATION OF PERSONS WITH ONE OR MORE CHRONIC PAIN PROBLEMS

SCREENING FOR PAIN IS THE SUBSTANTIVE SURVEY OBJECTIVE

Nuprin Pain Questionnaire (1) McMaster University Pain Questionnaire (2)

SCREENING FOR PAIN AS A DIMENSION OF GENERAL HEALTH STATUS

1978 Survey of Disability and Work (3) National Longitudinal Surveys (Surveys of Work Experience of Mature Men and Women) (4) Nottingham Health Profile (5)

IDENTIFICATION OF PERSONS WITH SPECIFIC CHRONIC PAIN SYNDROMES

HEADACHE

Migraine Headache Prevalence Survey Screening Questionnaire (6) Ziegler Headache Questionnaire (7)

OROFACIAL PAIN

Group Health Cooperative of Puget Sound Survey of Common Health Problems (8)

CHEST PAIN

Rose Angina Questionnaire (9)
1978 Survey of Disability and Work chest pain questions (3)
National Health and Nutrition Examination Survey I (NHANES I) Chest Pain Questionnaire (10, 11)
National Health and Nutrition Examination Survey I Epidemiologic Followup Study (NHEFS) chest pain questions (12)
National Health and Nutrition Examination Survey II (NHANES II) chest pain questions (13)
Hispanic Health and Nutrition Examination Survey Cardiovascular (HHANES) Chest Pain Questionnaire (14)
RAND Health Insurance Study Chest Pain Questionnaire (15)

ABDOMINAL PAIN

Hispanic Health and Nutrition Examination Survey abdominal pain questions (14)

BACK PAIN

Ohio State University back pain questions (16)

University of Vermont Back Pain Questionnaire (17)

Andersson Back Pain Questionnaire (18)

National Health and Nutrition Examination Survey I (NHANES I) Arthritis Supplement (11)

National Health and Nutrition Examination Survey I Epidemiologic Followup Study (NHEFS) back and neck pain questions (12)

National Health and Nutrition Examination Survey II (NHANES II) back and neck pain questions (13)

JOINT PAIN

National Health and Nutrition Examination Survey I (NHANES I) Arthritis Supplement (11) National Health and Nutrition Examination Survey I Epidemiologic Followup Study (NHEFS) joint pain questions (12)

National Health and Nutrition Examination Survey II (NHANES II) joint pain questions (13)

CLASSIFICATION OF PERSONS WITH CHRONIC PAIN INTO HOMOGENEOUS SUBTYPES

SCOPE IS ONE OR MORE CHRONIC PAIN PROBLEMS

Nuprin Pain Questionnaire (1) McMaster University Pain Questionnaire (2) University of Pittsburgh Multiaxial Assessment of Pain (MAP) (19)

SCOPE IS A SPECIFIC CHRONIC PAIN SYNDROME

University of Vermont Back Pain Questionnaire (17) Migraine Headache Prevalence Survey Natural History Questionnaire (20)

- Louis Harris and Associates, Inc.: The NUPRIN Pain Report. New York. Louis Harris and Associates, Inc., 1985. 1.
- 2. Crook, J., Rideout, E., and Browne, G.: The prevalence of pain complaints in a general population. Pain 18:299-314, 1984.
- Bye, B. and Schechter, E.: 1978 Survey of Disability and Work. Technical Introduction. SSA Pub. No. 13-11745. 3. Social Security Administration Office of Policy, Jan., 1982.
- Center for Human Resource Research: The National Longitudinal Surveys Handbook 1983-1984. Columbus, Ohio. 4. The Ohio State University, 1983.
- McEwen, J.: The Nottingham Health Profile: A measure of perceived health. In G.T. Smith (ed.): Measuring the 5. Social Benefits of Medicine. London. White Cresent Press, Ltd., 1983. Pp. 75-83.
- Personal communication with Martha Linet, M.D., M.P.H., National Cancer Institute. 6.
- 7. Ziegler, D.K.: Do certain headache syndromes occur in "pain-prone" patients? Headache 25:90-94, 1985.
- Von Korff, M.R., Dworkin, S.F., LeResch, L., Kruger, A.: Epidemiology of Temporo-Mandibular Disorders: TMD 8. Pain compared to other common pain sites. In the Proceedings of the Fifth World Congress on Pain, Hamburg, Germany, August, 1987.
- Rose, G.A.: Ischemic heart disease. Chest pain questionnaire. Milbank Memorial Fund Quarterly 43:32-39.
- 10. National Center for Health Statistics: Plan and operation of the Health and Nutrition Examination Survey, United States, 1971-73. Vital and Health Statistics. Series 1, No. 10b. DHEW Pub. No. (HSM) 73-1310. Public Health Service. Washington. U.S. Government Printing Office, Feb., 1973.
- 11. National Center for Health Statistics, A. Engel, R.S. Murphy, et.al.: Plan and operation of the HANES I augmentation survey of adults 25-74 years: United States, 1974-75. Vital and Health Statistics. Series 1, No. 14. DHEW Pub. No. (PHS) 78-1314. Public Health Service. Washington. U.S. Government Printing Office, June, 1978.
- 12. National Center for Health Statistics, B.B. Cohen, H.E. Barbano, C.S. Cox, et.al.: The plan and operation of the NHANES I Epidemiologic Followback Study, 1982-84. Vital and Health Statistics. Series 1, No. 22. DHHS Pub. No. (PHS) 87-1324. Public Health Service. Washington. U.S. Government Printing Office. June, 1987.
- 13. National Center for Health Statistics, A. McDowell, A. Engel, et.al.: Plan and operation of the Second National Health and Nutrition Examination Survey, 1976-80. Vital and Health Statistics. Series 1, No. 15. DHHS Pub No. (PHS) 81-1317. Public Health Service. Washington. U.S. Government Printing Office. July, 1981.
- 14. National Center for Health Statistics, K.R. Mauer: Plan and operation of the Hispanic Health and Nutrition Examination Survey, 1982-84. Vital and Health Statistics. Series 1, No. 19. DHHS Pub No. (PHS) 85-1321. Public Health Service. Washington. U.S. Government Printing Office. September, 1985. 15. Berman D.M., Brook, R.H., Lohr, K.N., et.al.: <u>Conceptualization and Measurement of Physiologic Health for</u>
- Adults. Vol. 4: Angina Pectoris. R2262/4-HHS. Santa Monica, Ca. The Rand Corporation, June, 1981.
- 16. Nagi, S.Z., Riley, L.E. and Newby, L.G.: A social epidemiology of back pain in a general population. J Chron Dis 26:769-779, 1973.
- 17. Frymoyer, J.W., Pope, M.H., Clements, J.H., et.al.: Risk factors in low back pain: An epidemiological survey. J Bone Joint Surg 65A:213-218, 1983.
- 18. Personal communication with Gunnar B.J. Andersson, M.D., PhD., Department of Orthopedic Surgery, Rush-Presbyterian-St. Luke's Medical Center, Chicago, Illinois.
- 19. Turk, D.C., Rudy, T.E., Boucek, C.D.: The contribution of psychological factors to the experience of chronic pain. In C.A. Warfield (ed.): The Anesthesiologists Guide to Pain Management. Hingham, Mass. Kluwer Academic Publishers. In press.
- 20. Personal communication with Martha Linet, M.D., M.P.H., National Cancer Institute.