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National Health Interview Survey Redesign: An Anthropological Investigation of Mental Health Concepts

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ABSTRACT

In connection with the redesign of the National Health Interview Survey, the National Center for Health Statistics funded some exploratory ethno-medical research. Specifically, several medical anthropologists were contracted to conduct field research on how various socio-cultural groups in the United States conceptualize the domain of mental health. Both in-depth, ethnographic interviews and focused interviews were used by the anthropologists. The paper describes the impetus for this research, briefly reviews the existing literature for research which may be relevant to an understanding of cultural effects in survey reports of mental health, and summarizes the initial field research results, with special attention on implications of the research for questionnaire design.

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1. INTRODUCTION

1.1 NHIS and the NHIS Redesign

The National Health Interview Survey (NHIS) is a major survey program of the National Center for Health Statistics (NCHS). Established by the National Health Survey Act of 1956, NHIS has been an ongoing primary source of health statistics for the United States since 1957. Analysts and policy-makers use information gathered in this survey to monitor the nation's health status, and to establish and prioritize national health policies.

Interviewers from the U.S. Bureau of the Census annually interview approximately 50,000 households for the NHIS. The current survey is composed of a "core" instrument (containing questions on basic health data and demographics) and several "supplements" (each containing questions on current health topics such as AIDS knowledge, cancer prevention, immunizations and food intake). Over the years, in response to changing needs for data on a wide variety of issues, the supplements have become an increasing focus of the survey and now represent about 60% of the total interviewing time.

In conjunction with the cyclical sample revision that follows each census, NCHS is currently redesigning the NHIS sample to enhance minority statistics by

oversampling Blacks, Hispanics and the elderly. NCHS is also planning to redesign the structure and content of the NHIS questionnaire. In doing so, NCHS sought input from several sources to develop a list of topics that will fulfill the nation's health data needs for the 1990's and beyond. Out of this process emerged an agreement that the Health Status module of the redesigned NHIS should address mental health issues.

1.2 Cultural Differences in Health Reporting

One concern raised in connection with the questionnaire redesign has to do with the comparability of health measurements across different sub-cultural groups, especially those for whom English is not the native language. Non-English speakers in particular, but also many others, might not interpret questions about health and mental health conditions in comparable ways. Differences in the way different groups interpret and respond to questions about health and mental health might result in apparent differences between groups which are more artifactual than real.

One need not venture into the anthropological realm to find intriguing illustrations of differences between groups in their reports of basic health events and conditions. Wagener and Winn (1991), for example, find that survey-reported non-fatal injury rates are higher for Whites than for Blacks, even though Blacks are much more likely than Whites to suffer fatal injuries. Gender differences in survey estimates are also fairly common. Women report more

symptoms of depression (Newmann, 1984) and anxiety (Dohrenwend, et al, 1980) than men, more episodes of hysteria (Dworkin and Adams, 1984), and generally report their health status less positively than men (Groves, et al., 1992). Although it is typically assumed that these survey-reported differences reflect true differences in the underlying characteristic of interest, the extent to which they are actually artifacts of the measurement system is unknown.

The anthropological literature, too, is rich with examples of cultural variations in health conditions and health care, including symptomology and prognosis. For example, researchers have noted that among Latin American, Asian and African groups, health conditions are categorized on a "hot-cold" continuum, and the appropriate treatment for a particular condition depends upon whether the condition is "hot" or "cold" in nature (Manderson, 1987). This view of health conditions is exemplified in Malay communities' treatment of measles, smallpox and chicken pox; these are considered "hot" conditions and a person suffering from them is instructed to avoid all hot foods until completely recovered. What this "hot/cold" organization means for survey reporting is unknown, although it is a reasonable guess that, in appropriate settings, embedding references to this

system in survey questions could serve to more effectively cue memory retrieval.

