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Beliefs and Attitudes about Mental Health and Illness of White Middle-Class Americans

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TITLE PAGE

BELIEFS AND ATTITUDES ABOUT MENTAL HEALTH AND ILLNESS OF WHITE MIDDLE-CLASS AMERICANS

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EXECUTIVE SUMMARY

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Introduction

The research reported herein was conducted from June to October 1992 under the auspices of the US Bureau of the Census, Center for Survey Methods Research. This report is one of four conducted in the same period, each focused on a different respondent population.

The respondent population for this research was white middle-class Americans; all interviewed were residents of the Washington-Baltimore Metro Area at the time of the survey. The research consisted in three sub-projects:

--a literature review of published data on the health, mental health/illness beliefs and perceptions of middle-class white Americans (Report 1).

--a depth interview proejct with 17 respondents to elicit their perceptions of health, mental health, mental illness, and five selected conditions of particular interest to the Census Bureau, namely, depression, depression lasting more than two years (dysthymia), anxiety, panic attack, and phobia (Report 2).

--an interview study with 15 respondents to elicit their reactions to an unfinished questionnaire provided through the Census Burea, and consisting of 45 questions about mental health (Report 3).

This Executive Summary contains summary statements for the three Reports and my Recommendations based on the literature and the respondent-based research.

Summary of Findings from the Review of the Literature

Apparently little research has been published on the actual belief and explanatory model structures of white middle-class Americans concerning health, mental health, mental illness, or the five conditions under special study. Much of what little there is focuses on severe conditions such as psychoses, and/or uses specialist-designed questionnaire formats to assess "beliefs"--actually merely assessing lay agreement with specialist beliefs.

Several themes identified from the literature prove important to the interpretation of the findings of this research:

--the conditions under study are cultural constructs, not "truths"--a fact repeatedly confirmed by the languaging of the respondents to the research. The fact that they are constructs does not make them "unreal"--people still suffer!--it just modulates the certitude with which one can create questions and think they will be interpreted similarly by different people.

--while specialists tend to "pathologize" (or medicalize) symptomatology, laypeople "normalize." Health is perceived to exist on a continuum: when specialists put "sickness" too near the middle of the continuum, they provoke resistance and suspicion from laypeople; this point is in the literature and recurs in this research.

--several folk illnesses overlap the ground of what specialists call mental illness, but are not perceived as mental illnesses by laypeople. These include stress, "nerves," and other conditions, and help explain why words specialists use for illnesses are used by laypeople to describe normal events.

Summary of Findings from the Depth-Interview Study

--17 white middle-class Americans were interviewed for 90 minutes each in open-ended interviews including a card sort of terms associated with mental illness and a second card sort of the connotations of terms commonly used to refer to dysfunctions. The sample included 8 women and 9 men, mixed as to education, occupation, and other demographic variables.

--few of the interviewees used specialist language or categories without prompting.

--of the five categories of mental illness under examination, only "depression" predictably recurred from interview to interview. The value loading of "depression" is mixed, with most respondents stating that there are circumstances (mainly losses) under which it is "normal" to become depressed, and that only exceptionally do people need professional help. Several responents stated that they didn't think depressions could last more than a few months...the "two-years-or-more" form is considered a matter of poor character rather than an issue of poor mental health. Though specialists often classify anger and its varients with depression, few of the respondents did. A minority of respondents conflated anxiety and depression (3) or panic and depression (1).

--the category of "anxiety" is somewhat clear to people, however, the value loading is mostly that of normality and "me-ness" rather than that of "needing help." Another grouping--"urban stress"--cross-cuts that of anxiety. "Stress" and "anxiety" are both perceived as more or less daily and inevitable events which rarely require professional help.

--the test categories of "panic" and "phobia" were unfamilair to most of the interviewees. They were typically categorized with "out of control," "scared for no reason," and "fearful," as well as with "unstable," and "unbalanced." Most of these conditions were considered non-normal; only within this group were respondents willing to say that "illness" might exist.

--the "size of normalcy" is significantly larger for most interviewees than it may be for most psychotherapists. Respondents often designated as "normal" symptom names that derive from lists of symptoms designed to elicit reports of abnormality. Offered stories of people diagnosed as mentally ill, respondents often denied the professional assessment or reinterpreted it in social terms. The term "mental illness" was perceived as extremely strong and forbidding by the majority of respondents. Most interviewees reserved this term for the most extreme symptoms, such as "out of control," "unstable," or "hopeless/despairing." A mid-category of "needs help" arose in the speaking of most respondents; however, most denied that one who "needs help" is mentally ill.

--the most neutral terms to refer to symptoms were judged to be "condition" and "issue." The most pejorative and frightening terms were "illness," "sickness," and "disease."

--several respondents reported that nouns--"depression," "anxiety"--are connotatively much stronger than the corresponding adjectives--"depressed," "anxious." The nouns designate what may very well be an "illness," whereas the adjectives designate, in most cases, everyday sensations and experiences.

--many other words are similarly ambiguous.

--respondents were deeply concerned about context when they tried to discuss mental health. Most significantly, specified time periods are not sufficient to diagnose abnormality: the time it takes to decide if a friend is "clincally depressed" (or anxious, etc.) "depends on the person."

Summary of the Findings from the Interview Study in Response to a Mock-up Questionnaire

--The Census Bureau provided a mock-up questionnaire containing 45 questions, for critique. A sample of 15 white middle-class Americans were interviewed for their reactions to the mock-up questionnaire. Their responses were strikingly varied; in critiquing the questionnaire they brought up many of the same issues and concerns that appeared during the depth interviews discussed in Report 2.

--Most but not all respondents thought the questionnaire was about "problems" that people might be having. The most popular generalizations about what these problems might be were "stress" and "depression." Few felt that the questionnaire was about "mental health" or "mental illness". Only one respondent thought the questionnaire included assessment of "anxiety," and none thought it assessed phobia or panic.

--Respondents split almost exactly down the middle on their report of whether the questionnaire affected, or did not affect, their own mood or feelings as they read it. Those who stated that it affected their feelings were unanimous in complaining about its "negativity," and felt that the presence of the two "positive affect" questions at the end was insufficient to rescue the tonality of the whole. Those who stated that the questionnaire did not affect their mood were, on the whole, more neutral in all their statements about the questionnaire, but most also stated that they thought starting with "depressed mood" was probably unwise.

--On format:

--only one reported difficulty with having the initial question stated only on the first page of the questionnaire.

--three noticed the confusion of tenses in the questions, but this minority was vocal in stating that they were irritated by this situation and it would prevent them from taking the questionnaire seriously or filling it out. Four others noticed "typos" (misspellings) that were actually misreadings of the grammar-as-offered.

--most respondents were reasonably satisfied with the response categories that headed the columns. However, those who were willing to put a time limitation on "most," "some," and "little" varied widely in their perception of how much time those words represented. Most were pleased by the non-specific character of the headings; only two stated they should be stated in terms of real-time (days). A few were dissatisfied with the headings,

stating that they were "too relative" or "subjective" and prevented them from answering.

--respondents split in half, again, over the issue of whether or not they liked/disliked the headings for the sub-sections of questions. Those who liked or accepted the headings stated that they were useful guideposts, and that the words used would be understood by all. Those who disliked the headings stated that they were intrusive, the language both frightening and too specialized, and that they were a major reason for the negative or poor tonality of the questionnaire. Asking respondents what they thought the words meant indicated that, in fact, respondents did not perceive or define the technical words similarly bamong themselves, or in comparison to specialists.

--another criticism leveled by about half the respondents was that the questions were ambiguous since they did not allow for assessment of context. They stated that many of the "symptoms" listed would be "normal" in certain contexts but abnormal in others, and that, as it stands, the questionnaire cannot distinguish these situations, hence is not interpretable.

--A small majority of respondents felt the questionnaire covered most issues they would notice in a friend who "was having problems." Others noted missing issues. The most popular missing issue named was "change in normal patterns of behavior". Others stated that positivity was the missing issue, and asked for ways to speak positively about their feelings and life satisfaction, not just their problems.

--language within the questions was judged clear and acceptable by a majority of respondents. (As noted, about half the respondents judged the language of the section headings as unclear, frightening or too specialized.)

--only one respondent stated that the questionnaire was too long. Two respondents felt that the questionnaire was boring. Only one respondent stated that he would refuse to fill it out on ideological grounds. Four respondents were actively repelled by the perceived negativity. Four respondents stated that it was "fun" or "made them think about important things." Remaining responents brought a greater neutrality--or passivity--to completing the questionnaire, one of, "well, if they ask it, I'll answer it, despite its limitations." While this last group stated that they felt comfortable with the fact that the questionnaire guided them to appropriate answers, those who read the questionnaire as negative objected strongly that the questionnaire should not "corner" or "force" them into reporting pathology. Again, while the more passive group felt people would be likely to give truthful answers to the questions, the rejecting group felt the tonality would prevent truthful answers.

--Respondents made the following useful suggestions:

--include some method to assess context

--start with a neutral category such as "eating" or "sleeping", or with "physical symptoms" rather than with something as value-laden as "depressed mood"

--write the entire questionnaire in the present or past tense, but don't mix them up

--make the group headings as neutral and descriptive as

possible, or, delete them entirely

--include some sort of reward structure: add some visual stimulation, link filling out the questionnaire to serving some social good, and/or allow people to report success, satisfaction, and comfort. Minimize the negative, objectifying and pathology-laden tone of the questionnaire.

--In sum, my conclusion based on repondent critiques is that questionnaire designers need to pay more attention to their goals in designing this questionnaire. If they are concerned about receiving inaccurate or uninterpretable responses from laypeople, then they must orient the questionnnaire toward the respondent, not toward their own professional concerns. The criticisms that this sample of laypeople brought up are all, at bottom, complaints that derive from feeling objectified--not taken seriously as thinking, experiencing, living human beings. Respondent issues of verb tense, intrusive specialist language, boredom and suspicion of researchers' motives, negative affect and "pathologizing" what most respondents consider normal aspects of life, and of lack of context to help respondents judge the accuracy of their answers, are all serious criticisms. What is needed is a user-friendly questionnaire--not so much in terms of layout (which seems generally to have been achieved), *as in terms of content and tone.*

General Summary and Recommendations

Population Sample. This white middle-class sample of 32 individuals was urban, relatively highly educated, verbal, willing to express opinions and analyze both their thoughts and the mock-up questionnaire. All understood and accepted both the idea of survey research and the concept that there exists an aspect of health that relates to attitude, mood, emotions and the like, and is formally called "mental health." This sample was familiar with the biomedical model, and 12 (of 32) had received psychotherapy; in addition, at least half had also sought health care from a wide range of non-biomedical modalities.

With their high levels of education, most recognized most of the words on the mock-up questionnaire, and used the condition-terms ("depression," "anxiety," and so forth) under study in the depth-interview study. However, individuals tended to think they used the words "like others" or that "most anyone can understand these words and would use them as I do" whereas, in fact, definitions and understandings varied widely.

This sample population resembled other samples reported in the literature, and did not differ from published reports in any significant way, despite the fact that other reports sampled populations that were not as highly educated. Specifically, this sample, like others reported in the literature, utilized folk concepts of illness ("stress," "nerves" etc.), explained symptoms in normalizing (as vs medicalizing) language, and expressed suspicion of the motivations of psychologists/psychiatrists with regard to "pathologizing" the normal.

Recommendations for Designing a User-Friendly Survey Questionnaire, Based on Respondent Assessments. A good survey

instrument will be interpretable by a wide range of readers, and the interpretations they put on each question will be reliably similar: if these criteria are not met, the answers that people give will be uninterpretable, hence, useless. As some respondents to this research noted, especially in response to the mock-up questionnaire they were asked to critique, the present formulation may respond to the needs of researchers, but it does not serve those who must fill it out, hence, cannot provide interpretable results. Because this respondent population understands the goals and problems of survey research, at least to the extent that edcuated non-specialists may be expected to, they made rather specific recommendations for improvement of the existing formulation. I will set these specific recommendations into a larger context.

1. The largest single issue is that laypeople commonly see normality where specialists find abnormality. Therefore, when faced with questions that imply or state that abnormality exists where they think normality exists, laypeople react with suspicion and resistance. Because so many laypeople conceptualize health along a continuum, that is, without abrupt switches between abnormality and normality, but with a slow modulation up and down the continuum, it is important to find the *points* on any given continuum where sufficient discomfort exists to allow both the respondent and the specialist to agree that "help" is needed. *It is at this pivot point that a reliable statistic can be projected.* Respondents in this study tried to identify such mid-line language (Report 2).

Questionnaire designers can deal with this issue of normalizing language/conceptualization in several ways:

--use as neutral and descriptive a language as possible, avoiding technical terms that are value-laden or pathologizing. Respondents stated that the mock-up questionnaire was excessively pathological in tone, or skewed, and they requested a greater attention to neutral language and to the inclusion of positivity to balance the negativity (that is, pathologizing language is interpreted as negative).

--when sequencing questions into groups, provide a series that moves from respondent-perceived "normal" symptoms to, several phrases away, respondent-perceived "extreme" symptoms. Provide mid-line choices that corespond to the respondent concept of "needs help/not sick".

--an alternative would be to focus a questionnaire on responent-perceived mid-line language, avoiding both extremes of the continuum. This would be more difficult and would require further research (eg., semantic differential) to reliably identify mid-line terms.

--provide a means to allow respondents to identify the context of the questions: respondents commonly fear being labeled abnormal, or having to wonder if they are abnormal, and insist that the way out of this is to be able to say what their life has been like recently. The logic is that if life has been unusually stressful, it is "natural" and "normal" to experience various symptoms, and this is a different situation from the person whose life is not stressed, and yet experiences such symptoms.

--an aspect of the context issue concerns time: while most respondents were satisfied with phrasing time in terms of days or weeks, a large number stated that "in reality" there is no specific time period sufficient to decide that someone's behavior has really changed in the direction of needing help. This is because people differ, and while for some only two or three days change is significant, in others, several months would need to pass. This is especially true in the case of major losses, such as the deaths of family members. Apparently a more cogent issue for most respondents was "change in pattern of behavior" or "behaving in out-of-the-ordinary ways." Perhaps ways could be found to call upon this thinking pattern is setting the context of the questionnaire, so that people knew that this change was what was being sought, not merely the presence/absence of symptoms that cannot be reliably judged abnormal in the absence of knowledge of context.

--always provide ways for respondents to talk about their successes, satisfactions, high energy, and comfort, even in the midst of also talking about their losses and distresses. Make this opportunity direct and clear; do not hide it within "no" answers to series of pathologizing symptoms.

2. Four more points are also useful recommendations:

--the grammar of the questionnaire must be impeccable and simple. The present document uses a complex form of the past tense that several respondents read as present tense. Other respondents simply found questions hard to interpret or found "typos" where they did not really exist.

--several respondents found physical symptoms easier to respond to than emotional ones, and recommended that these appear first on questionnaires.

--many words are ambiguous: respondents recommended the following:

a) avoid double-loaded phrases, eg., "tired for no good reason"--people who are tired and feel they have a good reason, don't know how to answer such a question.

b) avoid or be very careful of double-loaded terms. If a term is in common use as both a humorous descriptor and a term signifying pathology, perhaps a replacement term needs to be found, or some way to identify which of the several meanings in meant.

c) Adjective and noun versions of a word may have different loadings. Thus many respondents stated that the adjective is milder, the noun severer, with regard to the issue of normalcy. The pairs at issue here are depressed/depression, and anxious/anxiety.

d) A different form of linkage affects use of such words that a majority of respondents said were extremely similar in meaning, as worried, nervous, anxious, stressed. Another linked group includes sad, grieving, sorrowful, blue...depressed. It is probably wise to combine these sorts of terms in one question group, otherwise, respondents wonder if they've missed some significant issue (eg., the

current mock-up segregates "anxiety" and "worry"; as well as "motor agitation", "motor tension", and "motor retardation").

--the majority of respondents accepted the response choices phrased subjectively ("most of the time" etc.). While their interpretation of what these might mean varied widely, and would make a quantitative intepretation of their answers impossible, most respondents thought this issue would disappear if the language and context issues could be resolved.

3. Building in a Reward Structure

A majority of respondents to the mock-up questionnaire recommended building in a reward structure, that is, things that would make people more willing a) to fill out the form, b) more willing to "tell the truth." Things respondents defined as rewarding included:

--avoiding negative and pathologizing language

--providing ways to talk about success, satisfaction, etc.

--avoiding using a boring thythm, perhaps by the use of some sort of visuals, for example, an interesting border.

--using a cover letter or introduction to explain the purpose and link filling out the form with a "good cause"

--paying the postage [using a self-envelope].

ANNOTATED BIBLIOGRAPHY: AMERICAN WHITE MIDDLE-CLASS BELIEFS AND ATTITUDES ABOUT MENTAL HEALTH AND MENTAL ILLNESS.

by Claire M. Cassidy, PhD, Consulting Anthropologist
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One is unlikely to find what one does not look for, and very few scholars have looked for vigorous folk medical beliefs and practices among English-speaking, middle-class populations.
Hufford 1988:243

Generally, there is little published literature reporting the health beliefs of white middle-class Americans *in their own words*. There is a literature that analyzes how white Americans respond to specialist questionnaires that purport to describe their beliefs, but--it is important to realize--these actually describe only how respondents think about what the specialists have presented to them. There is also epidemiological data on the frequencies with which white Americans experience specialist-defined maladies, and a considerable literature in which specialists discuss mental conditions and how they identify them in patients. However, rarely have the narratives and vernacular beliefs of white Americans been studied or documented for themselves. As a result, there exists a considerable knowledge gap concerning the ethnomedical perceptions of laypeople who are also white, middle-class and American.

It is worth asking why this is so, since data does exist on the ethnomedical perceptions of non-white Americans. I suspect part of the explanation lies in the fact that (until recently) most researchers were themselves white and middle-class; many may simply have assumed something like "how I think is how most white middle-class people think." Certainly many of the respondents to this research made this assumption, and it may be common. Also, in anthropology at least, there exists an assumption that one cannot really perceive ones own culture. This has minimized (again, until recently) attention to the populations from which anthropologists generally come. Thirdly, many scientists have been trained in "cool" quantitative research techniques (which objectify the respondent/patient, seek a statistical norm, and measure "compliance" in terms of knowledge of and apparent acceptance of specialist categories) and the idea of using "warm" qualitative methodologies may seem significantly foreign. For these several reasons, there may not have seemed to be a researchable subject. To add to the difficulty, when data on white middle-class Americans does appear in print, it is often presented and reported as a "norm" against which the beliefs and behaviors of a "minority" are compared; that is, it is not considered as a subject unto itself (eg., Burnam et al 1984 and the associated references on Hispanic-Americans compared to Anglos; Sussman et al 1987 and others that focus on black-Americans).