Mental health, as a sub-domain of health in general, has also received

substantial attention in the anthropological literature, especially with regard to how societal definitions of normality and deviance vary from culture to culture (Kirmayer, 1989). There is also a rich literature on specific culture-bound syndromes, such as God-intoxication in Bengal (Morinis, 1985), Dhat and Possession syndromes in India (Akhtar, 1988), and anorexia nervosa among western culture women (Gremillion, 1992). This literature strongly supports the notion that mental health is in considerable measure a culturally constructed domain. How one experiences and talks about one's health is strongly influenced by one's culture. Mental health conditions which are well-defined and named in certain cultural contexts may be defined and recognized differently or not at all in others. Again, however, aside from the obvious problem of the potential underreporting of specific culture-bound syndromes (due to their exclusion from sets of retrieval cues), what isn't clear is how or whether these differing cultural perspectives will affect the accuracy of responses to, and inferences from, a mental health questionnaire.

Other research appears more clearly germane to the survey reporting issue. For example, an important focus of the health-care literature (e.g., Spector, 1985) is educating health care providers on the role culture plays during an illness, so that the best health care can be given to the patient. Research has found wide cross-cultural variation in how people express pain and discomfort. In some cultures members are encouraged to freely and openly display pain or discomfort, while in other cultures such displays are strongly discouraged. In a

study about pain, Zborowski (1969) found that Jewish and Italian patients tended to respond to pain in an emotional fashion while Irish patients tended to ignore the pain. Other researchers (Mechanic, 1963; Suchman, 1964, 1965; Zola, 1966) have found similar results.

Of course, for the anthropologist, a culture's discourse or display rules are an integral part of the entire cultural system, and thus on an equal footing with any other aspect of the culture--health perceptions and behaviors, for example--as a valid subject for study. On the other hand, the survey researcher's task is to use language and behavior (i.e., "discourse and display") as a means to understand some underlying phenomenon. Such findings as those described above are quite problematic for the survey researcher, because they strongly suggest that survey-based health assessments which derive from reports of pain or discomfort may be misleading regarding the prevalence of certain health conditions.

The survey research literature has recently begun to address cultural differences in survey reporting behavior. For example, a number of researchers have recently focused on Hispanics and measurement errors. Marin and Marin (1991) review the existing literature and find evidence suggesting that survey data collected from Hispanics across a number of different substantive topics (including health issues) may be biased by a tendency to provide extreme responses, a tendency that may be more pronounced among less acculturated

Hispanics. Acquiescence also appears to be more frequent among Hispanics than among non-Hispanic Whites, with the most acquiescing coming from less acculturated and/or less educated Hispanics. The authors also observe that Hispanics often give more socially desirable responses than non-Hispanic Whites, have higher under-reporting rates, have higher missing data rates, and may be less likely to self-disclose information to an interviewer. The authors properly caution against overgeneralizing from a small number of studies, many of which had small sample sizes. However, they do emphasize the need for researchers to be aware of, and control for, these potential problems in surveys of Hispanic populations.

2. EXPLORATORY RESEARCH ON MENTAL HEALTH CONCEPTS

2.1 Introduction

The health literature provides abundant support for the notion that culture plays a major role in the way different groups perceive and define their health; however, the literature is not nearly as clear about how these cultural differences might affect mental health survey data. Thus, as an early step in designing an NHIS mental health module, NCHS decided to fund qualitative, exploratory research to examine cultural effects on reporting of mental health. The guiding principle was that by understanding how various groups of people think about mental health, and how mental health terms and concepts are perceived and expressed, researchers could design mental health questions

that will yield more accurate mental health data. Joseph and Shweder (1992) offer a useful description of the potential perils when respondent and questionnaire designer embrace different health models:

> "Cultural models are mental and behavioral representations of a particular domain (e.g., health, religion, marriage) that are composed of, and reflect, the conceptual worlds which people inhabit. As such, they influence both talk and behavior. When two persons' cultural models of the (more or less) same domain differ, there is likely to be some lessening of their capacity to communicate about that domain, at least when compared with two people operating with the same cultural model. The potential for miscommunication is even greater, and also less easy to recognize, when the interlocutors are unaware, perhaps because similar words or concepts figure in both models, that they are approaching the conversation with different assumptions and systems of relevance [pp. 9-10]."