This report will emphasize articles that examine the "mental" health beliefs and related behaviors of white middle-class Americans. Since few indeed focus on the conditions under study in this project, depression, anxiety, panic, and phobia, also included

are articles that report data from people with "psychoses" and "alcoholism", the two subjects that apparently have received the most attention. I will include both those studies that use quantitative "instruments" to "assess belief"--really measuring respondent familiarity with specialist categories--and the few narrative studies that start with the minds and thoughts of the respondents themselves. Additional sources are also quoted that help explain the patterns of response in the respondent research described in Reports 2 and 3.

The following sources were searched:

--medline

--social science abstracts

--bibliographies of texts and articles.

My thanks also to several colleagues who shared data and perspectives to help me identify this unusual material, especially Roberta Baer, and Gretchen Lang, and Anne Scott.

The following sources describe the beliefs of white middle-class Americans as reflected through their responses to popular assessment instruments: Foulks et al 1986; Furnham and Rees 1988; Good and Kleinman 1984; Hall and Tucker 1985; Beiser in Kleinman and Good 1985; Meile and Whitt 1981, Naegele 1955, Stein 1973. The following sources describe interview studies in which respondents were able to express their beliefs and perceptions without the intermediary of an "instrument," and in which respondent narratives are provided to allow the reader to "hear" respondents speak [only some deal with mental health issues]: Ablon 1981; Cornwall 1984; Cumming and Cumming 1955; Estroff 1981; Harris 1989; Helman 1981; Hufford 1988; Kaljee and Beardsley 1992; Kirmeyer 1988; Kleinman 1988; Kurtz 1979; Ragucci 1981; Scheper-Hughes 1987; Scott 1992, Williams 1984; Young 1988. Data from the narrative studies most closely resembles the results of this research, reported herein.

Five themes emerge from the literature that are important to interpreting the present research, and to the Census Bureau's goal of designing user-friendly survey instruments:

1. This research was designed to assess white middle-class attitudes to a series of psychological/psychiatric disorders or illnesses officially defined in the DSM III. Although these disorders may seem very real indeed to users, non-users may find them less convincing. A significant literature in anthropology and other fields examines the processes by which symptoms become grouped into entities that can be named and whose borders can be argued over. This literature explains how all diseases are in some sense cultural constructs. Such constructs serve a variety of purposes, such as to reassure patients, to direct care, and to maintain unequal power relationships between practitioner and patient, as well as between one medical system and another. Powerful systems of health care often insist that their models of bodily reality are "correct," and demand "compliance" from patients, but as this research shows, and as is echoed in many published articles, laypeople are often both unwilling to fully accept specialist explanatory models, and determined to develop their own models. The following references consider the issue of disease construct: Brett & Niermeyer 1990; Cassidy 1982, 1991;

Clatts and Mutchler 1989; DiGiacomo 1992; Eisenberg 1977; Gaines 1992; Good and Kleinman 1984; Hufford 1988; Kirmeyer 1988; Kleinman 1980; Marsalla 1980; Marsalla and White 1982; Murphy 1976; Naegele 1955; Ritenbaugh 1982; Stein 1990; Wakefield 1992.

2. "Medicalization" is a process by which familiar or commonplace events and experiences become redefined as medical or pathological events. A familiar example is the way drunkeness became redefined in this century as a disease, "alcoholism." Similarly, one may argue that the enviable stoutness of the last century became in this century the disease entity "obesity," hunger became "protein-energy malnutrition," and sadness and grieving became "depression." Laypeople are often fully or peripherally aware of this process, even if they cannot use the term "medicalization." Instead, as we listen to their narratives about what constitutes health and disease, we see that their concept of normal, and the degree of deviance from the norm that they are willing to accept as within the bounds of normal, is typically wider than what specialists will accept as normal. We might say that while the specialists tend to "medicalize," laypeople tend to "normalize." This difference is not without value loading: Specialists often choose to interpret the normalizing process as evidence of denial, but laypeople insist that there is a distinction between needing help *while still normal*, and going so far along the health continuum that everyone could agree that sickness was present. In this study the issue of where to draw the lines distinguishing well, well/needs help, and sick/needs help was probably the single most potent source of complaints from laypeople about specialist misunderstanding of their needs and reality. This was true in both the depth interview and questionnaire critique steps of the research. The following references speak to the issues of medicalization and normalization: Brown 1982; Cassidy 1982, 1992; Clatts & Mutchler 1989; Cumming and Cumming 1955, nd; Davis & Guarnaccia 1989 [Van Schaik, Davis]; Estroff et al 1991; Hollingshead 1953; Hudson & Roth 1988; Ritenbaugh 1982; Wakefield 1992.

3. One reason why laypeople emphasize normality is because they are more concerned with the context of behavior than are specialists who are removed both by location and by training. "Cool" quantitative approaches attempt to minimize context, locate the mean, and find commonalities that will allow one disease entity to be distinguished reliably from another and treatments to be focused. This approach is also taken to "mental illness" even though its cardinal symptoms are behavioral, and specialists frequently utilize relational explanatory models. But laypeople live in a "warm" world of relationships, happenstance, expectations, and a wide awareness of connectivity. Thus they want to know more than symptoms--they want to know "what happened," and "why"; only then can they determine if something out of the ordinary has happened, something that might need a specialist who is, ipso facto, outside the community structure. Rarely, however, do things happen that are sufficiently out of the ordinary to be classified as abnormal: grief, accident, anxiety, restlessness, confusion, hunger, drinking, anger...all are the everyday experiences of everyday people, hence "normal." The centrality of

context to laypeople helps explain the high levels of suspicion aimed at constructs that seem to be defined in terms of normal events (such as anxiety or depression), and the discomfort with questionnaires that ask questions about daily events but seem to cast them in a pathological light. For more on these issues, see: Cassileth et al 1984; Cumming & Cumming 1955, nd; Davis and Guarnacci 1989; Eisenberg 1977; Estroff 1981; Estroff et al 1991; Good and Kleinman 1984; Jones 1976; Kaljee & Beardsley 1992; Kleinman and Good 1985; Ritenbaugh 1982; Scheff 1966; Scheper-Hughes 1987.

4. Laypeople also create constructs that help them make sense of their experiences, and often these constructs resemble or parallel those of specialists. Some popular--or "folk"--illness constructs are in common use among middle-class white people, including "hypoglycemia," "nerves," and "stress." While biomedicine, for example, would recognize these words as sounding much like scientific words, biomedicine does not recognize these as disease entities in the same way they recognize depression as a disease entity. References that discuss folk illnesses and folk health models, most related to mental health issues and in use by white middle-class Americans include: Blumhagen 1980; Counihan 1992; Davis & Guarnaccia 1989 [Van Schaik, Davis]; Harris 1989; Helman 1978, 1987; Hufford 1988; Hunt 1990; Saunders & Hewes 1969, Young 1980.

5. Add to this the fact that the English language allows the same words to be used in a myriad of ways, with the true meaning only revealed by the context of use, and we wind up with a situation in which specialists and laypeople may easily appear to be speaking about the same thing and perceiving the body similarly, when in fact they are not. Consider, merely, the many connotations, from mild and humorous to serious and dangerous, of terms such as "crazy," "freaked out," "unbalanced," and "depressed."

These issues--of psychological disorder as cultural/specialist construct, of specialists finding pathology where laypeople find normalcy, of the importance of context to laypeople, of laypeople using illness constructs that are not used by specialists, and of the same words having different meanings in different contexts--all reappear in this research, and all help explain the criticisms and the recommendations of the white middle-class American respondents to this study.

ANNOTATED BIBLIOGRAPHY

Ablon, J., ed
1981 Papers from a symposium on stigmatized health conditions. Social Science and Medicine 15(1): 5 - 44. Considers stigma in relation to four conditions, diabetes, deafness, extensive burns, and dwarfism. Though all consider mostly white middle-class Americans, only the article by Ablon herself provides narrative material on how dwarves view themselves (pp. 25-30). There is not discussion of mental illness and stigma (but see Scheper-Hughes 1987).

Blumhagen D
1980 Hyper-tension: A Folk Illness with a Medical Name. Culture, Medicine and Psychiatry 4:197-227. How some laypeople, including a sample of white middle-class Americans, perceive a condition of tension called "hyper-tension" which bears only a peripheral resemblence to the biomedically-defined condition.

Brett, JA and S Niermeyer
1990 Neonatal Jaundice: A Disorder of Transition or an Adaptive Process? Medical Anthropology Quarterly 4:149-161. Considers neonatal jaundice not as a biomedical pathological entity but as an adpative response of the huma neonate to the extrauterine environment.

Brown, P.
1982 Attitudes Towards the Rights of Mental Patients: A National Survey in the United States. Social Science and Medicine 16:2025-2029. Notes that patients' rights groups tend to have unfavorable attitudes towards the mental health establishment; does not discuss beliefs or attitudes of individuals, and race and class are not specific issues.

Burnam, M. D. Timbers, R. Hough
1984 Two Measures of Psychological Distress among Mexican Americans, Mexicans, and Anglos. Journal of Health and Social Behavior 25:24-33. This article and the seven listed with it all reveal aspects of Anglo perception of mental illness in the process of discussing Mexican-American perceptions.

--Golding, J. and A Burnam 1990 Stress and Social Support as Predictors of Depressive Symptoms in Mexican Americans and Non-Hispanic Whites. J of Social and Clinical Psychology 9(2):268-287.

--Golding, J. M. Karno, and C. Rutter 1990 Symptoms of Major Depression Among Mexican-Americans and Non-Hispanic Whites. American Journal of Psychiatry 147:861-866.

--Karno, M. and R. Edgerton 1969 Perception of Mental Illness in a Mexican-American Community. Archives of General Psychiatry 20:232-238.

--Montgomery, G., B. Arnold and S. Orozco 1990 MMPI Supplemental Scale Performance of Mexican Americans and Level of Acculturation. Journal of Personality Assessment 54: 328-342.

--Parra, F. 1988 Perceptions of Mental Illness Among Mexican-Americans: The Influence of Education. Sociologia Internationalis 26:85-93.

--Parra, F. and a. Yu-Cheong So 1983 The Changing Perception of Mental Illness in a Mexican-American Community. International Journal of National Social Psychiatry 29:95-100.

--Salgado de Snyder, N., R. Cervantes, A Padilla 1990 Gender and Ethnic Differences in Psychosocial Stress and Generalized Distress Among Hispanics. Sex Roles 22:441-453.

--Vega, W. et al 1984 The Prevalence of Depressive Symptoms Among Mexican Americans and Anglos. American Journal of

Epidemiology 120:592-607.
--Vega, WA, B. Kolodny, G. Warheit. Psychoneuroses among Mexican-Americans and other whites: prevalence and caseness. American Journal of Public Health 75:523-527.

Cassidy, CM
1982 Protein-energy Malnutrition as a Culture-bound Syndrome. Culture, Medicine and Psychiatry 6:325-345. Study of how biomedicine has constructed PEM as a disease; does not include narrative materials.

1991 The Good Body: When Big is Better. Medical Anthropology 13: 181-213. Shows bigness is preferred virtually worldwide, including fatness; expalins white middle-class American attitudes of distain for and medicalization of fatness as "obesity" as a response to increased security from food scarcity and infection. Does not contain much narrative material; emphasizes belief structures.

Cassileth, BR, et al
1984 Contemporary Unorthodox Treatments in Cancer Medicine: A Study of Patients, Treatment, and Practitioners. Annals of Internal Medicine 101: 105-112. Though it doesn't deal with mental health issues, this report is useful because it quantifies that white middle-class educated people are the most likely population sub-group to use medical care outside the biomedical mainstream, and that they often have well developed explanatory models that integrate biomedicine and alternatives in ways that differ from the non-integrative models of biomedical specialists.

Clatts, M and KM Mutchler
1989 AIDS and the Dangerous Other: Metaphors of Sex and Deviance in the Representation of Disease. Medical Anthropology 10: 105-114. Study of professional and lay perceptions of AIDS and how these affect how PWAs can express their illness. Of a man who died without discussing "his disease," the authors say, "He denied us our predilection to classifyk, categorize, valorize and stigmatize" (p. 105). Although not about mental illness, this article underlines a point many social scientists and laypeople make: that the naming of an entity, and its medicalization, are dehumanizing, frightening, and often (additionally) a misinterpretation of the user's perception.

Counihan, C.
1992 Food Rules in the US: Individualism, Control and Hierarchy. Anthropology Quarterly 65:55-66. Study of US college students, mostly white and middle-class, and how they view food and self-control. From this and the work of others, Counihan explores a deep cultural model featuring "control," and the dangers of "lack of control," and stigmatization associated with looking/acting as if one "didn't have control."

Cumming J and E Cumming
1955 Mental Health Education in a Canadian Community. In: Health,

Culture and Community, Case Studies of Public Reactions to Health Programs. BD Paul, ed., Russell Sage Fd. NY, pp. 43-70.

A six-month program intended to change townspeople's perceptions of mental illness and the mentally ill failed. Two researchers compared the assumptions of the researchers with those of the townspeople to find out why. a) The specialists argued that there is a continuous gradation from normal to abnormal, but townspeople tended to see an abrupt transition between the two; b) townspeople considered "normal" to be a very much wider concept than did specialists, a concept which abruptly translated to "ill" when behavior became distinctly bizarre or harmful to others; c) willingness to associate with those who had been mentally ill--defined as having been in a mental hospital--varied by class and age, younger and more educated people being more willing; d) most respondents distinguished between 'mental illness' which was thought to be serious and virtually permanent, and 'nervous disorders' which were less serious and amenable to treatment; e) townspeople agreed with specialists that mental illnesses had "causes" (were not random events) but their ideas of causation were more complex, ramified, and contextual than those of specialists. *(These findings closely match those found in the present research.)*

More on this project can be found in The Blackfoot Project: An experiment in Mental Health Education, Commonwealth Fund [date after 1955; unpublished at time of 1955 article.]

Davis, DL and PJ Guarnaccia, eds
1989 Health, Culture and the Nature of Nerves. Special Issue: Medical Anthropology 11(1). Though none of the articles deal with middle-class white Americans, two deal with whites, one underclass group in Appalachia, and one working class group in Newfoundland. The other articles deal with Greek immigrants to Canada, and Latino/Hispanic Americans. The two articles most relevant to this report are:

Van Schaik, E. Paradigms Underlying the Study of Nerves as popular Illness Term in Eastern Kentucky, pp. 15-28.

Davis, DL. The Variable Character of Nerves in a Newfoundland Fishing Village.

"Nerves" is a popular condition which is talked about in a wide variety of settings, and overlaps (but is not identical with) specialist categories of "anxiety" and "panic attack." "Nerves" does not express itself identically in each setting, but is culturally modulated. Users explanations of cause also vary, but the most important point for this report is that users <u>do not</u> generally interpret "nerves" as an illness requiring specialist help. Instead, most report that "nerves" is a normal or predictable response to disempowerment, poverty, family stress, and the like. It can be dealt with within the family and community; only when family and community systems have broken down does the concept of "nerves" become "medicalized"--that is, take on an aura of "needing professional help." Van Schaik warns that interpreting "nerves" as a clinical condition ignores the meanings that users attach to the term. Davis concludes that "nerves" are not about a health/illness discourse, but a measure of the success of one's on-going social performance.

DiGiacomo, SM
1992 Metaphor as Illness: Postmodern Dilemmas in the Representation of Body, Mind and Disorder. Medical Anthropology 14:109-137. Excellent study of major explanatory models within medical anthropology. It doesn't focus on mental health issues, but illuminates various dangers in interpretaton of illness narratives, and emphasizes the culture-laden character of all medical explanation.

Eisenberg, L
1977 Disease and illness: distinctions between professional and popular ideas of sickness. Culture, Medicine and Psychiatry 1:9-23. This is an excellent theoretical paper but provides no narrative data. He discusses how much of biomedicine can closely define "disease" in physical terms, but that, although psychiatry and psychology attempt to use the same paradigm, they are faced with a different problem, that of defining conditions whose primary expressions are behavioral, and whose somatic expressions are also highly variant, even cross-culturally. Thus mental health workers cannot afford to delete the social from their care or research.

Estroff, SE
1981 Making it Crazy: An Ethnography of Psychiatric Clients in an American Community. UC Press, Berkeley. Monograph, including lengthy narrative material, that details the coping strategies of people with advanced mental illness who are released from custodial care, and must "make it" while still "crazy"--that is, without allowing the majority to know their condition. They must find ways to "normalize" their behavior, and often, many also perceive themselves as closer to normal than might their psychiatrists. A large proportion of the respondents were white.

Estroff, SE, WS Lachicotte, LC Illingworth, A Johnston
1991 Everybody's Got a Little Mental Illness: Accounts of Illness and Self among People with Severe, Persistent Mental Illness. Medical Anthropology Quarterly 5: 331-369. Study of the perceptions and languaging of patients (half white, no comments on social class) with long-term severe mental illness. A section relevant to the present research details "normalizing" language--that is, how the patients describe themselves as much like other people. Also discussed the the difficulty some patients have with "labeling" while others seem to accept psychiatric labels.

Foulks, E., JB Persons, LR Merkel
1986 The Effect of Patients' Beliefs about their Illnesses on Compliance in Psychotherapy. American Journal of Psychiatry 143:340-344. Sixty mostly white Pennsylvanians completed the Cause of Illness Inventory, which is supposed to measure the congruence of beliefs between therapist and patient. On different measures, these responents chose biomedical (congruent) answers 38 - 71% of the time, as well as a variety of non-congruent answers (3 - 12%). Those who were most congruent were also most compliant. No narrative material and no real study of patient beliefs.

Furnham, A. and J. Rees
1988 Lay Theories of Schizophrenia. International Journal of Social Psychiatry 34:212-220. A British sample of 120 adults provided questionnaire data on their beliefs about mental illness, especially schizophrenia. A quantitative study similar to the above.

Good, BJ and AM Kleinman
1984 Culture and Anxiety: Cross-cultural Evidence for the Patterning of Anxiety Disorders. in: Anxiety and the Anxiety Disorders, AH Tuma, JD Maser, eds., Erlbaum, Hillsdale NJ. Discusses several models of anxiety and critiques cross-cultural studies of anxiety; emphasizes non-white non-Americans. Two points relevant to the present research: the authors assume, and find many respondents assume, a continuity from normal to pathological, that is, no abrupt movement from normal to "ill" is perceived with regards to anxiety. Second, they state, most cross-cultural studies have not made efforts "to establish the full range of expressions of anxiety" because they use work from prepared questionnaires.

The remainder of this text similarly contains no narrative data; it is all interpretive and written from the perspective of the specialist. However, the book is useful for illustrating the lack of uniformity in defining anxiety, and how close anxiety comes to "normal" stress and life, a perception these specialists share with the respondents in the present research.

Hall, LE and CM Tucker
1985 Relationships between Ethnicity, Conceptions of Mental Illness, and Attitudes Associated with seeking Psychological Help. Psychological Reports 57:907-916. A sample of 513 schoolteachers completed three instruments. The white teachers gave answers more like mental health professionals and more had been in therapy; the black teachers gave more "stereotypic" answers. A highly quantitative, abstracted article, which claims to show that the public "denies" mental illness. No interviews or narrative material.

Harris, GG
1989 Mechanism and Morality in Patients' Views of Illness and Injury. Medical Anthropology Quarterly 3:3-21. Interview study of mostly-white mixed class sample of Americans which examines user notions of "stress." Author argues that while biomedical specialists sometimes use "stress" as a medico-moral term, they tend to desocialize it, whereas laypeople in this study implicated "stress" in "actions and interactions evaluated as undesirable or wrong." The concept of "stress" was linked in this study with other words such as anger, tension, worry, upset, fear, anxiety, hurt feelings, and other "unpleasant feelings."

Helman, CG
1978 Feed a Cold, Starve a Fever--Folk Models of Infection in an English Suburban Community, and Their Relationships to Medical Treatment. Culture, Medicine and Psychiatry 2:107-137. Does not

deal with concepts of mental illness, but does show the ancient logic of folk care, and its tendency to remain active in educated white people, here British, but with the same beliefs and actions also documents in the US (see Hufford 1988).

1981 'Tonic,' 'Fuel,' and 'Food:' social and symbolic aspects of the long term use of psychotropic drugs. Social Science and Medicine B 15:521-533. Pilot interview study of 50 British patients, all white, who had taken psychotropic drugs for years. Distinguishes three sub-groups: those who keep control over taking the drug ('tonic'), those who take it as habit and have partial control ('fuel'), and those who have given up control over the drug and are passive ('food'). Contains narrative material; good article.

Hudson, CG and JA Roth
1988 The Social Class and Mental Illness Correlation: Implications of the Resarch for Policy and Practice. Journal of Sociology and Social Welfare 15:27-54, 1988. Authors posit an interactive relationship between socioeconomic status and mental illness, even though they recognize difficulties inherent in defining both social class and mental illness. No narrative material.

Hufford, DJ
1988 Contemporary Folk Medicine. In: Other Healers, Unorthodox Medicine in America, N. Gevitz, ed. Johns Hopkins University Press, Baltimore, pp. 228-264. Documents normative character of "folk medicine" (his term for practices and systems other than biomedicine) among all Americans. Contrasts the models of biomedicine and folk medicine. Critiques stereotypes associated with folk medicine, eg., that it is used only by isolated or ignorant people, showing that the systematized versions thereof are most likely to be used by more educated, especially white middle-class people. No discussion of mental health per se.

Jones, MO
1976 Doing What, with Which, and to Whom? The Relationship of Case History Accounts to Curing. In: American Folk Medicine, a Symposium. WD Hand, ed, University of California Press, Berkeley, pp. 301-314. Methodological essay on the character and limitations of case history approaches to understanding the point of view of the respondent, using stories from white (mostly lower class) Americans and illustrations; no discussion of mental health per se.

Kaljee, LM and R Beardsley
1992 Psychotropic Drugs and Concepts of Compliance in a Rural Mental Health Clinic. Medical Anthropology Quarterly 6:271-287. Contrasts physician ideas of compliance with patient ideas in a rural mental health clinic in the Mid-Atlantic region; about 1/3 of patients were white, not necessarily middle-class. Most had long histories of relatively severe mental illness. Most of the paper discusses the contrast; the patients "speak" in only a small part of the paper. The focus is not on patient perceptions of mental

illness, but on patient perceptions of the doctor-patient relationship.

Kirmayer, LJ
1988 Mind and Body as Metaphors: Hidden Values in Biomedicine. In: Biomedicine Examined. M. Lock and DR Gordon, eds., Kluwer, Boston, pp. 57-93. Sophisticated complex theoretical paper that assesses hidden values in biomedicine, and uses patient narratives to illustrate these values at work.

Kleinman, A.
1980 Patients and Healers in the Context of Culture: An Exploration of the Borderland Between Anthropology, Medicine and Psychiatry. UC Press, Berkeley. Despite its promising title, focuses mostly on Chinese people and on psychiatric description rather than respondent narrative or belief.

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1988 The Illness Narratives: Suffering, Healing, and the Human Condition. Basic Books, NY. Divides health care into several realms, each dealt with in a chapter; each chapter contains narratives of one to several patients. A fascinating text that explores the meaning of subjectivity. Race and class of patients not noted.

Kleinman, A. and B. Good
1985 Culture and Depression: Studies in the Anthropology and Cross-cultural Psychiatry of Affect and Disorder. UC Press, Berkeley. Though a thick book, none of the chapters reviewed contained narrative material. Three were somewhat relevant to the present research:

Beeman, WO. Dimensions of Dysphoria: The View from Linguistic Anthropology, pp. 216-243. An effort to explore whether the symptoms of depression are "universal" in all human populations; find that the behavioral signs are less reproducible cross-culturally than the somatic, though these too vary widely. Reviews explanatory models of depression.

Beiser, M. A Study of Depression Among traditional African, Urban North American, and Southeast Asian Refugees, pp. 272-298. The white population is from New York City, 53 responents who filled out questionnaires. One question was felt to be "culturally specific" to white Americans: "Have you felt you were going to have a nervous breakdown?" All results are expressed in terms of factor analysis; there are not people and no narratives in this work.

Carr JE and PP Vitaliano, The Theoretical Implications of Converging Research on Depression and the Culture Bound Syndromes, pp. 244-266. This author again describes characteristics of depression and questions its universality, but gives not data from actual patients.

Kurtz, E.
1979 Not-God: a History of Alcoholics Anonymous. Hazelden Educational Services, Center City MN. Gets at the logic of the movement's beliefs with respect to alcoholism by looking at the

observations and intellectual connections AA founder Bill Wilson was making as he developed the movement. Contains data on members' beliefs; most were white if not middle-class.

Meile, RL and HP Whitt
1981 Cultural Consensus and Definitions of Mental Illness. Social Science and Medicine 15A: 231-242. Three samples of mostly-white people from Omaha NE completed several assessment instruments. They wondered if the public saw mental illness as "stigmatized" and concluded "no." No narrative or interview data.

Murphy, J. M.
1976 Psychiatric Labelling In Cross-Cultural Perspective. Science 191:1019-1028. Labeling theory proposes that the concept of mental illness is a cultural stereotyping referring to a residue of deviance which each society arbitrarily defines in a distinct way. The author's study of Yupik and Yoruba people, and data from other peoples leads him to reject labeling theory, stating: "Mental illness is not a violation of norms, but the manifestation of affliction."

Naegele, Kaspar D.
1955 A Mental Health Project in a Boston Suburb. In: Health, Culture and Community, Case Studies of Public Reactions to Health Programs. BD Paul, ed., Russell Sage Fd. NY, pp. 295-321. Sociological study of differing perceptions of mental health/illness by psychiatrists, school teachers and ministers, all middle-class and white, but all with differing goals and perceptions. No narrative material; a rather distancing article.

Ragucci, A T
1981 Italian-Americans. In: Ethnicity and Medical Care, A. Harwood, ed., Harvard University Press, Cambridge. Includes an extensive discussion of Italian-American beliefs and habits, including a small amount of narrative material, but no reall discussion of mental health/illness. A quality article.

Ritenbaugh, C.
1982 Obesity as a Culture-bound Syndrome. Culture, Medicine and Psychiatry 6: 347-361. Study of how biomedicine has constructed obesity as a disease; does not emphasize the perceptions of laypeople.

Saunders, L. and G. Hewes
1969 Folk Medicine and Medical Practice. In: The Cross-cultural Approach to Health Behavior, LR Lynch, ed., JB Lippincott, Philadelphia. Does not focus on mental health, but does show that white middle-class people do have and use folk models of illness and disease that differ from those of specialists.

Schaeffer, NC
1991 Hardly Ever or Constantly? Group Quantifier Using Vague Quantifiers. Public Opinion Quarterly 55:395-423. The authors conclude that there are significant differences by race, education

and age in the meaning of phrases conveying relative frequency: such phrases stand for higher absolute frequencies ofr whites, for better educated, and for younger respondents.

Scheper-Hughes, N.
1987 "Mental" in "Southie": Individual, Family and Community Responses to Psychosis in South Boston. Culture, Medicine and Psychiatry 11:53-78. Study of deinstitutionalized mental patients in an ethnically diverse, but heavily Irish-American, section of Boston. Includes much narrative material; a true interview study. This population explained behavior in terms of ethnic expectations. Most respondents feared the hospital and mistrusted psychiatrists; most also expressed themselves in "normalizing" language. Author asked respondents to rank-order 7 "behaviors common in mental illness." The four (white) ethnic groups did it differently, but all ranked cognitive symptoms like hallucinations and deviant speech as less upsetting than physical/movement abnormalities or violence. Author comments on the irony of psychotropic drugs which control hallucinations (which psychiatrists fear) but cause motor abnormalities (which stigmatize patients among their peers much more than hallucinations). Author details how "Southies" "make it crazy"--that is, cope--also see Estroff, above. Author concludes: "While madness invariably disenfranchises, it does not necessarily deculturate the individual" (p. 53).

Scott, AW
1992 Alcoholics Anonymous, Handling Conventional Medicine One by One: The Example of Bill Wilson and his Psychiatrist. paper delivered at the Annual Meeting of the American Folklore Society, October 13-18, Jacksonville FL. As yet unpublished, but reports interview data in narrative form, focused on alcoholics.

Stein, HF
1973 Cultural Specificity in Patterns of Mental Illness and Health: A Slovak-American Case Study. Family Process 12:69-82. Intensely psychologizing study of one family with a schizophrenic member; not recommended.

1990 American Medicine as Culture. Westview Press, Boulder CO. General text on the cultural components of the practice of biomedicine in the United States.

Wakefield, JC
1992 Disorder as Harmful Dysfunction: A Conceptual Critique of DMS-III-R's Definition of Mental Disorder. Psychological Review 99:232-247. Example of specialists trying to find solid definitions for words that are commonly used loosely; in this case the issue related to problems of telling normal from abnormal, hence validity.

ADDITIONAL TITLES IDENTIFIED BUT NOT LOCATED/READ

Barsky, AJ

1988 Worried Sick: Our Troubled Quest for Wellness. Little Brown and Co., Boston.

Calnan, M.
1987 Health and Illness: The Lay Perspective. Tavistock, NY.

Cornwell, J.
1984 Hard-earned Lives: Accounts of Health and Illness from East London. Tavistock, NY. Reputedly contains good narrative material.

Cumming J and E Cumming
Affective Symbolism, Social Norms, and Mental Illness. "An attempt to define some of the variables that assist in determining when a person will be considered mentally ill by his friends and acquantances and how these variables are related to the toleration of the symptoms of mental illness by lay people." [Unpublished in 1955 at time of citation; not located or read.]

Fitzpatrick, R.
1984 Lay Concepts of Illness. In: The Experience of Illness. R. Fitzpatrick et al, eds., Tavistock, NY, pp. 11-31.

Gaines, AD, ed.
1992 Ethnopsychiatry, The Cultural Construction of Professional and Folk Psychiatries. State University of New York Press, Ithaca. A new book not located. From the publicity: "The authors view both ethnomedical practices and illness as local cultural constructions. The book demonstrates that professional and popular psychiaatric medicines lie along the same local cutlural continua...[having] aspects of common cultural discusourse on normality and abnromality. The essays reject the notion of a universal, uniform reality of psychopathology beyond cultural boundaries....

Helman, CG
1984 Culture, Health and Illness. Wright-PSG Publ Co., Boston.

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1987 Heart Disease and the Cultural Construction of Time: The Type A Behavior Pattern as a Western Culture Bound Syndrome. Social Science and Medicine 25: 969-979.

Herzlich, C and J. Pierret
1987 Illness and Self in Society. E. Forster, translator. Johns Hopkins U Press, Baltimore.

Herzlich, E.
1979 Health and Illness: A Socio-Pyschological Approach. Academic Press, London.

Hollingshead, AB and FC Redlich
1953 Social Class and Psychiatric Disorders. In Interrelations Between the Social Environment and Psychiatric Disorders, Milbank Memorial Fund, NY. "In dealing with differential rates of mental

illness by social class, this article, along with other works by these authors, opens up the possibility that there exists a different toleration of deviance among socioeconomic strata." Does not emphasize lay narratives.

Kleinman, A.
1988 Rethinking Psychiatry. The Free Press, NY.

Levin, L, A Katz, E Holst
1976 Self-Care: Lay Initiatives in Health. Prodist, NY.

Lewis, M. amd C. Saarni
1985 The Socialization of Emotions. Plenum Press, NY.

Lorencz, B.
1991 Becoming Ordinary: Leaving the Psychiatric Hospital. In: Illness Experience: Dimensions of Suffering. JM Morse and JL Johnson, ed.s, Sage Publ, Newbury Park CA, pp. 140-200.

Lynd, R. S. and H. M. Lynd
1937 Middletown in Transition. Harcourt Brace and Co., NY. "Chapter 12 of this classic community study of a midwestern town is a still relevant presentation of the general values by which a majority of people in the United States attempt to live. Recent concern with 'mental health' can be better understood within the framework of these general values."

Mezzick J. and C. Berganza.
1984 Culture and Psychopathology. Columbia University Press, NY.

Marsalla, AJ
1980 Depression Expresions and Disorder Across Cultures. In: Handbook of Cross-cultural Psychology. HC Triandis and JG Dragnus, eds., Allyn and Bacon Publishers, Boston, pp. 237-290. One Marsalla quote offered by another author: "Depression apparently assumes completely different meanings and consequences as a function of the culture in which it occurs." (p. 261)

Marsalla, AJ, GM White
1982 Cultural Conceptions of Mental Health and Therapy. Reidel, Dordrecht, Holland.

Reynolds, DK and NL Farberow
1977 Suicide: Inside and Out. UC Press, Berkeley

Sandborn K and M. Katz
1980 Perception of Symptomatology in Ethnic Groups. In: Psychopathology of Depression. Proceedings of a Symposium by the Section of Clinical Psychopathology of the World. K. Achte, V. Aalber, J. Lonnavist, eds., Psychiatric Assn, Psychiatria Fennica Supplementum 315-319.

Scheff, TJ
1966 Being Mentally Ill. Aldine, Chicago. Discusses the

normalizing effort that most people apply to mental illness labels, but redefines it not as "normalizing" but as "denial"--that is, arguing that most "deviant" behavior is ignored, rationalized away, or denied.

Scruton, DL
1986 Sociophobics: The Anthropology of Fear. Westview, Boulder CO

Star, Shirley A.
?d The Dilemmas of Mental Illness: An Inquiry in Contemporary American Perspectives. "An exhaustive analysis of public attitudes toward mental illness, basd on a research project of the National Opinion Research Center. [in preparation in 1955 by Commonwealth Fund.]

Stein, HF and WG Neiderland
1989 Maps from the Mind: Readings in Psychogeography. University of Oklahoma Press, Norman.

Sussman, L., L. Robins, F. Earls
1987 Treatment-seeking for Depression by Black and White Americans. Social Science and Medicine 24: 187-196.

Terminsen, J. and J. Ryan
1970 Health and Disease in a British Columbian Community. Canadian Psychiatric Assn J 15: 121-127.

Townsend, JM
1978 Cultural Conceptions and Mental Illness: A Comparison and Germany and America. University of Chicago Press, Chicago.

Williams, G.
1984 The Genesis of Chronic Illness: Narrative Reconstruction. Sociology of Health and Illness 6:175-200.

Young, A.
1980 The discourse on stress and the reproduction of conventional knowledge. Social Science and Medicine B 14:133-467.

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1988 A Description of How Ideology Shapes Knowledge of a Mental Disorder. In: Analysis in Medical Anthropology, S Lindenbaum and M. Lock. Dordrecht.

REPORT 2: RESULTS OF IN-DEPTH INTERVIEWS OF HEALTH, MENTAL HEALTH AND MENTAL ILLNESS WITH WHITE MIDDLE-CLASS AMERICANS

by: Claire M. Cassidy, Ph.D, Consulting Anthropologist
Date: October 1992

Plan of the Research

The goal of this segment of the research project was to explore how middle-class white Americans think and speak about mental health/illness, and specifically, five conditions specified as depression, depression lasting more than two years (dysthymia), anxiety, panic attack, and phobia. Because the data are intended to shed light on communications issues related to the design of standardized questionnaires, the emphasis in this report will be on respondent language and perception of specialist language, rather than on respondent models of body and mind.

The plan of research was to do depth interviews with 16 white middle-class Americans, none of whom were associated by occupation with biomedicine, and four of whom were practitioners or users of non-biomedical health care systems.

The in-depth interviews were designed to provide the respondent with the widest latitude in response. The first question asked the respondent to define 'health' [Questionnaire in Appendix 1]. The interviewer then used the respondent's language and categories to elicit further responses, as about 'emotion,' 'mental health,' 'mental illness,' or specific conditions mentioned freely by the respondent. The next step in the interview consisted in asking the respondent to sort a set of 40 cards, each printed with a word or phrase that could be construed as referring to 'mental health' or 'mental illness.' These terms were taken from Mental Health Screening Scale Items (version of June 3, 1991) and modified on the basis of the first five respondents' commentaries. The purpose of the card sort was to gain greater detail on respondent attitudes and languaging, based on their responses to sorting the cards into groups of "related" words. If, after the first interview period and the subsequent card sort period, respondents still had not used language that matched the test categories ("depression," "anxiety," etc.), these terms were offered directly and the respondents were asked to explain them.

Results

Sample

The preferred sample was to be divided equally by sex, with 6 in each of two younger age categories (18-30; 31-60), and 4 in the older age category (over 60). In addition, respondents were to be sought from a wide range of occupational and educational backgrounds. However, the most cogent characteristic sought in respondents, after willingness to be interviewed, was that respondents be verbal, or easily able to express themselves.
Tables 1 and 2 summarize actual sample characteristics. The number of respondents expanded to 17 because one husband-wife team was interviewed. Ten respondents were interviewed by the PI, two under-30s were interviewed by an experienced female interviewer

(JW), and four 60+ respondents were interviewed by an experienced male interviewer (DM). Data in Table 2 are summarized from a one-page anonymous cover sheet completed by each respondent. In sum, the sample was urban and educated; all were clearly willing to discuss their perceptions of health, an dmost had well-developed explanatory models.

Because one aim of this research was to include practitioners or users of alternative health care, all respondents were asked what kinds of health care they had ever used. The results show that this sample of respondents used a wide range of health care modalities. One professional of an alternative health care system was interviewed (a traditional acupuncturist). Three other persons were interviewed *because* they were known to use alternative health care systems (shamanic healing, traditional acupuncture). However, others interviewed also proved to be users of alternatives to biomedicine, women more than men. Use of biomedicine alone was limited to men, with 5 of 9 men using only biomedicine, but all women using biomedicine plus other modalities. Table 3 summarizes the data. Other reseearchers have also noted that educated white people are likely to use alternative forms of health care (Cassileth 1984; Hufford 1988: Suanders and Hewes 1969).

Definitions of Health, Mental Health, and Mental Illness.