2.2 Anthropological Research Methods

This research was designed to help guide survey researchers in developing the redesigned NHIS questionnaire, with a primary focus on the new mental health section. The emphasis on cultural differences led, quite naturally, to the decision to use anthropologists to conduct the field research. Anthropological research methods vary from traditional qualitative survey research methods in a number of ways. Perhaps the most telling is the fundamental difference in the

role of the participant. While survey research typically refers to the participants as "respondents," anthropology uses the term "informant." For the most part, the respondent is seen as a passive participant in the survey questioning process, who merely responds to the interviewer's previously designed questions. In anthropological ethnographic interviews, as noted in a recent article by Bauman and Greenberg Adair (1992), the anthropologist takes on the role of pupil to the informant's role of expert with the explicit objective being the understanding of an informant's experience from his or her point of view. As much as possible, any prior understanding of the research topic is deliberately set aside by the anthropologist. Thus, in a matter of speaking, the informant is the one determining the research questions.

2.3 Exploratory Research Design and Methodology

With funding from NCHS, proposals were solicited from ethnographers and medical anthropologists to conduct field work during the summer of 1992. Five contracts were awarded to researchers studying the following groups: Mexican and Mexican-American migrant farm workers in Florida; Appalachian, Anglo residents of rural West Virginia; White, middle class Americans residing in the Washington-Baltimore metropolitan area; African Americans in North Carolina and a diverse collection of Chicago residents, including German, Polish, Haitian, Hispanic, African-American, Chinese and Japanese. (The reports resulting from the five contracts are noted in the "References" section: see Baer (1992), Boone (1992), Cassidy (1992), Illingworth (1992) and Joseph and Shweder

(1992).)

The specific interview formats used in this project were an in-depth ethnographic style interview to explore health and mental health concepts, and a focused interview format to elicit comments on the cultural appropriate-ness of a set of proposed survey measures[1]. These interview formats differ from one another in a number of ways. Ethnographic interviews are very unstructured and nondirective with the intent being the collection of descriptive data. As already mentioned, the interviewer takes on a subordinate role to the informant's role of expert. This type of interview also treats the informant's language as data; thus, ethnographic interviewers avoid introducing their own words and, whenever possible, repeat the informant's own expressions when probing for more detail. In contrast, the focused interview is structured and focuses on informants' reactions to a specific experience or situation, using a stimulus to trigger discussion (here, specific mental health question wordings).

The anthropologists used several mechanisms to recruit informants to try to ensure a heterogeneous sample within each of the chosen socio-cultural groups. In most cases, they conducted about 18 ethnographic interviews and

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[1] A 45-item mental health screening questionnaire designed to assess anxiety, depression, panic and phobia was given to each of the anthropologists to be used as a stimulus for the focused interview portion of their field research (see attachment).

17 focused interviews. It is important to keep in mind that all of the anthropologists' samples were quite small and not representative of any larger population. The substantive findings cannot be generalized, although they are useful in suggesting hypotheses about differences in reporting and interpretation of reports of mental health symptoms which could be explored further.

3. FINDINGS AND DISCUSSION

3.1 Health Models

As noted earlier, Joseph and Shweder argue that cultural differences in how health is perceived and defined in general ("health models") can severely hinder effective cross-cultural communication about health. To the extent that this is true, their findings and those of the other researchers are rather daunting to the survey designer. Joseph and Shweder report a plethora of widely diverging health models from their interviews in the Chicago area, including: health as an absence of pain and/or disease; health as measured by energy; health as the ability to carry on the activities of everyday life; health as fitness (including weight and endurance as well as diet or food); the body as inherently diseased; and health as the purity or hardiness of one's genetic stock. Amongst Appalachian, Anglo residents of rural West Virginia, Boone (1992) detects models concerning activity and mobility, absence of pain, and modern health style standards (e.g., exercise regularly, eat properly, do not smoke).

Additionally, Boone notes that some informants felt good health was an ideal state that was not obtainable or that good health meant having good fortune. Furthermore, some informants related good health to socio-economic status ("good health = being middle class"). Lastly, Baer (1992) finds that some Mexican-Americans migrant farm workers believe good health means the absence of pain, having a robust body and being able to function adequately (that is, borrowing Schreiber and Homiak's (1981) explanation of adequate functioning: "a high level of energy output and physical activity which ensures that adult men and women successfully perform the routine tasks of everyday life" [p. 300]). Conversely, Baer notes that illness is thought of as a change in the normal physical functioning or/and an inability to perform expected roles.

Although some of these models appear to be similar across the socio-cultural groups, it is not possible to determine which models are most salient to which group with the current limited samples. However, what is apparent is that a large number of divergent models exist, and that how respondents talk about their health may vary greatly depending on what health model is embraced, which may result in survey reporting difficulties.

3.2 Folk Illnesses and Cultural Definitions

As the previous literature suggests, in many instances, health phenomena may be highly specific to a particular sub-cultural group. A particular condition may be unique to a group, or a common phenomenon across different groups may

be imbued with very different meanings. Baer's work for this project among Mexican-American migrant farm workers provides a number of examples. For instance, Mexican tradition recognizes a number of folk illnesses of a psychological sort, including *susto* and *nervios*. Susto is believed to be caused by a frightening experience, which may cause the departure of the soul from the body. Nervios, or nerves, is a term used to characterize everyday problems causing distress, as well as symptoms such as hopelessness, nervousness, depression, and schizophrenia. When talking to Mexican-American migrant farm workers, Baer asked informants to classify the term "nervios" as an illness, a mental illness, or a normal part of life. Very few considered it a mental illness. In fact, many informants viewed "nervios" to be a normal part of life. It isn't surprising that very few informants classified nervios as an illness because the prevalent health model of this cultural group views illness as the inability to perform expected roles and/or a change in the normal physical functioning. Those experiencing nervios, at least in its milder forms, may very well be able to perform and physically function without difficulty. Cultural differences such as these in categorizing illnesses could result in missed mental health conditions, if the health model of the respondents differs significantly from the standard biomedical model of health.

If a symptom by which the survey designer intends to measure a mental health condition has some other cultural meaning then false positives can result. One of the proposed mental health screening questions tested in Baer's research

was how often the informant has thoughts about "death and dying." In Mexican culture, thinking about death and dying is culturally appropriate and has religious significance, and it therefore may not be appropriate to interpret it as a symptom of depression and suicidal ideation. Similarly, the Mexican culture places great value on "the tragic sense of life." The fact that in Mexico the emotion of sadness is highly elaborated, and that it is appropriate and desirable to feel sad, certainly affects the interpretation of a report of "sad feelings" as a measure of psychological depression for this group.

An example of a false negative impact on survey reporting is illustrated in interviews conducted by Cassidy (1992) with White, middle class Americans in the Washington-Baltimore area. Cassidy notes that her informants tend to have a wider boundary for normality than do health specialists, a phenomenon labeled "normalization" in the literature. When Cassidy asked informants to sort a stack of symptom cards derived from lists of symptoms designed to elicit reports of abnormality, informants often claimed the symptoms to be normal. Furthermore, many informants differentiated "needs help" from "ill" whereas the specialists do not. A related element is the value placed upon "stress" and "anxiety" by these same informants. While specialists may classify these conditions as mental illnesses, the informants thought them to be a normal part of urban life. Again, these examples suggest that if questionnaire designers opt to use survey measures that follow a standard biomedical approach, which is not adequately sensitive to sub-cultural variation from the prevailing model,

measurement errors may result--in this instance the reports may underestimate the prevalence of various conditions.

3.3 Response Bias

In addition to a great deal of material specifically concerned with health and mental health constructs, the anthropological interviews also suggest a variety of more general hypotheses about culturally-influenced sources of bias in survey measurement of mental health conditions.