The first question asked respondents to say what they thought health was, or what words came to mind when asked about health. Eight people gave answers that indicated that, to them, the term "health" provokes mostly thoughts about the physical body, eg.,:

--[female age 26]: physical well-being, feeling good about one's body and not just feeling good, but having one's body feel good....

--[male age 36]: good working order of your metabolism...your respiratory system especially...being clean of diseases.

Nine respondents gave answers that included remarks about mental or emotional functioning, or "attitude." Of these, five gave answers about the need for balance of mind and body, three emphasized mind/emotions, and one focused on the social environment and whether or not one can work.

--[female age 43]: When I think about the word "health" I think of exercise, I think of aerobic exercise, I think of really taking care of your heart, watching what you eat. I also think of mental health, of how your attitude is, so I think of both the emotional and physical when I think of health.

--[male age 37]: Health is a sense of being well, emotionally and physically...being open to those feelings, to the world around you. Correspondingly your body is less tense, less contracted, so it tends to be healthier. ...feeling a certain amount of ease and acceptance of life circumstances, not fighting against the current of life.... Health grows out of our own--perhaps rootedness is the word--the notion that you can define yourself independntly of the kind of things you see on TV or read in magazines.

--[male age 80]: ...you can get up in the morning and feel fine, you can eat an average breakfast, have the energy to do different things, have nothing on your mind, be able to relax,

watch TV and go to bed with no problem...

Interviews were designed to follow respondent's thoughts, so those who did not mention "mental health", or made no mention of emotions, spirit, attitude or the like, were not asked directly to define such terms. Instead, they were urged to describe "healthy" and "not healthy" people, or asked (eventually) if attitude had anything to do with health, or how body and mind were related. Only two respondents were distinctly unable to speak about mental health issues, one elderly man who was taken up with concern about his physical problems, and one man of 36 who comes from a dysfunctional family and responded to all questions about mood, attitude, or emotions with remarks about diet and exercise.

While mental health was seen, by this sample, in positive terms, and as generally linked to physical health (though the perceived details of that linkage varied widely), the majority of respondents expressed discomfort with both the term and the concept of mental illness. The two leading themes in these answers were a) that "illness" represented a close-to-permanent take-you-away-from-society situation, whereas most of what we had been talking about was reversible; or b) that the idea of linking illness to behavior is a social or professional ploy related to maintaining the status quo. For example:

[male, age 21]: [mental illness is] instability in carrying on daily social activities, not being able to carry on conversations or function in society...inability to keep a regular competitive lifestyle, to control what's going on in your life, I guess inability to focus....I would say 'mental illness' to describe a particular, 'mental health' describes a general overview of mental problems.

--[female age 43]: I would think of mental illness as something that is more permanent, not as something that is temporary, whereas I like to look at depression as something that is temporary. A mental illness could ...incapacitate, where you can no longer function in our society independently. When somebody is mentally ill I think that they have a severe problem, they cannot live a normal functioning life. [told of a manic-depressive confined to home]: *I wouldn't call him mentally ill...I would say he functions within a certain framework. If you took his mother away he wouldn't have a job, he wouldn't have any income, then he would be homeless, being called mentally ill. I mean, a mentally ill person to me is somebody who murders for the sake of killing, because that's fun to do...like a woman kills her husband because he's abusing her, I don't consider that mentally ill. I think of the mentally ill as people who live in their own world and think that everybody has to conform to their world...they can't fit in to the society we've placed them in.* [A person who can hold a job?] *...is not mentally ill.* [A person who is deeply unhappy and seeks the help of a therapist?] *...is not mentally ill.*

--[male age 36]: [asked if his anorexic girlfriend is "sick"]: *No, I mean she ran her own furniture store with her mother, she had a good family, she was just obsessed with keeping her body weight down...she was beautiful!* [asked if a friend who takes drugs is healthy]: *very healthy, sure, she was a hiker, she was an extravert, I think she took depressants to slow her down and*

stuff...you have to do what you have to do, to numb the pain, such as myself, I like to drink beer, to me it's a form of relaxation because life around here is very boring...a year ago I had alcohol poisoning.... [Mental illness is (an inherited)] imbalance--what do you call it, your chemicals--yah, some people need lithium, other people need, whatever it takes to make you normal....

--[male age 37]: What [mental illness] means [to me] has changed over time. What it means is some kind of disintegration or non-integration of the person's being or outlook, process of thinking and feeling...a person who had difficulty connecting or relating, [lacked] clear thinking or coherence...inappropriate affect, perhaps delusion...[and] from a spiritual point of view, the underlying sense that [the person is] unable to move easily or fight and consequently [acts] frustrated, unhappy, angry, or sad. When I was much younger ...I had some medieval sense of crazy people in an asylum or something like that, just forever lost and raging...so there's been some progression. My own sort of bias has to do with labeling. I prefer not to do it. I hate using traditional mental health category terms. It has to do with labeling...defining people by labels. I want to stay in the descriptive mode.

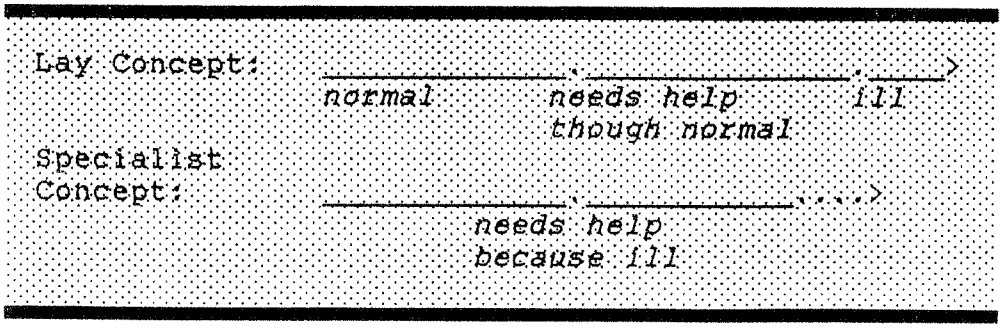
--[male age 47]: I guess my view is that there may be a million ways to be healthy, but there is only one way to be sick...and that is when one becomes disempowered, when one loses that sense that what one does matters. I would find all these things linked in the same person, an emotionally ill person...oh! I shouldn't have used that word! It's a bad word! I don't think there is such a thing as an emotionally sick person, particularly in the way the mental system prescribes it...I don't think of it as an illness the way I don't think of a pregnancy as an illness. I would call [such a person] distressed, confused is also a very good word...the mind is essentially and always very capable of working very well, and that is an essential thing to realize about restoring health to distressed people. [about therapists]:*I don't like their model of treatment. They're very disempowering...in many ways it's a form of oppression....*

--female age 26]: I guess I have a problem with the notion of mental illness. I think...that it's kind of contextual. I think that chemical imbalances in people's brains are caused by social contexts. If a manic depressive tried to understand the social situation which brought about this mental or chemical imbalance in the brain, and tried to change one's [sic] life situation, that chemical imbalance would change. So, when I think of mental health I immediately think of mental illness, I think of psychiatry and psychology and people trying to cure these people and I just don't...people go through good and bad times and I don't think you're supposed to go in there and try to cure. So when I think of mental health, I think of it as an artificial construct, whereas health I think of as kind of true.

Whichever model a speaker preferred--and some used both--the point of significance to the present research is that <u>the range of normalcy recognized by the respondents in this research was much wider than what psychotherapists would be likely to recognize</u>.

This point has been repeatedly made in the literature, though authors interpret it differently (Cumming and Cumming 1955; Good and Kleinman 1984; Hall and Tucker 1985; Scheper-Hughes 1987; Scheff 1966). It represents a fundamental difference in perception and valuing between laypeople and specialists that could bias survey responses, especially if words "too close to normal" (or, at the other extreme, to "illness") were used in survey instruments.

This situation was clarified by asking respondents to sort their card sort piles (below) from mildest to severest symptoms. Respondents spontaneously noted where, on the continuum, "needs help" occurred, and questioning as to whether "needing help" signaled the presence of "illness" provided the second piece of data, that "needs help" and "ill" do not necessarily overlap, particularly in the case of well-known conditions such as depression, and anxiety/stress. Instead, illness was characteristically identified only at the extreme of these distributions, though "needs help" was located closer to the center of the distribution. However, sorts of "out of control" groupings tended to locate "needs help" closer to the beginning of the continuum, and some respondents stated that any of the symptoms they grouped as "out of control" were, by definition, in need of help. In contrast, several respondents made groupings that they stated were about "minor" or "everyday" symptoms, all of which were "normal" , did not require professional help, and would disappear by themselves with time.



For specific examples, see examples at the end of the discussion of the results of card sorts. However, before we leave this subject, a little more discussion: While many observers have noticed this "normalizing" tendency of laypeople--a tendency which counters the biomedical tendency to "medicalize"--some authors have rejected it, by claiming that laypeople are in "denial" (eg., Scheff 1966; Hall and Tucker 1985). I argue differently. This sample of laypeople had a well defined concept that there is a continuum from wellness to illness (also see Good and Kleinman 1984, Scheper-Hughes 1987), and state that one can move back and forth upon it:

[e.g.,female age 39]: *People exist on a continuum of mental illness and they move back and forth on this just as they do with their physical health.....*

A person can move to a point where there is discomfort and they want "help" (that is, professional help), but still consider themselves not nearly far enough along the continuum to be in a

state of "illness." This is clear from the quotations above: the point at which one arrives at "illness" is both distant and frightening. Some people equate it with the point at which one arrives at institutionalization.

I surmise that the dynamism and complexity of the lay position has not been understood by many who wish to offer help, and who have conflated "needs help" with "being ill." Consider, for example, the assumption (underlined) in this quotation:

The point at which patients define sleeping problems and subjective emotional states as being "abnormal" and thus constituting an "illness," depends...on personal, social and cultural factors, and these factors my in turn shape both the perception of symptoms and how they are described to others.

Helman 1981:524

While everything else that Helman says is backed by a huge body of evidence, this phrase is an assumption: in fact, laypeople typically do not conflate "abnormal" or "needs help" with "illness." This point is significant here because it implies that questionnaire designers should provide ample response space to allow people to report levels of discomfort that are real but short of "illness."

Definitions and Descriptions of Specific Conditions under Study.

Five conditions were under study, including depression, depression lasting more than two years, anxiety, panic attacks, and phobia. Of these, depression appeared to be most familiar to respondents, who used the terms "depressed" and "depression" freely and spontaneously. However, respondents were less sure that depressions could last as long as two years. Everyone also recognized the sensation of anxiousness and used the term "anxiety," but both denotation and connotation varied quite widely from person from person. Anxiety was fairly often linked to "stress" or "urban stress" identified as environmental variables, and by a minority with "nervousness" which seemed to be "built-in" or characterological. Both panic and phobia appeared to be less familiar concepts to respondents, and both were perceived by the inexperienced (those who had not experienced panic attacks) as more serious than they were by the experienced.

A majority of respondents described the conditions in relation to their own experience or to those of family members and friends; relatively few abstracted and tried to generalize.

Depression. This condition or experience was familiar to everyone in the sample, though they differed on how clearly they described it or how serious they considered it to be. With probing, nearly all respondents produced models that put depressive symptoms on a continuum from mild, everyday, insignificant symptoms, to symptoms serious enough to suggest help was needed. Few felt that depression was really serious, unless, as a minority stated, it "went all the way" to attempted suicide. The word "suicide" was not offered either orally or in the card sort, but it was used spontaneously by several respondents to describe the endpoint of an untreated depression, often the point at which "more

than help" or "institutionalization" was required, and "illness" existed.

Although respondents all linked "depression" with sadness and grieving, the connotations of the words "depressed" and "depression" varied from respondent to respondent. "Depression" was often used to denote a settled, hence more serious, condition. Meanwhile, many argued that "depressed" was a commonplace experience, signifying little; however, for a few it was a strong term, as strong as "depression." Two respondents specifically stated that the noun form was stronger than the adjectival form; others simply used them this way.

Respondents were also united in stating that depression was changeable, that is, that it comes and goes, that it is typically temporary and not very serious, but that "if it lasts too long," something has changed, and help is needed. However, none were able to specify what might have changed, or how they would know a friend had moved from the commonplace form to the serious form of depressed/depression. One respondent described in detail her frustration in being unable to distinguish a man about to commit suicide from his friends, none of whom were depressed, and apparently, none of whom themselves realized the danger their friend was in.

Finally, respondents agreed that there is no specific time frame within which one can determine that the way a person feels is no longer "normal." How much time must pass, respondents argued, depended on the person him- or herself: depression in someone who was usually up and energetic might be suspected within two days, but in someone who was usually quiet and inturned, perhaps not for weeks. In short, the experience of depressed states--being sad, blue, down, discouraged--is so familiar, and is thought to be so predictable (i.e., "normal") a response to upsets, trauma, and loss, that few are willing to consider it an "illness" unless it prevents the person from performing as expected, and even this, only after a significant amount of time has passed. These points are relevant here since so many existing survey questionnaires specify a period of time within which the respondent is supposed to report certain symptoms. Possibly some further thought needs to be given to this approach: some way of reporting if the behavior is *out of the ordinary for that person* may make more sense to many respondents, for whom the context of behavior is more important than the time frame.

--[male age 36]: *Depression is long term and depressed is a momentary situation...depressed you are put in a bind at this moment, but it's temporary...depression it's on-going. [long-term depression]: people are usually old and you've learned to accept them for what they are...it's a default in their personality.*

--[female age 26]: *I'm not sure how I would define depressed anymore because it is tossed around so much. I think it's lost meaning and I can use it in so many different ways. It must mean listless, but I would love to have a list of 10 questions and if you answer yes to 8 of them you are classified as depressed, but I don't think that works....*

--[female age 39]: *"chronically depressed"--how long does it*

have to be? It depends on the individual and it depends on the etiology of the depression...for some people there are chemical imbalances. An acute depression is something that focuses on a single event, travels its course and after a reasonable amount of time, our spirits lift and you can reflect back upon the event that precipitated the depression. But when you can't reflect back and your spirits don't lift and you go on for weeks and months or years, that's chronically depressed. ...this is going to end with suicide, you keep a person depressed long enough. ... I think depression is normal is you are grieving...depression is abnormal if you can't look back and reflect, if you are about ready to slit your wrists. I probably wouldn't be concerned unless someone I knew was pretty much constantly depressed for say, two to four weeks. The things I would notice would be sad facial expressions or lack of affect, monotone voice, lethargy, lack of interest in exterior events, lack of interest or too much interest in eating, difficulty sleeping...or waking, not going to work....

--[male age 73]: *blue, sad, feeling hopeless, if you are depressed that's how you feel. You can't see the end of the tunnel, you don't know which way to go.* [is a person who is depressed sick?] *No, not necessarily. They could be, but people often are depressed I would think.*

--[male age 47]: depression...is one of the earliest forms that powerlessness takes, and I think it has definitely an emotional base in anger and fear.

--[male age 21]: I think it's where somebody has lost touch with what is actually around them. I think it's triggered by various things in their lives that cause them to get overly sad, and it's just, like a cat chasing its tail, it gets worse and worse if you don't treat it. And I think some people have a disposition to it, whether it be the way they were raised or the way they were born, I don't know. [how long in depression?] *That would have to be a judgement I made when I saw it, I can't give you a time like two weeks or six weeks, but there would come a time when I would say, 'boy, this is serious'--when I could no longer bring them out.*

--[female age 43]: You're usually out of depression after 10 months, it has a cycle. I mean, I know people who are always unhappy with their life, that's their life, that's just how they live, they think everybody's against them...that's [not an illnes, that's] an attitude.

--[female age 69]: [Have you ever heard of someone who is depressed for two years or more?] *I don't think so. ...this one who I said is diagnosed as manic-depressive, but she is functioning, she has her highs and lows, but she cooks, she keeps house, she cleans, she goes out, she does all kinds of things.* [Would you think of her as ill, mentally ill?] *I would think so.* [And this woman who is attending Yale, is she mentally ill?] *No, she's just depressed. The one who is going to Yale was well, then her husband got sick, he had cancer and it took him almost two years to die, but I think it's normal after a death that it can take you a few years to get over it, you don't snap out of these things. [But] to tell the truth, the woman who is manic-depressive is my sister and we had a hell of a rotten upbringing, she reacted one way and I reacted another; she's been like this for years,*

since I was a kid.

Anxiety. Some aspect of "anxiety" seemed familiar to all respondents, but they interpreted the condition widely differently. One theme is that being anxious is commonplace, an expression of stress in urban society. A second theme saw anxiousness/anxiety as a characterological condition--some people are always 'anxious,' or 'nervous' or 'hyper' or simply, energetic. In both cases, note, anxiousness is commonplace and in that sense normal, but in the first case it is environmentally caused and not pleasant to experience, whereas in the second it is in some sense built-in to the person, and is, in fact, desirable and--if not entirely comfortable--at least a good motivator.

The third theme was that 'anxious' and 'anxiety' do not mean the same thing, and cannot be used interchangeably. Some noted that one was an adjective and the other a noun; more commonly, people said that anxious meant a momentary condition in response to something specifiable, while anxiety was a state, even a steady state or condition, perhaps inescapable, and often in response to something that no-one can quite identify. When asked to link the terms to illness, a majority stated that 'anxious' had nothing to do with illness, while 'anxiety' could become so bad that an illness existed. Another tendency was to see 'anxiety' as a technical or specialists' term, and 'anxious' as the sort of thing everyone experiences in daily life.

[female age 26]: *I see this as me, as part of my character...this might be my psychological self. I see it as a necessary part of me because it motivates me, it keeps me...humble and keeps me in school. I guess I kind of glorify the word anxious because that's what people told me I was, like a person who wants to get moving, wants things to change. [But] anxiety, they're not necessarily anxious people, they're experiencing anxiety, they present it as being grouchy or being terribly impatient, being rude. Anxiety I see as a state; anxious I see as a descriptive term I would use for someone who is trying to get out of a bad situation or an uncomfortable one. You anxiously await your lover, a feeling of future and movement and progress, whereas, anxiety is a steady state.*

[male age 37]: *Every single word* [in his 'anxiety' card sort] *is me, everything. I'm impatient, I just got to do it, nervous about time, going to get it done now...this is my life. I work, I'm very hyper. You know, if I do work, I could charge by the hour, but I charge by the job because I can do the work in half the time of anybody else.* [Would you ever think a person who was anxious or nervous was in need of help?] *If you were a housewife or something, and you are angry, and you are waiting for your husband and you are anxious, impatient...then you got a problem, you should go into some counseling.*

[female age 39]--[You link anxiety with depressed, and anxious with stressed out--could you tell me what you perceive anxiety to be?] *Anxiety just comes from worrying about something. It's*

different from being anxious. I think the way you feel when you feel anxious versus what you feel when you have anxiety is different because when you're anxious you are tense, [but] you might not necessarily be tense when you feel anxiety, you might be more depressed. Anxious to me means being very tense...and tension to me is a reaction to stress.

[male, age 73]: ...it's wanting something to hurry and get over with...you are worried about a situation until that situation is over, you may have a tendency to get nervous or anxious, and there's always a situation there. [could anxiety ever be a sickness?]: *I would say that it could develop into a sickness, but I wouldn't say that it would start out as a sickness.*

--[female age 43]: *When you're excited your're anxious, but if this word had been anxiety, you would have had a totally different meaning for me than anxious. You know why?: because you don't hear of people who have anxious attacks, you hear about anxiety attacks. Anxious and tension will go together, but anxiety and tension will not. Anxiety attack is not anxious.*

Panic and Phobia. Respondents reported relatively little familiarity with these conditions; three women reported having experienced panic attacks and one woman stated that she suffered from claustrophobia, and several others told anecdotes of people they knew who had phobias. Despite lack of familiarity, respondents expressed opinions about these terms, mostly linking them with fear.

Anxiety and panic may not be greatly distinct for some people. For example, a majority of respondents who attempted a definition of panic, defined it in relation to anxiety, using the word "attack" for both.

The card sort--below--showed that, using cards, respondents did--or could--distinguish anxiety from panic, because panic was more often categorized with phobia, and with a series of other words grouped as "out of control," while anxiety was more commonly grouped separate from these. Concern about "control" is central to a popular model of value or virtue among white Americans (see, for example, Counihan 1992), and was expressed here by several respondents, though in none so cogently as in one woman who reported having experienced four of the test conditions, depression, anxiety, panic, and phobia. She linked the latter three under the rubric "out of control." A second woman also linked anxiety and panic with control issues, but argued that being "out of control" was actually rather fun, a way to rebel against social strictures.

Thus, though the concept of "out of control" arises from the thinking of a majority of respondents, its connotation is partly dependent on familiarity with the symptomatology, and partly dependent on personal expectational patterns. Those who are more familiar seem to experience a degree of adaptation that makes the conditions less frightening, while those who are less familiar tend to emphasize the "abnormality" or "scariness" of panic and phobia.

This issue of adaptation, and the associated connotational ambiguity of the words, may prove to matter to the design of survey questionnaires.

--[female age 39]: [This last group: "confused, unbalanced, scared for no reason, unstable"...what do we have here?] *They are people who have just gone over the edge.* [What edge have they gone over?] *The mental health edge. They're mentally unhealthy.* [They're mentally unhealthy. And the other people are not, they have not gone over the edge?] *They're depressed folks.*

--[female age 43]: I was getting panic attacks--all of a sudden you panic and you don't know why and it lasts for a couple of seconds and it goes away. It feels out of control, heart racing, palms sweating. It happens real fast. Some people have them and they go on and on, that's when they have to be hospitalized. A panic attack is actually when you feel...have you ever heard the expression "flight or fright"? It's actually a survival technique that we have as animals so that if we are under attack immediately adrenalin shoots up and then we run. I can have a panic attack sitting here talking to you and you wouldn't even know I had one, but my whole body will go out of whack for about two seconds. I would just catch my breath, take a deep breath, it goes away.

Let's say I was shopping and there were tons of people and I'm rushed and I get disoriented...if I got on the elevator, and it was packed with people and we got stuck, I would have a panic attack, there's no doubt about it. But it doesn't run my life. [If you avoid situations that is] abnormal because you can't live a normal life. [But] if they get by, I don't call that abnormal. She says she has agoraphobia and claustrophobia and is asked how phobia relates to panic attacks]: *It's like the panic attack is a reaction to the fear that I have in close surroundings. When I was a flight attendant I wasn't that way. A phobia is a fear of loss of control. As a flight attendant I was in control, I was the boss, I had the uniform on, I told everybody else what to do, and I was fine. But as a passenger if I'm on an airplane and ...we're circling I may get a couple of attacks on the plane. That's because I'm out of control. When you think about yourself, that's when you get out of control; if you're worrying about your children or somebody else, then you don't go crazy, your energies are directed toward helping someone else and you don't go out of control.*

--[female age 26]: A panic attack to me is when it just hits, there's no control, it just hits and I panic. Anxiety attack is because I've been lazy and I've let it build up, I kept putting things off. If I procrastinate I'm going to be prone to an anxiety attack the night before my paper is due. A panic attack might occur when I get too much information at once. I start breathing deeply, I hyperventilate. Panic attack would be more because of other people, because they drain me for stuff...like anxiety is my fault, and panic is like where people need me, it's too much, and I have no control. I begin to feel lightheaded, I whisper...I

can't really speak. I see myself as agent, I cause the anxiety attack; the panic attack is a reaction to, more out of control kind of. [asked about fears of everday things]: *...that's where I would use this nice little psychobabble, I would call it phobia. I guess I think it's temporary and people can overcome it. It's not an illness. I would suggest that person try to get in touch with his or her inner self.*

But if I romanticize it, it's really fun, but when I feel fearful it's really awful. I just associate fear with being out of control. Yet sometimes it's fun because you can meet some freaked out crazy people that are kind of fun to be with. [tells of a friend] *I thought she made things kind of eventful...she's been diagnosed as like bipolar, but I think that's bull. I think she's had a rough childhood and she has some issues and she's going through this stage and she needs to get in touch with her inner force. She is out of control but I don't think it's so negative. When the therapist tries to help her, I think she's [the therapist] cutting this life force. It seems to be more of a problem for other people than for her.*

[male age 75, defining by telling a story]: *My wife...years ago when we were first married, our first child, we were living in an apartment...there was a fire next door to us in the row house and all she did was shake all over. I had to grab her and shake her, I said, 'put your robe on', got the baby and bundled it up and went outside, before that she was just going around in circles, not doing anything.*

[female, age 26]: I think you feel different degrees of anxiety. It can be a precursor to a panic attack if it goes unchecked, but I think it's OK if you experience anxiety, I think you should allow yourself to experience the full range of emotion, but you need to recognize and appreciate the experience without letting it control you.

[female age 45]: *I used to have phobias, fear of water and my face and fear of closed spaces. Both have gone away with past life regression. I think it [was] an illness in the sense that it controlled certain aspects of my life, as it does with everyone.*

[female age 39, tells story of LA lawyer who fears flying, drives East to see his mother. "And is he mentally ill?"]: *No, I would say there is a little bit of a problem.*

Linkages Among the Five Test Mental Health Categories.

Although people were willing to more or less segregate the five test categories, in fact, their borders were not particularly rigid for the majority of respondents. It appears that two different models were at work, though further research would be needed to clarify this point. The first model linked depression and anxiety as two ends of an activation continuum, that is, with depression at the deactivated end, and anxiety at the activated end. People who expressed this model argued that the symptoms inherent to the conditions would probably not be all that

different, but would express themselves either in an activated or deactivated form. Some argued that the tendency to be an "active" or "quiet" person was probably in-born.

The second model segregated anxiety and depression, instead linking anxiety with panic and phobia. Again, a linear continuum seemed to be in play, but in this case, degrees of activation or the causes of activation were the focus of attention. On this continuum, anxiety would be toward the less activated end, with panic, and increasing overt lack of control, at the more activated end.

These distinctions are epistemologically interesting and might be important in a clinical situation, but may not be very significant to the design of survey questionnaires.

Card Sort to Find Terms that Associate, and User Names for Mental Conditions.

The card sort technique is a qualitative research technique that involves offering a deck of cards to respondents, each card carrying a term or phrase, and asking the respondent to sort the cards into groups according to concepts that belong together (refs). The card sort provides a mechanism for deepening the interview, enabling respondents to reveal ideas that they cannot readily speak about, and to open areas for comment that were not opened in interviewing. Card sort data can be analyzed statistically, but this was not judged helpful in this small sample.

In the present instance, 40 cards were offered. Respondents were asked to sort them into as many groups as desired, putting terms together that they thought fit together or that they thought would occur together in "real life." No further guidance was offered--the respondents were not prompted by using mental health designators or by suggesting that the groupings might represent mental illnesses or even refer to mental health issues.

The 40 terms in the card sort included (in the order presented): *tense, procrastinating, lazy, restless, down in the dumps, tired, unpleasant thoughts that won't stop, anxious, frustrated, feelings easily hurt, depressed, worried, unstable, trapped, impatient, stressed out, irritable, blue, breathless, despairing, confused, hopeless, sad, down-hearted, jumpy, sleepless, worn out, unbalanced, nervous, angry, scared for no reason, paranoid, disconnected, phobia, panic, anxiety, freaked out, fearful, out of control, grouchy, frantic, depression.*

Of the 17 respondents, two elderly men had difficulty understanding the directions; one of the two was dropped from the analysis. In addition, one middle-aged man stated that all the terms represented conditions of "disempowerment" and could not properly be further categorized. The first five respondents received less than the full deck of 40, since the deck was finalized partially as a result of their comments on the test deck. Thus there are complete sort results from ten individuals, plus partial results from an additional five individuals.

Eleven individuals did a second sort of the piles they

constructed that most closely corresponded with those under study, to distinguish milder from more severe symptoms or conditions. The rationale behind this second sort was to find which of the various terms most often provoked an image of a person "needing help." This is important to know, since use of overly "mild" terms in survey questions are more likely to provoke false positives ("everyone has had this symptom at some time") and use of overly "strong" terms in survey questions are more likely to provoke false negatives ("hey, that's sick!--I'm not sick!"). The concept of the person "needing help" as falling more or less midway between commonplace symptoms and symptoms of extreme abnormality was provided by the respondents themselves (above).

Respondents created from four to eight piles, with four and seven being modal numbers. Two pile concepts emerged from most respondents, one best categorized as "depression," and another best categorized as "out of control." The first concept contains terms that fit fairly closely with specialist concepts of depression. However, while specialists include anger and similar emotions as symptoms of depression, few respondents did, commonly sorting the anger-related words into a separate pile. The "out of control" pile contained the most extreme terms, and commonly included both panic and phobia, which specialists segregate and may not define as quite as extreme as do many lay respondents. The specialist category "anxiety" only occasionally emerged under that term in respondent card sorting, though the terms "anxious" and "anxiety" were sorted somewhat predictably with some other terms. About half the respondents created a grouping that they categorized as "physical" symptoms that, they felt, didn't fit with the other "emotional" symptoms.

It should be noted that respondents did not necessarily *call* their piles by specialist designators. For example, piles best categorized as referring to depression were given, by respondents, names such as depressed, unhappy, out of sorts, dissatisfied, unsatisfied, emotional downness, locked in, victim, and so forth. The categorization as "depressed" was determined based on the respondent's description of the pile or the person who would show this constellation of symptoms; and by inclusion of the test words "depressed" and "depression" in the sort grouping.

Three Excerpts from Actual Card Sorts

These excerpts give the flavor of the process of card sorting in providing insight into respondent thinking patterns. The numbers in the excerpts refer to the card identification numbers, and the words underlined are the card terms the person uses to define the concept. Words in regular type are the interviewer's questions.

The first excerpt is from a college student, age 21, who was the only respondent to divide the cards into three piles which he spontaneously labeled by specialist designators. Because I was surprised by this outcome, I asked him if he'd studied psychology, had psychotherapy, or had a friend or family member who'd had close contact with psychological specialists--he denied any special exposure, including reading, and could not explain his choice of words.

I've segmented these piles into, one is phobia, one is depression, and one is stress or anxiety, and they include symptoms and causes, and lazy I think is not a characteristic of any of them, I think it is a word that is used by people to describe other people unfairly...lazy implies that it is purposeful, and that you don't do things because you just don't want to, it's not because you don't have the ability or you can't go beyond this block that you have.... [Unbalanced] fits all of them, all of them have to do with unbalance. I mean if you have any of them, all of them have to do with unbalance. [It means] easily pushed into losing control. For example, someone is depressed and you tell them they need help, an unbalanced person would take that as an insult, and if someone were paranoid they would think you were pushing in on their space or something...so I think that one word applies to all three piles.

[Pile 1] Phobia is...it's more of a paranoid behavior in which everything around you is subject to scrutiny and you don't trust anything. I put in feelings which hurt very easily because you are not about to trust anyone, and you are very susceptible to them hurting your feelings. Scared for no reason, you know if you have a phobia it's an irrational fear, frantic, unstable, and freaked out, they go together, you are teetering on the edge of being unable to control yourself. Whatever the panic is, the point at which you lose total control, you are out of control which is another word.

[He is asked to sort from mildest to severest]*: 54, 52, 57, 13, 47, 36, 53, 10.* [The most severe is out of control and the mildest is feelings easily hurt. Can you find in the sequence where "needs help" begins?] *...probably between scared for no reason and panic. ...the last three, 52, 57, 54, are illnesses, out of control, frantic, and freaked out.*

[Pile 2]: 58, 11, 27, 25, 21, 7, 41, 24, 19, 5, 12, 23...they are symptoms of depression, depressed behavior, some of them are not very severe, while others are severe. Basically this is the one I'd consider mild depression, mild and normal, down in the dumps, blue, sad, down-hearted, depressed. [And the group where help was needed?] *confused, worried, hopeless, disconnected, unpleasant thoughts that won't stop, despairing...especially hopeless, disconnected, and unpleasant thoughts that won't stop--[that] the most, that implies some inability to control your own thoughts, and that is serious.*

[Pile 3]...the nouns are anxiety and stressed out. They mean the same thing. 34, 30, 4, 20, 18, 29, 16, 56, 35, 28, 8, 9, 1, 2, 6, 14 [nervous, worn out, restless, breathless, irritable, sleepless, impatient, grouchy, angry, jumpy, anxious, frustrated, tense, procrastinating, tired, trapped]--these are things which I think can be normal reactions to a stressful situation: procrastinating, tense, frustrated, anxious, jumpy, angry, grouchy, impatient, and worn out. These are things where you are stressed out to the point where you need help: trapped, tired, sleepless, irritable, breathless, restless, nervous. Breathless and sleepless are particularly severe. [What's this one about trapped?] *That's just a feeling of a person, it's kind of a paranoid reaction to anxiety, I think.*

The second excerpt is from a man, age 39, who is a professional acupuncturist (MAc), and also has an MA degree in experimental psychology. He made seven piles, labeling them 'inability to move,' 'activated unhappy,' 'deactivated unhappy', 'activated tense', 'deactivated weary', and 'no anchor.' He says, *My own sort of bias has to do with labelling. I prefer not to do it.* He queries the reality of the DSM categories, wanting to stay in a descriptive mode.

[Piles 2 & 3] actually go together in my mind, this is the activation side of things where you are physically and emotionally aroused, negative way arousal, you know, being sort of tense and anxious and restless and worried and stressed out, and the other side of that are these numbers, the deactivated side of arousal, the depressed side of it, scared, deluded, hopeless, sad,...some sense of emptiness and dissatisfaction in both of these. One is tense about it and the other is 'nothing-I-can-do-about-it-anyway' kind of feeling.

[Pile 4] fits in some ways with [Pile 2] this activation type because it has to do with movement and activity and body feeling, but it has more to do with anger, a feeling of struggling against great odds. And [Pile 5] is generally more like [Pile 3] , it's not an activation, it more about tired, not having enough sleep, not having enough energy and being exhausted. [Pile 5] speaks to me more of physical exhaustion and [Pile 3] of emotional exhaustion.

[Pile 6], numbers 13, 31, 36, 14, 10 [unstable, unbalanced, scared for no reason, trapped, feelings easily hurt]--this has sort of a direction of being, well, the top one says unstable so that's the direction, emotional or spiritual imbalance. I imagine it would be sort of an aroused, tense state in the body, and in terms of the emotional, spiritual side of a person, there is no anger, no clue as to what to do about it....

The third excerpt is from a woman of 69, who is a mother (grandmother) and widowed housewife who lives in an apartment complex mostly inhabited by elderly people. She created six groups which she named "normal--can't classify," "anxiety," "depression," "minor," "major/panic," and "major/see someone." She says:

I don't know where to put some of them. Freaked out, I'm not sure. I think of breathless as being in love; what's that got to do with mental health? Sleepless you can just put wherever you want.

[Pile 2]: Grouchy, angry, anxiety, jumpy--these are things that upset you, how you react to things that upset you.

[Pile 3]: Sad, downhearted, confused, depression, tense, worried, frustrated, depressed, trapped, down in the dumps, blue--they are all the same to me, about having something you can't have...the normal anxieties of life, that everyone goes through at times. I guess having been through a lot, I guess everybody my age would say the same thing, these words are really so insignificant, we have all been sad, we have all been blue, we've all been tense, confused, blue, sad, downhearted...is depression different from depressed? Now if you mean depression as deep down depression then you need help, but if you mean it as a depression that goes up and down as the days go on, then it's not that important. ...

[Pile 4]:...stressed out, worn out, hopeless, confused, restless, impatient--these are minor things...you relax for a little bit you get over it. You get over restless, impatient, easier, I think; impatient--we are all impatient, I was born impatient! Hopeless, that might be a little stronger than the others but not much. People are stressed out a lot, but what the hell does it basically mean, something that was just picked up for this generation.

[Pile 5]: ...scared for no reason, unpleasant thoughts that won't stop, fearful, paraniod, frantic, panic, feelings easily hurt--those are bigger items. Something is wrong. These panic attacks people have, I don't know much about it, but they sound awful. I've read about people...that have a panic attack everytime they go outside, I don't know but it sounds terrible, not to be able to do things, to be controled by fear....

[Pile 6]: unbalanced, phobia, despairing, unstable and out of control--they better go see somebody quick. [asked to sort the cards from mildest to severest symptoms she said that "paranoid" was a symptom that demanded help, and] *...well, oh, panic, before you get to that you better go...I wouldn't go if I was just nervous. I don't know about disconnected, frantic...I often get frantic and fearful...I also think of it as degrees, 'how fearful?' I'm fearful of falling but it doesn't stop me from moving. I often get frantic when I can't find one of the kids, where they should be, the "mother syndrome"....*

General Comments on the Words Offered.

--several respondents objected to the term *lazy*, stating it was characterological and pejorative and didn't belong in a list of mental health terms. *Procrastinating* less often received the same complaint.

--several respondents had difficulty categorizing terms they felt were "physical" or referred to physical health, such as *tired, worn out, tense, restless, breathless, sleepless.*

--slangy terms like *stressed out* and *freaked out* were accepted by all ages from 21 - 80. Two people stated that *blue* was confusing, one because she didn't think people were colored that way, and one (age 36) because he felt the term was old-fashioned.

--some terms just seemed to puzzle people: *unpleasant thoughts that won't stop, confused, feelings easily hurt, trapped.* These were terms that tended to be categorized in many different ways, and to be graded markedly differently by different respondents. For example, one respondent stated that "Anyone who is at all together would feel trapped in the urban setting...so it's just an everyday thing;" while others stated (paraphrase) that anyone who felt trapped "must be in terrible condition to hate life so much."

--both adjective and noun forms were given for key terms, since respondents in early interviews stated that adjectives represented "milder" or "normal" expressions of the conditions designated by the nouns. Thus *anxious/anxiety; depressed/depression.*

--in addition, the key terms/nouns *phobia and panic* were added to the final card sort, but a majority of respondents categorized these under an apparently more favored term, *out of control.*

Depression. The concept of depression seemed to be more familiar to respondents than the other test categories. Fifteen respondents (that is, all who actually did successful card sorts) spontaneously created one or two piles that could be categorized as "depression."