One set of issues has to do with the threat posed by the questions, often tied to cultural values about the conditions themselves, and about talking about such matters. In several settings, the anthropologists found that respondents stigmatized the symptoms and mental conditions as weaknesses or as character flaws. This was found among Japanese respondents as well as Appalachian whites, and appeared more common among male respondents than among females. (This latter gender difference may be a contributor to the sorts of gender-based health reporting differences noted earlier.) If they are generally held within particular groups, such cultural values may introduce reporting bias due to social desirability effects. In some cases, such values affected reactions to particular words in the questions: for example, several Appalachian men would not acknowledge fear, but would admit to being scared.

A related issue is cultural differences in the rules of discourse defining the acceptability of complaining, and expressing emotion. As noted earlier, these may affect how willing respondents are to talk about the symptoms in question, since acknowledging having the symptom is in some sense "complaining" to the interviewer. To illustrate, Joseph and Shweder highlight two interviews with Japanese informants in Chicago. One elderly female rated herself a "9" on a 10 point scale (10 being best) even after mentioning that she had had an attack of shingles and other ailments. When asked she noted: "I don't think that I have very many aches and pains that I can complain about..." Her husband explained that even if his health was worse than it was, he would probably still rate it about the same: "I don't think I'd say much differently. I don't think we've ever been complainers." Other Japanese informants talked similarly. Thus, it is very plausible that some responses to standardized survey instruments may be more a function of the respondent's cultural discourse rules than a true representation of a specific condition.

Another cultural difference that may affect health survey results has to do with social status perceptions and behaviors. Joseph and Shweder note that the Japanese culture, in particular, has very distinct views with regard to social status. Individuals are apt to exaggerate their health state towards the positive end when talking to someone who is considered higher in social status (i.e., "above one's eyes") but, while talking to someone who is lower in social status (i.e., "below one's eyes"), individuals are apt to exaggerate their health state

towards the negative end. Since interviewers come in all ages, genders, colors, etc., it is important for researchers to understand how the interviewer's social status is perceived by the respondent, and what the respondent's culture's "rules" are regarding communication across versus within status.

3.4 Language Comprehension

A final set of issues explored in the anthropological research pertains to the wording of questions and response categories. Misunderstandings were especially common for respondents who did not speak English well. An example of a question which many respondents did not understood as intended was, "Have you ever had a spell or attack when all of a sudden you felt frightened, anxious, or very uneasy in a situation when most people wouldn't be afraid?" Many respondents confused this question, intended to measure panic disorder, as asking about real situations that made them very afraid, so several migrant worker respondents told about their fear of lightning when working in the fields (Baer, 1992), Appalachian respondents talked about their fears of bears (Boone, 1992), and the like. Part of the problem here may be cultural in origin, since in some groups panic and anxiety conditions were not readily labelled and distinguished from real fears, but part of the problem is the question itself. "Anxious" for many respondents did not connote anxiety, but had a positive meaning (like eager, as in, "anxiously awaiting") which made the question and its context confusing. Some interpreted "attack" literally, as a physical attack, or did not know the meaning of "spell", or thought "uneasy"

must be the opposite of "easy," as in difficult or impossible (Joseph and Shweder, 1992), and so on. Hence, anthropological interviewing can be informative about specific words and cues which may make it possible to reword or design new questions which respondents with different cultural backgrounds are more likely to interpret as intended, thus improving the accuracy of reporting.

4. CONCLUSIONS AND RECOMMENDATIONS

An inherent difficulty in survey measurement of mental health, as opposed to physical health, is the relative dearth of clear, externally observable evidence of an objective health condition. To a large extent, the evidence may reside mostly in the respondent's head. The anthropological literature shows, and the research described here confirms, that cross-cultural communication about health is at best a difficult business; it is reasonable to assume that the difficulties expand when even the most basic phenomena under investigation lack solid, external referents.

This leads to three immediate conclusions regarding the redesign of the NHIS or other surveys that address mental health issues. The first is the most obvious. The authors of any questionnaire containing mental health questions must approach their task with the understanding that mental health perceptions, definitions, and values can vary substantially from the mainstream, western, biomedical "norm;" even better would be an understanding of the actual nature

of those variations for major cultural subgroups.

Second, it may be useful to supplement subjective questions about internal states with questions about the objective, observable, behavioral phenomena which are thought to be associated with the various mental health conditions the subjective questions are intended to measure. This would make it possible to examine the consistency of correlations between objective and subjective measures of mental health across subgroups of the population. However, since one's culture also affects one's behavioral responses to health conditions, it provides no guarantees against culture-based measurement error difficulties.

The third conclusion ties in directly with the first two. Analysts of mental health data which derive from large-scale, standardized survey measurement must bring substantial cultural sensitivity to their task as well. Making sure that survey questions elicit valid responses is only part of the battle; to the extent that analysts misread the meaning of those responses, then the survey fails to do what it is supposed to do--accurately describe the health-related conditions of the society.

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ATTACHMENT:

Mental Health Screening Questionnaire

During the last 30 days, *about how often* did .....

	Most of the time	Some of the time	A little of the time	None of the time
• **Depressed Mood**				
. . . you feel unhappy	___	___	___	___
. . . you feel sad or blue	___	___	___	___
. . . you feel depressed	___	___	___	___
. . . you feel so sad that nothing could cheer you up	___	___	___	___
• **Lack of Interest**				
. . . you feel that nothing was worthwhile anymore	___	___	___	___
. . . you lose interest in the people and things you usually care about	___	___	___	___
• Eating				
. . . you have a much bigger appetite than usual	___	___	___	___
. . . you have a much smaller appetite than usual	___	___	___	___
• Sleep				
. . . you have trouble falling asleep or staying asleep	___	___	___	___
. . . you sleep much more than usual	___	___	___	___

	Most of the time	Some of the time	A little of the time	None of the time
• Motor Agitation				
. . . you feel restless or fidgety	___	___	___	___
. . . you feel so restless that you could not sit still	___	___	___	___
• Motor Retardation				
. . . your thoughts come more slowly than usual	___	___	___	___
. . . you feel like everything was happening in slow motion	___	___	___	___
• Fatigue				
. . . you feel tired out for no good reason . .	___	___	___	___
. . . you feel that everything was an effort . .	___	___	___	___
. . . you feel full of energy	___	___	___	___
• Worthless Guilt				
. . . you feel worthless	___	___	___	___
. . . you feel ashamed or guilty	___	___	___	___
. . . you feel inferior or not as good as other people	___	___	___	___

	Most of the time	Some of the time	A little of the time	None of the time
• Concentration				
. . . you have trouble making simple decisions	____	____	____	____
. . . you have trouble keeping your mind on what you were doing	____	____	____	____
• Death				
. . . you have thoughts of death or dying . . .	____	____	____	____
. . . you have thoughts of killing yourself . .	____	____	____	____
• Anxiety				
. . . you feel nervous	____	____	____	____
. . . you feel anxious	____	____	____	____
. . . you feel so nervous that nothing could calm you down	____	____	____	____
. . . you get upset by little things	____	____	____	____
. . . you feel fearful	____	____	____	____
• Worry				
. . . you feel worried about things that were not really important	____	____	____	____
. . . you worry about things that were not likely to happen	____	____	____	____
• Motor Tension				
. . . you feel physically tense or shaky	____	____	____	____
. . . your muscles feel tense, sore, or aching	____	____	____	____

	Most of the time	Some of the time	A little of the time	None of the time
• Hypersensitivity				
. . . your heart pound or race without exercising	____	____	____	____
. . . your mouth feels dry	____	____	____	____
. . . you feel short of breath without exercising	____	____	____	____
. . . you have indigestion or an upset stomach	____	____	____	____
. . . you have trouble swallowing	____	____	____	____
. . . your hands feel sweaty or clammy	____	____	____	____
. . . you feel dizzy	____	____	____	____
. . . your face feel hot and flushed	____	____	____	____
• Vigilance				
. . . you feel keyed up or on edge	____	____	____	____
. . . you feel irritable	____	____	____	____
• Positive Affect				
. . . you feel in a really good mood	____	____	____	____
. . . you feel happy	____	____	____	____