--words typical of the state (13-15 respondents included these terms in their sort): *down in the dumps, depressed, blue, sad, despairing, down-hearted, depression.*

--words often associated with the state (7-10 respondents included these terms in their sort): *tired, worried, unpleasant thoughts that won't stop, hopeless, worn out.*

--words not or rarely associated with the state (zero to two respondents included these terms in their sort): *unstable, breathless, paranoid, out of control; lazy, restless, anxious, impatient, jumpy, nervous, angry, scared for no reason, phobia, panic, freaked out.*

Nine respondents sorted their piles into continua from mildest to most severe symptom, and told the interviewer where "needs help" began. The most severe symptoms were thought to require immediate intervention including hospitalization; the mildest symptoms were thought to be the experiences of daily life, too commonplace to worry about.

--commonplace/normal symptoms: *down in the dumps, tired, worried, blue, sad, down-hearted.*

--severe terms: *hopeless, depression*

--mid-way or "needs help" terms: *despairing, confused*.*

--ambiguous terms: terms that people split on, some viewing them as commonplace, some as more serious, and some as severe: *unpleasant thoughts that won't stop, depressed, trapped*.*

[*confused and trapped are terms that a minority of repondents associated with depression, but that minority included those who did the secondary card sort, hence their appearance in this list but not in the preceding list.]

Note that the term *depression* carries a connotation of severity for the respondents in this research, and the term *depressed* is distinctly ambiguous, being used widely differently by different respondents. Many respondents were aware of this situation.

Anxiety. The concept of anxiety was ambiguous for many respondents. Thirteen respondents spontaneously created categories that could be classified as anxiety, giving them such names as anxiety attack, activated-unhappy, mild-normal, anxious, up, tense, dreamer, etc. As noted, the words *anxious* and *anxiety* carried different connotations for respondents. Thus, while many felt that anxiety was a developed state that was serious and probably required help, anxious was often described as not only commonplace but positive in connotation, a condition of readiness and aliveness that people recognized as healthy. This healthy alertness was commonly contrasted to *worried*, which was thought to have a darker tone, a degree of helplessness or compunction that anxious lacked. Based on the card sorts it appears that the older term *nervous* may

mesh fairly well with the newer specialist term anxiety: respondents categorize nervous with anxious, and treat anxiety as representing what was formerly categorized as "nervous breakdown"--that is, while it is fine to be energized as in "nervous," activation can sometimes proceed too far, yielding a condition that requires help from a specialist.

Another sign that the specialist category of anxiety may not mesh well with laypeople's usage is that several respondents, during card sorts, conflated anxiety terms with either depression terms (N = 3 males) or with panic/phobia terms (N = 1 female). This situation was also observed during the open interviewing, as summarized above.

On the basis of the sort:

--terms typical of the state (9-11 respondents included these in their sort) *anxious, jumpy, nervous, anxiety.*

--terms often associated with the state (6-8 respondents included these in their sort) *restless, worried, breathless.*

--terms never or rarely associated with the state (0-1 respondents included the term in their sort): *lazy, down in the dumps, depressed, blue, despairing, blue, downhearted, unbalanced, disconnected, depression; procrastinating, tired, unpleasant thoughts that won't stop, unstable, hopeless, worn out, freaked out, out of control.*

Seven respondents made secondary sorts that were suitable for examining the connotations of severity of the terms.

--commonplace/normal terms included (3-7 respondents stated these were commonplace or normal): *anxious, jumpy; tense, restless, angry; worried, impatient.*

--severe terms: none.

--mid-way terms signifying that the person "needs help": *anxiety.*

--ambiguous terms: *nervous* received equal numbers of categorizations as "normal" and as "needs help."

Out of Control/Panic Attack/Phobia. Only 3 respondents spontaneously created categories labeled "panic", or "panic attack", and one conflated panic and depression to create a category he called "panic/depression." Only one person created a category labeled "phobia." However, 10 created categories that they labeled "out of control" or by similar designators such as "over the edge," "no anchor," and "confusion." One woman categorized panic, phobia, and other terms that commonly were classified in the "out of control" group as "psychobabble" signifying her lack of belief in their reality. However, the majority of respondents stated that this category contained symptoms that were closest to what they would be willing to designate "mental illness."

On the basis of the sorts:

terms typical of the state include (9-11 respondents included the term in their sort): *unstable, unbalanced, scared for no reason, freaked out, out of control*

terms often associated with the state (6-8 respondents

included the term in their sort): *fearful, disconnected, phobia, panic, paranoid,frantic*

terms never or <u>rarely associated</u> with the state include (0-1 respondents included the term in their sort): *procrastinating, lazy, down in the dumps, tired, frustrated, depressed, irritable, sad, down-hearted, worn out, angry, anxiety, depression; tense, restless, anxious, worried, impatient, blue, despairing, hopeless, jumpy, sleepless, grouchy.*

Only four people were able to do a secondary sort of their grouping of "out of control." Five others simply stated that anybody that has these symptoms "needs a therapist," because they are "crazy, off the wall," "spinning inside" or "without an anchor." Of the four who attempted to sort from milder to more severe, only "fearful" was considered more or less normal by more than one person. This was the only category in which respondents spontaneously claimed that "sickness" or "mental illness" was present.

This category also contains many words with uncertain or ambiguous meaning. For example, respondents rarely spontaneously used the term "phobia," though a majority claimed to understand it when offered the word. "Paranoid" is used both jestingly, and to designate a feared behavior that many considered extreme and "a sickness." Both "unstable" and "unbalanced" also proved to be ambiguous, for to some people these are everyday phenomena, while to others they are symptoms of extreme abnormality or derangement. Even "panic" has mixed connotations, for those who had experienced "panic attacks" readily admitted to them, described them, and stated that they were bothersome but not a big deal; while those who had not experienced panic attacks viewed "panic" as a severe and incapacitating condition. Quotations illustrating these points were given above. In sum, the meaning of the words categorized under "out of control" is even more affected by the filter of personal experience than are the terms categorized as "anxiety" and as "depression."

<u>Word Pairs</u>. Most of the respondents were asked to say if several word pairs were synonyms ("mean the same thing") or not. The results:

depressed/depression: people mostly categorized these as related, but tended to argue that depressed was milder on a continuum than depression.

anxious/anxiety: same as above

anxious/nervous: about half saw these as synonymous

anxious/tense: a majority stated that they weren't synonyms because tense refers to a state of muscular readiness, while anxious refers to something internal/psychic/emotional. However, they were seen as linked, in that a person who is anxious would probably also be tense; tense people were not seen, however, as necessarily anxious.

anxious/worried: some saw these as very close in meaning though none felt they were synonyms. What tended to happen was that one of the two was viewed as more normative and everyday, with the other having a stronger or darker tone of negativity. However, the sample split as to which had the more positive, and which the

more negative connotation.

Terminology to Refer to Mental Conditions in Survey Questions.

During the meeting of the research team in July 1992 it became clear that researchers were using different terminology to refer to the conditions they sought information on, and that existing survey questions also used different terminology. Since my early interviews had indicated a concern among respondents that "not too strong language" be used, I decided to add a card sort to my interview, during which respondents were asked to sort the tonality (connotative weight) of ten words from "mildest" to "strongest," and indicate any which they felt to be neutral in tone.

The ten words were (in the order presented) *condition, challenge, sickness, problem, concern, illness, trouble, disease, worry, and issue.* Of these, some words refer to states of the body/mind (eg., disease, illness, condition), while others are more processual, or contain a sense of evolution and change (challenge, issue, concern). Some contain a built-in connotation of negativity (disease, illness, trouble, worry), while others leave the interpretation open to the user (issue, condition). The term "challenge" carries a mild connotation of positivity, that is, of taking something on, something one thinks one can control or surmount.

Nine of the seventeen respondents did this card sort (some interviews preceded the establishment of the card sort; some respondents were judged not able to do this card sort). In sum:

--the most neutral terms were felt to be *condition, concern, and issue.*

--moderately popular, not extreme, words included *challenge, worry, trouble, and issue.* The terms *issue* and *challenge* were better liked by younger respondents, and the terms *worry* and *trouble* were more accepted by older respondents.

--*problem* was felt to be connotatively loaded by all respondents, but not nearly so strong as

--*illness, sickness, and disease* which were considered unacceptably strong and frightening by all respondents.

TABLE 1. SEX AND AGE DEPTH-INTERVIEW SAMPLE CHARACTERISTICS

Age	Female	Male
18 - 30	3	1
31 - 60	4	5
>60	1	3
Total	8	9

TABLE 2. DEMOGRAPHIC CHARACTERISTICS OF DEPTH INTERVIEW SAMPLE POPULATION

Sex	Age	Education	Occupation	Religion	Home	Self-report of Health
F	26	BA	Grad Stud	"none"	city	better than average
F	26	BA	Bank Trainer	"none"	city	much better than average
F	26	MA	Cashier	"none"	city	worse than average
F	39	LLD	Adminis-trator	UU	suburb	average
F	43	BA	Homemaker	Jewish	suburb	better than average
F	45	HS+	Secretary	Buddhist	suburb	much better/worse
F	69	HS+	Retired Homemaker	Jewish	city	worse than average
M	21	HS+	College Student	"none"	suburb	better than average
M	36	BA	Lawn Care	Protestant	suburb	much better than average
M	37	MAc	Acupunc-turist	"none"	suburb	better than average
M	47	BA+	Systems Analyst	"believer"	suburb	much better than average
M	48	LLD	Lawyer	Buddhist	suburb	much better/worse
M	60	HS+	Retired Machinist	Catholic	rural	better than average
M	73	HS+	Retired Officework	Protestant	suburb	average
M	75	HS+	Retired Treasurer	Catholic	suburb	average
M	80	HS+	Retired Carpenter	Protestant	suburb	average

Key to Table 2

Education: HS+: some courses beyond Highschool
BA+: some graduate courses

Religious Affiliation:
UU: Unitarian-Universalist
"none", "believer": as stated by respondent; all were raised as some denomination of Christian.

Self-Report of Health:
Respondents answered the question: *Compared to most people your age and sex, how would you say your health is?* They were offered a five-point scale. The couple with an * stated that their spiritual health was way above average, but their physical health was much worse than average.

TABLE 3: HEALTH CARE SYSTEM USE REPORTED BY DEPTH INTERVIEW RESPONDENTS

Health Care System	Women	Men
Acupuncture	2	1
Chiropractic	3	3
Herbal Therapy	3	1
Homeopathy	4	0
Massage/Manipulation Therapy	4	3
Osteopathy	1	0
Psychotherapy	4	2
"Regular" medicine with an MD	8	9
Surgery	6	5
Twelve-step Program	3	1
Other (write in)		
Gestalt Therapy	0	1
Podiatry	1	0
Re-evaluation Counseling	0	1
Shamanic Healing	1	1
Shiatsu	1	0

REPORT 3: RESPONDENT COMMENTARIES ON CB-PROVIDED SURVEY QUESTIONNAIRE MOCK-UP.

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date: October 1992

Introduction

In this second research step, fifteen white middle-class American respondents, stratified as in the first research step, were asked to critique a mock-up questionnaire provided by the Census Bureau (Appendix 2). This questionnaire consisted of 45 statements phrased in response to the same question, *During the last 30 days, about how often did....* The lead question was presented only on page 1; the questionnaire covered four pages. Respondents were offered four check-off answer choices for each question, in columns identified at the top of each page, namely, "most of the time," "some of the time," "a little of the time," and "none of the time." The 45 phrases were grouped under 16 headings such as "depressed mood," "worthless guilt," "vigilance," "eating," "motor retardation," and "death." The last two questions were labeled "positive affect" and represented a departure from the previous 43, all of which were phrased in the direction of problems and pathologies.

Questions were asked in an open-ended format (Appendix 3) to elicit opinion on content, format, and tonality of the questionnaire. Interviews were tape-recorded and lasted from ten to 90 minutes.

Results

Sample. The sample consisted of 15 white middle-class urbanized Americans, all from the Washington-Baltimore Metropolitan area. Respondents were interviewed in their homes, in malls, shops, public eating spaces, and a theater. The sample was stratified to include 6 younger, 6 middle-aged, and 4 older responents, and equal numbers of females and males, though this stratification was not perfectly achieved (Table 1). Additionally, respondents were sought who were verbal, that is, willing and easily able to express their opinions. Another goal was a mix of educational attainment and occupation. Since the sampling technique was by convenience, and respondents were often not known before the interview began, not all these goals were fully met. Specifically, this is an unusually educated respondent sample, with even those self-identifying in non-professional occupations often reporting advanced education (Table 2). As was the case with the first research sample (see Report 2, attached), this population sample reported use of a wide variety of health care modalities, well beyond biomedicine (Table 3).

Of the fifteen respondents, two had difficulty critiquing the questionnaire. One elderly male apparently could not understand the concept of giving his opinion <u>about</u> the questionnaire, and simply reiterated that he was healthy, very healthy. Another older male saw the undertaking as politically loaded and was incensed by it; he found himself unable to do more than a superficial critique

of the questionnaire itself.

Orientation of the Respondents. Respondents were told that the questionnaire was for the Census Bureau, that it was unfinished, and that their opinion about it was sought. They were told that it was not intended to be used to assess individual people, as in a doctor's office, but would form part of a larger questionnaire intended to survey the American populace. They were told they could express positive as well as negative opinions, and that the interviewer had not herself written the questionnaire.

Perceived Content of the Questionnaire. When asked what they thought the questionnaire was about, a majority stated that it was about feelings or moods, especially negative ones or "problems." Five used relatively neutral language (*'health issues,' 'responses to life experiences,' [about] 'living, my interior, me', 'quality of life', 'what a person is like and feels, thoughts of the future'*). The remainder reported a sense that it was about negativity. Some used language that sounds like specialist language ('depression' was most popular), but more used the popular diagnostic category "stress," or simply phrased themselves in commonplace feeling language: *"It's about morbid things, people in pretty deep trouble...;" "...heavy degrees of bad things."*

Several respondents stated that they weren't quite sure what the questionnaire was about or what respondents expected to get out of it. They would hazard a guess--as above--but sensed they were missing something. One man of 19 looked it over and said, in a puzzled tone, "It's strange! It goes from depressed to being in a car!" A probe question elicited the fact that he read "Motor Agitation" as about what happens to you when you're in a car, and he knows "most people" are fidgity and restless in a car.

Many respondents suspected ulterior motives in the questionnaire. For some, these were positive--someone was "trying to help." More often, the underlying motives were thought to be less benign. Respondents suspected specialists of trying to label and objectify them--hence the frequent complaints about pathologizing language and lack of context for answering the questions (see under Format). One female respondent saw in the questionnaire a mechanism for identifying public perceptions of the normal so that these could be excluded from insurance coverage; she perceived the questionnaire as a governmental cost-control measure. Two male respondents thought it was a covert way of trying to find if teenagers or others were taking drugs, and one elderly male thought it was aimed at senior citzens because it "emphasized" death and dying, and seemed to "*follow the lifespan from depression to death.*" One older male was deeply offended by the idea of national health surveys, calling them "boondoggles," and questionnaires "invasions of privacy." A young man also queried the undertaking, stating that it is not relevant to count symptom frequencies, and that the work is in any case redundant since academic psychologists do better (i.e., face-to-face) surveys all the time.

Perceived Tonality of the Questionnaire. Perceptions of

tonality of the questionnaire were revealed in criticisms, and in response to a question about whether their own mood had been altered by reading the questionnaire.

Approximately half the respondents felt the questionnaire was acceptable in tone, and the other half felt it was unacceptably negative in tone. Most of the time (not always) those who found it acceptable also stated that their own mood did not change as they read through the questionnaire, while those who found it unacceptable stated that their own mood changed for the worse. Those who were accepting tended to have shorter interview times, use fewer words, and respond with generally lower affect; the opposite was true of those who objected to the questionnaire's tone. Several of those who leveled strong criticism described themselves as highly responsive or sensitive people; this group tended to use rich metaphorical language.

a) Those who felt it was acceptable in tone tended also to say it was clear, easy to understand, and unambiguous. In addition, they argued that it was useful or interesting to be asked these things, eg., [male age 20] *[It's] a lot of questions people should ask themselves and answer honestly.* This group had, on the whole, less difficulty imagining themselves filling out this form. They seemed glad that the form provided "guideposts" to let them know what the researchers wanted to know, that is, they didn't mind that their answers were guided and they were less likely to query the reality of specialist categories.

b) The other half of the respondents disliked the tone of the questionnaire, labeling it negative and pathology-driven, and stating that they felt resentment about being forced into specialist categories, eg., [male age 50] *It's terrible! It makes me feel bad! I feel like I'm being shoved into a corner! I feel <u>all</u> of these things "most" of the time, <u>and</u> I'm also very happy, probably the happiest I've ever been! All of this is always present. It's like the water of happiness flowing all the time around the islands of unhappiness...after reading this, no-one will feel happy!*

These respondents often stated that reading the questions made them wonder if something was wrong with them. They argued that "most" people would not want to discuss such things, would not want to face such things, hence would not be truthful in answering:
[female age 66] *It's all such negative stuff that ordinarily--the average person--they don't want to hear the negative side and don't want to tell you. They're going to fudge it.*
[female age 60] *How honest do I want to be? It's reassuring to see familiar things there, it tells me I'm not alone. But my mood drops, I feel angry, resentful, defensive--this could set up a barrier to giving totally.*
[male age 22] *[It's] all real broad and general, you won't get a lot of solid information. People wouldn't blatently lie, but wouldn't know how to answer. Because <u>everybody</u> is unhappy sometimes, has these sorts of problems...eating, sleeping...I'm tempted to be outrageous and "ruin" the questionnaire* [by making himself look severely pathological].

Some of those who found the questionnaire "a downer" or "depressing," were angered by this, said they wanted more

positivity, more chance to express themselves "as they really are;" one man, however, stated that while depressing, the questionnaire was not "threatening." The distinction is apposite: the languaging of most of the reactive readers suggests they did indeed feel threatened by the questionnaire.

Significantly, both accepting and critical groups made similar suggestions about how to improve the tonality of the questionnaire. That is, acceptors were as likely to *see the potential for negative response* as rejectors, and agreed (all unknowingly) with the strong critics in stating that the negative tonality should be modified.

These suggestions included the following:

--from the largest group: Don't start the questionnaire with questions labeled "depressed mood." Start with something more neutral like questions about "the physical body," or eating and sleeping.

--a majority: reword the questions so they are less extreme, and/or modify or delete the section headings. Remove specialist and "frightening" language. (For concrete examples, see under Format, below.)

--build in some sort of reward structure.

--make the page more attractive with some visuals. This form is too left-brained, too rhythmic, boring (one respondent); too long (one respondent)

--let people know why they should fill this out--link it to some important cause (one respondent)

--be sure it comes with return postage (one respondent)

--let people talk about their fulfillment, satisfaction (a very frequent suggestion).

--be sure to provide a context for response--it's a different thing to be depressed because your husband died, because the world is such a mess, and because you're sick...but this questionnaire mixes [conflates] causes, confusing normal with abnormal, making respondents fear they will be judged "abnormal" when their response is "normal" (a very frequent [paraphrased] concern and suggestion).

Comments on Format of the Questionnaire. Questions were asked about the way in which the questions were presented on the page, phrased, or sequenced. These questions about format provoked the most specific responses and suggestions.

a) Heading Question Page 1 of the questionnaire is headed by a partial question in large type which is intended to be read as the first half of all the questions that appear as phrases listed down the left side of four pages. Only one respondent stated that having the first half appear only on page 1 was a problem. Four respondents stated that they had, or thought others would, skip or not notice the top of the page, and would try to answer the questions without having read it. The remainder of the respondents had no difficulty linking the top half-question to the subsequent phrases.

Two people objected to the phrasing of the question--see under Grammar, below.

b) Thirty Day Recall Period The heading question asked

respondents to consider their behavior over the previous 30 days. A majority of people were satisfied with this time period, though what they thought 30 days might represent differed considerably. Thus one respondent explained that 30 days is "the present" not the past, while others said that "really" they could only remember back one week but they figured people would just project back from there. One person asked for a one-week period, one for a two-week period, and four suggested that a longer period, 2, 6 or 12 months would be more appropriate. One respondent stated that while she "notices," "most people" are vague about time and symptoms and the 30 day period was fairly meaningless in a quantitative sense though acceptable in a qualitative sense.

Based on efforts to specify time as revealed in the answers to questions about the column headings, it appears that about half the respondents in fact thought in terms of one week, and then multiplied to achieve the 30 day period--they "projected back." I interpret this from responses to "What would "most/some/little" mean to you in a 30 day period?" --receiving answers [to "most"] such as *6 to 7 days a week; most of a week; 5-6 days out of seven.* Other respondents spoke in terms of percentages, days, or number of weeks out of a month. It is unclear which is most cogent for more people, days, or weeks.

c) Response Categories Each page reiterated a set of four response categories at the top of the page, consisting of "most of the time," "some of the time," "a little of the time," and "none of the time."

A majority of respondents stated that they were satisfied with these response categories. Two people congratulated the questionnaire designers on having left out "all of the time" as too absolute. Two people requested that the categories be quantified into "days", and one asked that a middle category be added. Two respondents said they'd prefer "Yes/No" choices, because it was "easier," but both admitted that this might not produce detailed enough responses. However, these and at least two others felt the response categories were pretty vague anyway, and they didn't think the questionnaire designers were after answers comparable between respondents. Two respondents stated that they thought the questionnaire designers were purposefully phrasing response categories in subjective form, knowing that "people" do not think in quantitative terms about time. On the other hand, more than half the respondents quantified the qualitative labels when asked if they could do so.

This quantification shows that the words "most," "some," and "little" mean very different things to different respondents, and are, in fact, effectively qualitative whatever the questionnaire designers actually intended. Thus, in 30 days:

"most" range: 15 to 30 days
"some" range: 4 to 24 days
"little" range: 1 to 24 days

The last category "none of the time" was read as "never" by all respondents. However, they queried it in other ways. One female respondent, concerned with "skew" in the questionnaire, commented, *There are three ways to say yes, and only one way to say no.* Some people suggested it didn't really need to be there

because there was "only one question" in which it would be used, namely, the one about having thoughts of killing oneself. [This question was uniformly seen as the strongest and most abnormal on the questionnaire; see below.] Others noted that a healthy person would probably use the "none" column for most answers; reversing the pattern for the last two questions about "positive affect."

Several noted that they wondered how the specialists were going to interpret the answers, that the whole thing seemed vague, lacking the means for distinguishing normal from abnormal, and focusing on the abnormal (see Schaffer 1991 for a specialist discussion of this issue). One respondent thought she understood: [female age 66]: *It's a problem document. It's to make me reflect on myself and my problems, coming out with more problem areas than I'd thought about. If I answered "little" or "none" [then] it's about quality of life and good condition. Turn it upside down* [from what the questionnaire designers arranged] *and you get good quality of life. "Most", "some" is poor quality of life. [This way] you get at the mixture of cause.*

This interesting mix of interpretation revealed by responses to the "none" category suggests that though all the respondents thought they could, in a mechanical sense at least, complete this questionnaire and it would "make sense," in fact, many misinterpreted the use of the columns, and might have had difficulty had they actually been called upon to answer.

Respondents were asked how they'd mark their pages if they experienced a symptom a part of each day, but not all of every day. A majority stated that they'd use the category "some" to deal with this contingency. However, three made special distinctions. A woman of 66 stated that what mattered was not whether the symptom was present or not, or how often, but *how much it affected what she could do*. Thus if it limited her activities a lot, she would label it "most" even if it didn't occur for long or very often, but if it didn't much affect her activities, she'd label it "little" even if it was present frequently. A second respondent, age 60, stated that the category "some" would mean to her that a serious symptom occurred once or twice a week, or that a less serious symptom occurred parts of everyday or skipped days, or that a very debilitating symptom occured only 3 days in the whole month but colored her experience of the whole month. A young male also stated that if one were "blue" for even two days it might seem like a whole month.

d) <u>Group Headings</u> Sixteen group headings separated the 45 questions into groups of topics the questionnaire designers presumably see as linked. These group headings provoked the greatest amount of discussion of any aspect of the questionnaire.

A minority were satisfied with them as they are. A majority suggested they be modified or deleted. One respondent stated that she had not consciously noticed them as she read through the form.

Criticisms fell into two broad categories. Either the words were seen to be leading, intrusive, psychologizing or pathologizing, or "frightening," or they were seen to be misleading, that is, that the meaning of the heading wasn't reflected in the choice of questions below.

In sum, the majority of respondents can be interpreted as

classifying the group headings thusly:

--neutral words: eating, sleep

--somewhat negative words: lack of interest, fatigue, concentration, worry, anxiety

--very negative/frightening/pathologizing words: depressed mood, worthless guilt

--hoity-toity words: positive affect

--puzzling words: vigilance, motor agitation, motor retardation, motor tension, hypersensitivity

--special case word: death

Taking these one by one:

--No-one was offended or upset by the words 'eating' and 'sleep'; however, several noted that if one had the '-ing' ending the other should as well, to be parallel in structure. Many respondents thought these words should begin the questionnaire, replacing 'depressed mood.'

--In the second set, people expressed hesitation or discomfort with these words, yet were not overly troubled by them. They seemed to be read as familiar, normal though not necessarily comfortable.

--In the third set people reported that these were measures of "things wrong" and a large proportion complained that these were "downers" , "value-laden," and/or words that forced them in the direction of specialist notions of pathology. A number of respondents suggested that these words could be "rescued" by deleting the adjectives, that is, by removing "worthless" and "depressed" they would be converted to familiar descriptors more like those just above.

--The term "positive affect" was unknown to some, stated to be misspelled by others (it should be "effect" they said), way over the edge as an example of specialist jargonism for another group, and acceptable to a minority. The word "hoity-toity" was used by one respondent, though others used similarly denigratory language about this heading, eg., "affected". Respondents recommended using a more commonplace term like "attitude" or "outlook"; a large minority recommended combining the concept with mood, and putting all the "depressed mood" and "positive affect" questions together under this single heading.

--The group I've labeled "puzzling" was confusing to a majority of people, even if they claimed to know what they meant. These are, fundamentally, specialist jargon words, but since they resemble common speech, people thought they understood them. Asked what "motor" meant in this context, all stated that it had to do with movement and the body; most said it <u>didn't</u> have to do with thinking--*The brain isn't a motor* [male age 22]--though one man [age 39] did link muscle movement with the brain : *The brain is one big synapse.* Confusion arose partly because people expected muscle/movement questions and didn't get them under motor agitation and motor retardation; partly because for many people "retardation" refers to mental retardation and they didn't think the questionnaire or the associated questions dealt with that subject; partly because these categories were distant from, yet (in respondents' minds) the "same as," the category called "motor tension." Again, people recommended dropping the adjectives,

and/or, combining all the "motor" questions under one heading, such as "tension," or "muscles." The young man [19] who confused "motor" with cars noticed his error and laughed, saying he was "stuck on cars" and had had some bad luck with them; at the same time he argued that it is natural for people to be fidgity or unable to sit still in a car.

The word "hypersensitivity" was commented on by most readers. They thought it was a good idea to have some "body" questions on the questionnaire, because they at least sounded familiar, but they didn't see what relationship these had to "hypersensitivity." In defining this word, respondents said it meant "extra sensitive"--that sensitivity was a good thing to have, but it wasn't about the body...it was a characterological thing. One person thought hypersensitivity referred to allergies. One person said he thought it was about high blood pressure, then corrected himself, saying, *"That's hypertension."*

Vigilance got varied responses, from puzzlement in those who didn't know the word, to confusion because the person thought it was a psychiatric term referring to symptoms of paranoia, to respondents who thought it was good thing to be watchful and alert and found the questions associated with the term not really connected, that is, too pathological in import. One person suggested folding Vigilance in with Fatigue or Tension.

--The grouping labeled "death" provoked responses from all respondents, but the responses varied widely. Some felt that even having the word on the page was too frightening, while others thought it was good because it was realistic. More comments were directed at the two questions within the category. A majority considered the phrase "you have thoughts of death or dying" as trivial and misplaced because it signifies health and normality--how can anyone not think of death, they argued, given the newspapers, the TV, knowing those who are dying...? Since most thought death was normal, and thoughts of death equally normal, having this phrase on a page in a questionnaire that seemed heavily loaded toward the pathological made them uncomfortable: this was one of several questions very likely to provoke resistance in the respondants, one that made them think the questionnaire makers or psychologists/doctors were trying to make them appear abnormal when in fact they were normal.

Equally strong and dismissive reactions greeted the second question in this sequence, "You have thoughts of killing yourself." Most respondents either rejected this one out of hand, or, complained that the two questions under death were not in balance, that they went from normalcy to extreme abnormality without passing through a middle-ground. For some, death was an aspect of loss, and the greater, commoner, category was here ignored. For example: [female age 48]: *[Here] death and dying escalate to killing yourself with nothing in between! There are losses, lesser than killing yourself, divorce, the small deaths, moving away--put that in there somewhere. This doesn't tell you anything about losses.*

Several respondents also stated that some of the headings were ambiguous. In noting this, most went on to distinguish common usage from technical usage, and note that in common usage these words were non-pathological, so they were concerned that

interpreters of the questionniare would find pathology where the respondents didn't. For example:
[female age 48]: *What's normal? We deal so much [in this questionnaire] with what's pathological and don't get around to what's normal. Concentration--could be lot of people with trouble concentrating, how can you determine a different line separating pathology from normal? ...Hypersensitivity has two meanings. The scientific one is 'highly sensorially aware.' The common one means you're touchy, irritable, thin-skinned. The source is the same but the common one is focused on personal interaction, not [the person's] interior.*
[male age 50]: *The questionnaire makes you think depression is an illness, but often it's a sign of being in your right mind.*

Respondents were approximately split on whether the group headings helped or hindered the questionnaire. Some viewed them as helpful, as guideposts telling them what the questionnaire makers wanted to hear. Others disliked them for the same reason--they didn't want to fit others' categories, but wanted to express their own. Asked if the questionnaire would be better off without the group headings, a majority said it wouldn't make much difference, while split minorities said it would become difficult to answer, or would be much improved and "Lose them!" Interestingly, the more questions asked along this line, the closer people approached one another, and *the mid-ground seemed to be about keeping the headings, but modifying them.* The modifications recommended were about language, grouping, and sequencing.

--simplify the language, and bring it in to line with neutral everyday language. No adjectives, and especially, no value-laden adjectives like "worthless" and "depressed". No jargon terms. No overtly psychologizing/pathologizing terms. No affected terms.

--group the questions so as to have fewer categories. For example, combine "positive affect", "lack of interest," and "depressed mood" into one category labeled "mood." Combine all the "motor" things into one group. Combine "worry" with "anxiety." --

--modify the sequencing to put more neutral questions first (eat, sleep, body complaints). (A small minority recommended doing away with the group headings and scrambling the questions instead.)

--my own observation is that a significant proportion of the respondents did not reliably distinguish the questions from the headings, that is, conflated them. Thus the heading meaning bled in to the questions in such a way that people either felt they could not have answered the questions in the absence of the headings, or, that the meanings of the questions were modified, and usually value-loaded and pathologized, by the presence of the headings. To give a concrete example, I often asked people to look at the "last two questions" and comment on them. Invariably, people looked at the last four, that is, they looked at the last two *headings* ("Vigilance" and "Positive Affect") instead of the last two questions.

e) <u>Content of Questions Themselves</u> There are 45 questions on the questionnaire, and respondents were not asked to consider them one by one.

In contrast to the case with the group headings, all respondents stated that the wording of the questions themselves was

clear. Two noted that when an uncertain word was offered, it was usually defined within the questions, so they could "understand from context." This remark applied to, for example, "you feel sad or blue," "you feel inferior or not as good as other people."

Respondents who felt the questionnaire was negative in tone tended to argue that the questions were phrased in extreme language. For example, "you feel so sad that nothing could cheer you up" would be more acceptable if it were phrased "ou feel so sad that <u>almost</u> nothing could cheer you up." *Nothing*, with *none* and *never*, were widely recognized as absolutes, and a majority of respondents stated that they distrusted absolutes, that use of this sort of language in the questionnaire was one reason they felt they were being forced in the direction of reporting pathology.

Another complaint concerned the content of the question sets. For example, the "depressed mood" group seemed to some respondents to follow an internal sequence from more minor to more severe, whereas, the other groups did not seem to follow that logic. Other groups might follow the logic of offering opposites: 'you have a much bigger appetite than usual', 'you have a much smaller appetite than usual.' Some people were bothered to find the "opposite" of Depressed Mood at the very end of the questionnaire, grouped under Positive Affect. It was, in fact, quite troubling to respondents to find things they associated together, separated. They wondered why the two items under Motor Tension weren't grouped with the other "body" issues found under Hypersensitivity. They wondered why Anxiety and Worry had been separated, not because they thought they meant the same thing, but because the difference, they felt, were minor and whatever was grouped under these headings actually went together (see the discussion of these words in Report 2, attached). They also wondered why 'nervous' and 'anxious' were separated under Anxiety, but 'tense' and 'shaky' were not separated under Motor Tension. Or, of course, sometimes things were grouped that did <u>not</u> seem to go together: 'thoughts' with Motor Retardation; 'fearful' under Anxiety; 'irritability' and 'on edge' under Vigilance.

They complained that some forms of negativity were listed, but not others, for example, "worthlessness" was emphasized, but not the potentially equally difficult condition of "feeling superior" to others.

Some words were said to be ambiguous, again raising the issue of context and how researchers were going to interpret the results. Hence people asked: "What's 'usual'? What's 'important'? What's 'little things that don't matter'?" Although respondents could have taken these as subjective, a matter of comparing themselves to themselves, many looked outward instead, trying to find an external measuring rod to determine "usual in comparison to what?" "important to whom?" Or, a recently widowed woman of 60: *Tired out for no good reason?...I <u>have</u> a good reason!* In short she faced a conundrum: she <u>was</u> tired, but she also had a good reason--how was she to answer the question? Either she had to deny her fatigue, or she had to deny her good reason. Many people felt boxed in by this type of double-loading of the questions.

There was also an issue of skew, somewhat hard to summarize, that had to do with the relationship between the questions within

the groups. It seems that some of the entries seemed trivial because they are everyday events or predictable accompaniments of living life, but these appear in the same questionnaire and sometimes cheek by jowl with entries that are non-trivial, signs if real pathology (se discussion of Death above). It troubled respondents to find both these kinds at once, at least, in the absence of some positivity. Thus people would argue that both the mild and severe problems could be present but it was "only fair" or "only made sense" if, in addition, there were ways to tell about being healthy, satisfied, and fulfilled. Although some respondents realized they could give positive assessments of themselves by their choice of (say) "none of the time," this degree of indirection confused many, and didn't reward the rest. The questions under Fatigue provide an example of a group that allows the respondent to make a direct positive personal assessment.

The two overtly positive questions on the questionnaire come at the end, under Postive Affect. About half the respondents accepted the presence, location, and phrasing of these questions without comment. Only one person suggested that these were set at the end to provide "balance" to their opposites which appeared first, under Depressed Mood. Some saw these two questions as a reward for putting up with the previous negativity, but several stated that this amount of reward wouldn't save the questionnaire, and one many suggested that they were "trick" questions actually put in there to identify those who were "cranked up" (with mania). One person said putting them at the end would provoke depression, because of the contrast of those questions with all that preceded them. Most respondents thought the questions were trivial, non-specific. Several suggested that "happy"--a word with a multiplicity of meanings, all vague--be replaced with something more precise, like "satisfaction": "you felt satisfied with your life."

All of these sorts of comments come under the headings of <u>logic and coherence</u>--and a signficant proportion of respondents felt the questionnaire lacked coherence and solid logic. In this section they recommended a) that all the groups have the same internal logic: that all groups cohere according to one structure (i.e, from mild to severe, or, containing opposites); b) that redundancy be deleted yet that abrupt changes of pace be ameliorated; c) that related topics be grouped under single headings; d) that double-loaded questions be deleted or rewritten.

f) <u>Grammar</u> Closely related to the issues of logic and coherence is the issue of grammar. Three respondents, all women, noted that the questionnaire suffers from using conflicting tenses, and that this is distracting, confusing, and ultimately, irritating. One of the three wanted the questionnaire written entirely in the present tense, and the other two were satisfied with the past tense, but all wanted only one tense to be present. Four more respondents noted "typos" on the fourth page, which actually derive from a confusion of tenses.

The issue of grammar is closely related to the reading of the initial question. Thus without the initial question, the questionnaire seems to refer to the present, but with it, in a complex grammatical move, to the past. Two of the three

complainants made concrete suggestions for correcting this problem, one of an unnecessarily complex grammatical approach:

--[female 47] *'Did you feel' is distancing. Write 'you felt'--it's warmer. "During the last 30 days, tell us about how often... you felt unhappy....you slept much more than usual...you had thoughts of dying and death..."*[and so forth].

--[female age 66] *Treat the last 30 days as the present--the questionnaire would read much easier. Rewrite the top question: "most recent 30 days"; put in "do," not "did"--then you can use "can" instead of "could."*

g) Issues Missing from the Questionnaire. Respondents were asked if the questionnaire seemed complete to them, or if they thought there were issues missing. They were asked to think of themselves considering a friend they were beginning to wonder about, and tell if they'd look for other tips than those covered in the questionnaire.

About half the respondents said it seemed complete as is. The other half had suggestions.

--One male stated that the subject of anger was missing, that "upset by little things" wasn't sufficient to cover anger.

--one male noted that there is nothing about alcohol or drug problems on the questionnaire.

--several stated that the issue of stress is not covered. Stress is a popular illness term (see references in Report 1), not officially recognized by biomedicine.

--Weight gain or loss were mentioned by two young women respondents. A change in dietary habits was mentioned by at least two more respondents. All stated that the two questions under Eating were insufficient to guage normality of eating patterns. Appetite can change for nonpathological reasons (a better chef in the cafeteria, taking up a new sport, the death of ones cat). But if weight fluctuates, then something significant is going on, and if a formerly careful eater becomes a sloppy or uncaring eater, that is a sign of trouble.

--Weight and dietary changes are an example of the most frequently mentioned missing issue, namely "change in habitual patterns." At least a third of respondents stated that if a friend changed their established pattern of behavior, that would be a tip-off to something going wrong. Examples offered were: increased cigarette or alcohol use, tantrums in a normally calm person, cleaning house in a normally messy person, getting up early in one who habitually slept late as well as its reverse, weakness and muscle pain not associated with known trauma, withdrawal from usual life activities and from friends, and so forth.

--Of course, the single most "missing" thing from this questionnaire is positivity. About half the respondents stated this directly or indirectly, calling for questions about life satisfication, ability to satisfy their own standards, a sense of feeling mentally healthy, and balance to the question groupings.

h) Lack of Context for Behavior in the Questionnaire Many of the criticisms already listed above relate to a "missing issue" in the questionnaire that several respondents were able to state directly, namely, a lack of context for answering. The issue here is that people claimed that the ability to decide whether a symptom

represented normalcy and healthy coping or abnormality and perhaps sickness, was heavily dependent upon the life circumstances of the person, an issue not covered anywhere in the questionnaire. Two respondents noted that homeless people, or those who'd had tragic lives eith divorce, loss of job, poverty and so forth could be expected to display these symptoms, that this would be normal. Two respondents stated that it was their perception that "doctors" tended to pathologize the normal. So how were researchers going to interpret the answers they got on this questionnaire? Despite the fact they knew their answers would be anonymous, a majority of respondents worried that they would be misinterpreted:

[female 47]: *[The questionnaire] doesn't deal with the issue of circumstance vs constancy. Is this [symptom] typical or due to recent circumstances? Sometimes life is realistically burdensome, and the person feels trapped for good reason; sometimes this is just a perception.*

[female 48]: *[There's] no standard to which to compare for either the responder or the evaluator to use to make sense of the answer. They've got no data! ...Something fundamental is missing, a standard for evaluation. You can't get a deviation from the norm unless you have one. Where's the anchor? Got to have feet on the ground. ...Doctors ask questions with an answer in mind too much of the time--to confirm or rule out 9that's one of their favorite words) what they've already guessed at. This questionnaire may have little to do with the patient and a lot with the doctor/researcher. Notice that not having a symptom doesn't describe having something else. If [respondent says] "most", it's interpretable. But if [respondent says] "none", it's a negative answer but doesn't tell about the person. It's not necessarily a true negative, but you wouldn't know if it meant something. Like with clammy hands--it's an anxiety-type thing, but there are genes for clammy hands! Are these people interested in people, or in hands?*

[male age 22] *It's not relevant to count up frequencies. It's not accurate because the questions are so general and open to so many interpretations. Everyone has their own interpretation....[and] everybody is unhappy sometimes in 30 days, ditto thinking about death and dying.*

[male age 50] *"Little things"--it's a matter of scale. What do you mean, "important"? Sure I'm tense, excited, my muscles ache--I'm hunched over the computer, I've got a deadline, I like my work!*

i) Incentive to answer the questionnaire. Many respondents were asked if they would fill out this questionnaire if it came in the mail. All but one (who said it invaded his privacy) said they would fill it out, but several had suggestions for making this more likely. These suggestions come down to making the completion of the questionnaire both interesting and rewarding. The specific suggestions were reviewed above under Tonality, and are repeated here without modification:

--build in some sort of reward structure.

--make the page more attractive with some visuals. This form is too left-brained, too rhythmic, boring (two respondents); too long (one respondent)

--let people know why they should fill this out--link

it to some important cause (one respondent)
--be sure it comes with return postage (one respondent)
--let people talk about their fulfillment, satisfaction (a very frequent suggestion).
--be sure to provide a context for response--it's a different thing to be depressed because your husband died, because the world is such a mess, and because you're sick...but this questionnaire mixes [conflates] causes, confusing normal with abnormal, making respondents fear they will be judged "abnormal" when their response is "normal" (a very frequent [paraphrased] concern and suggestion).

Summary

The questionnaire can be considered to have content, tone, format, and layout. Respondents seemed to be satisfied with layout. About half the respondents were also fairly satisfied with content, tone and format; this half were more often male, less verbal, and more willing to accept guidance from the questionnaire. The remaining half were less to much less satisfied, but all felt concrete modifications could be performed to make the questionnaire work well. These modifications include:

--researchers clarifying their goals and audience (is the audience to be themselves, or those who fill out the questionnaire?; is their goal to speak a specialist pathologizing language or to learn about how laypeople are experiencing and coping with daily life and its stresses?). Assuming researchers wish to learn about laypeoples' perceptions, then

--modifying the language of the questionnaire to remove jargon, increase readability, increase neutrality, and provide opportunities to report good health and life satisfaction

--providing means to define context, so that 'normal' symptoms are not interpreted as pathological.

It is interesting to realize that these well-educated white Americans--a group that presumably closely resembles the group who create psychological models and psychological questionnaires--nevertheless report attitudes similar to those reported by less mainline populations (see references in Report 1), and critiques the questionnaire in the direction of normalizing language and perception. It is also interesting--and perhaps touching--that so many of these respondents understand the problems of accuracy that researchers face, and express their criticisms in familiar terms (as when mentioning 'false negatives' or speaking of data) and in ways that emphasize that amelioration is possible. In short, though critical, this respondant sample by no means rejects the concept of surveying health attitudes; they are accepting of it, but, at the same time, they want it done "right." It is to be hoped that their perception of "right" proves useful to the designers of the questionnaire.

TABLE 1. Sex and Age Distribution of Respondent Sample

Age	Female	Male
18 - 30	2	3
31 - 60	3	3
61 +	1	3
Totals	6	9

TABLE 2. SELECTED DEMOGRAPHIC DATA ABOUT RESPONDENT SAMPLE

Sex	Age	Education	Occupation	Religion	Home	Health
F	23	BA	Unemployed	Jewish	S	0
F	30	BA	Buyer	Catholic	S	++
F	47	MA	Homemaker	Jewish	S	0
F	48	BA	Homemaker	Believer	S	+
F	60	MA	Artist	Jewish	S	+
F	66	MA	Retired Bookeeper	UU	S	+
M	19	HS+	Student	Catholic	S	0
M	20	BA	Computer Programmer	None	C	++
M	22	BA	Photo Clerk	None	S	++
M	39	MA	Mgr Radio Station	UU	S	++
M	50	MA	Journalist	None	C	++
M	51	BA	Store Owner	Protestant	S	+
M	62	BA	Store Owner	Jewish	S	-
M	76	HS+	Retired Machinist	Protestant	S	++
M	77	HS+	Retired Govt Worker	Catholic	S	++

Legend
HS+--some schooling beyond highschool
UU--Unitarian-Universalist. "Believer"--self-title by respondent
S-- suburbs; C-- city
++ perceives health as much better than others own age and sex
+ somewhat better
0 about the same
- not quite as good

TABLE 3. SAMPLE POPULATION REPORTED USE OF HEALTH CARE

Modality	Female	Male
Acupuncture	2	2
Chiropractice	1	3
Dance/Art Therapy	2	1
Herbal Therapy	1	1
Homeopathy	2	1
Massage Therapy	3	4
Osteopathy	2	1
Psychotherapy	3	3
"Regular" medicine	6	9
Surgery	2	5
12-step program	0	0
Other		
Co-counseling	1	
Diathermy		1

APPENDIX 1

Second DRAFT--CB OPEN-ENDED/GUIDED DEPTH INTERVIEW FORM (7/17/92, CMC)(Drafted with two helper interviewers in mind.)

The goal is to ask questions without offering professional or your own vocabulary, that is, to get at the respondent's ideas, beliefs, attitudes, and language, without requiring them to use DSM III-type language or conceptualizations. Thus, use few formal questions, keep track of the respondent's language, and feed that back to them, trying to lead them ever deeper into the issues of interest to the CB. When they spontaneously mention something of specific interest to CB, draw them out gradually to learn what the symptoms, cause, treatment, temporality and incidence of the condition is, in the respondent's opinion. They will automatically tell you much of this...track so you can ask only about the things they didn't spontaneously mention.

Use the card sort as a method to get deeper into their model, by offering words that they sort and then reveal more by their categorization of the words. There are two sets of words: symptom words, taken from one of the questionnaires originally supplied by Nancy Mathiowetz and added to on the basis of early interviews; and condition words, words which are used or avoided by various questionnaire writers to name the thing/state that DSM III distinguishes.

The issue to to find the concepts and vocabulary of laypeople, in order to reduce this to 6 - 20 questions which could be used on a national questionnaire with a wide range of respondents, and would communicate what the researchers intended. Thus, the final words chosen, and questions chosen, must not be so commonplace that most everyone will feel they are familiar with these conditions and will say 'yes,' and not so negative and loaded and extreme that hardly anyone will say they've experienced them. In addition, the general term used to refer to these conditions must be as neutral as possible. (I am using 'conditions' but it may not be the most neutral.)

[Before beginning, orient the respondent briefly--don't give the whole story. Say you want to talk about health, not their health, but their ideas about what health is. Don't mention mental health. Tell them you are going to tape the interview, and when you begin, get the date, time, number of interview, location [eg., living room of Nancy's home] on the tape, get their agreement to be taped on the tape, and play back the tape to make sure it is recording. Then begin the interview.]

1. *I'd like to talk with you about health. To start, can you tell me what 'health' means to you, or what words come to mind when you hear the word 'health'?*

[If not enough emerges from this question, probe:]
How can you tell if a person is in good health? or
Think of someone you know whom you consider to be in really good health. What is that person like?

What tips you off that a person is in poor health? or

Now think of someone you know whom you consider to be in poor health. What is that person like?

[These questions should reveal something of the respondent's concept of the body and health. If they haven't mentioned anything about emotions, mind, attitude, spirit or the like in their definition, probe again, without using terms like 'mental health' or 'mental illness.' Instead, repeat the body terms the respondent has so far offered, and say something like...]

Sometimes people speak of the body as if it had different parts, such as the [use their word, eg., 'physical'] *body, as you mentioned, as well as other parts. What other parts do you think of?*

[Use their terminology thereafter, but be sure you understand it. If they get confused you may want to offer them the chance to draw their idea, say, in circles or boxes, with connections. If so, keep the drawing. Go on to ask questions to provoke answers to the kinds of illness the different parts can display. Be sure to get clear on whether mental and emotional, or spiritual, illnesses are considered different or synonymous. Note their terminology so you can reflect it back later on. Move directly to the issues of interest to CB if the respondent uses the key terminology, such as mentioning depression, anxiety, panic or the like. Always be sure to get the respondent's definition, even of common words like 'depression'--don't assume you know what they mean.]

[Other possible approaches:]

You've described health in terms of [itemize in their language]. *One thing you haven't mentioned is attitudes, moods, or emotions--things like that. Do you think those have anything to do with health?* [Then follow this string.]

Sometimes people talk about health and illness as if they could occur in different parts of us...as if one part could be well at the same time another part was ill. What do you think of that idea? ... [Follow the string.]

Is it possible to, say, have a physical illness and be perfectly healthy in your [emotions and mind (use their terminology)]? *Is it possible to be perfectly physically healthy, while suffering in* [spirit, emotions or mind]?

[If the person spontaneously uses the term 'mentally ill', get information on what they think that means. If they don't use that term, try to find out as much as possible about how they do think of the issues of interest to CB, but eventually, perhaps near the end of the interview, you must ask something like the following (choose). You can try for the term 'mental health' as well, or instead, if the respondent appears anxious.]

Sometimes people are said to be mentally ill. What does 'mentally ill' mean to you?

[Probes: *Suppose you met a person for the first time, at a party or at a workshop or something...what would suggest to you that this person was mentally ill/was not mentally healthy? Is there a difference between mental and emotional illness/health?]*

Have you ever known someone who was said to have a mental illness? Think about a specific person, and tell me something about how they behaved, what you perceived. ...Would you say this person was unhealthy?--please explain.

Ask: *"What kinds of words do you use with your friends or family, to refer to someone who acts like that?"*

[If a person tells stories of real people, let them tell the story. Note language throughout. Listen for the model being revealed. Check by reflecting back that you have understood what they are saying. Try your interpretation on them, and ask if you are interpreting/hearing them right. Corrections offered are often interesting and revealing.]

[Listen for a model of some sort of differentiation between health and non-health, perhaps a continuum, or something. Try to get the respondent to locate the people they describe, or the conditions they mention, on the continuum from healthy to sick--it's hard to ask this without imposing your model, but the idea is to find out how 'abnormal' the respondent perceives the various mental health conditions/illnesses they have mentioned to be. For example, do they think 'anxiety' is normal, sick, or somewhere in between? What are the characteristics of this in-between state? Do they think the person needs professional help? Do they need institutionalization? Again, putting various conditions on a continuum may help here (drawing it). Or, hang loose on this issue, because the pile sort will be used to provoke these sorts of answers.]

[Just before doing the pile sort, ask]

A phrase we hear a lot nowadays is "quality of life." What does that mean to you? Tell me about someone you know who has a really good quality of life. Now describe someone you know who has poor quality of life. What relationship is there between quality of life and health? [probe using whatever subdivision of the body they've come up with.]

PILE SORT

Turn off the tape recorder after noting what you're going to do. Offer the deck of cards sorted by number. Tell the person to sort them into stacks/piles of words or ideas that go together. They don't have to mean the same thing, but you might expect to see them happen in the same person, or the idea behind them is similar.

Tell them they can make as many piles as they wish. Tell them that if there are any words in the deck that they don't know, or don't like, to put those aside. It will take about 5 minutes to do the sort. If they talk alot while sorting, you may want to record their musings. Do turn on the tape again when they signal they are done sorting. Ask them to read off the numbers of the cards in each pile while you write them down--let them choose the piles. When they have read off the numbers in one pile, ask them what they call the pile, or what it is about. Be sure this is recorded, and it is wise to write it down too. If they go off talking in detail about that pile before moving on to another pile, let them. Follow their lead, probing as needed. If they change their mind as they talk, wanting to move a card to another pile, let them do it, recording the change and their reasoning for the change.

We are especially interested in two stacks, one that the respondent may call 'depressed' and another that the respondent may call 'anxious'. You may have to decide which these stacks are if the respondent uses other terms. Or, a respondent may call one 'panic,' and so forth. For any piles that seem to be particularly meaningful to the respondent (they may keep a hand on it, or talk about it, or jiggle the cards up and down), and for piles that represent ideas of particular interest to CB, ask the respondent to sort the cards within the pile from 'most mild' to 'most severe.' Then, with careful questioning, get them to tell you where in the sequence 'something out of the ordinary' begins--for example, the respondent may say, 'this is where the person really should seek help,' or they may say 'this is definitely abnormal' or use some other language. There will probably be at least three locales of interest, those which are essentially normal because they are brief and commonplace (eg., crabby, blue), those which are definitely signs of 'sickness' (or whatever term they use), and those which are loaded in the middle, requiring help but...try to find out if they are 'normal/needs help' or 'needs help/sick' or whatever. Try hard not to impose your model or to reveal what you want too directly--let it come from the respondent as spontaneously as possible. Some respondents may spontaneously sort all the piles; record whatever they say.

Of particular interest are what the respondent perceives about the relationship between the following words:

anxiety and anxious
anxious and worried
anxious and tense
tense and worried
depressed and anxious
depression and anxiety

You can probe quite directly for these once the respondent has put them into stacks, because these words are, by now, 'on the board' so you won't be putting words into their mouths. However, keep being careful not to put concepts into their mouths.

Also track their comments about words. For example, some people find 'unbalanced' to be a strong word (very sick) while others see it as describing a commonplace condition of every day. Where does your respondent sort this word?--you don't need to comment, just if they comment, pay attention and follow the string.

There is a second short card sort pile, containing words like 'issue', and 'condition.' You will already have noted which sort of word this respondent tends to use--it could be 'problem', and you will have reflected this choice back throughout the interview. The goal of the second card sort is to find the value loadings of these sorts of terms, so ask the respondent to sort them from the mildest or most neutral term to the most value-loaded or strongest term. Again, try to get the respondent to name the center of the distribution, i.e., by associating one of these terms with the conditions s/he's been describing throughout the interview. If, for example, he's been referring to depression as a 'problem,' note where 'problem' falls in the card sort, and ask the respondent to comment again on the issue of the continuum from normality to abnormality, that is, how strong (how sick) a word is 'problem'--is it mild, something everyone has? or is it something that requires professional attention...and yet is not a sickness? Or, is it a sickness?

When the card sort is complete, if the person has not spontaneously mentioned the five issues of interest to CB, then you must offer these terms and see what happens. The five conditions are,

depression (symptoms lasting two weeks or longer)
depression lasting two years or longer (technical term is dysthymia but don't use it unless the respondent does)
panic attack
anxiety
phobia

Again, be sure to get at respondent perception of symptoms, cause, incidence, temporality, and treatment.

Example questions to get at their perceptions are:

Have you ever known anyone who is depressed? Tell me about that, how that person acted that was part of being depressed.
How long must a person be depressed for you to think that the situation is out of the ordinary?
Is a person who is depressed sick?...
Do you know other words for depression?
Do you think it's possible for a person to suffer from depression for a really long time, two years or more? How would you refer to that situation?

Have you ever known anyone who, very suddenly, gets panicky, even when there's nothing nearby to explain it? Tell me more.

Have you ever known someone who is deeply afraid of something common, such as dogs, or high places, or crossing bridges, or being in crowds? I mean someone so deeply afraid that they really can't be near dogs, must avoid crowds, or need to hold someone's hand to cross a bridge? Tell me about it. Do you think this kind of fear is a kind of mental illness, or is it something else, maybe just normal, in the sense that everyone in the world

fears something.

Another word you hear a lot is anxiety. Have you ever been anxious? [remember:some people don't think anxious and anxiety are the same--use this respondent's language]? *What does it feel like? Can anxiety get so out of hand that you would say the person was sick or ill? Is it a form of mental illness? Did you ever know someone like that? Tell me more.*

This is the end of the interview. If you feel there are loose threads in the argument, or something you don't understand, follow up. Then, tell the person the interview is finished, and ask

Is there anything else you'd like to tell me, anything we didn't finish discussing?

When the respondent is through talking, state the time on the tape and turn off the machine. Be aware that when the tape recorder is turned off, many people will start talking all over again. If so, and it isn't obviously a personal story for your ears only, turn the tape on again. You can always add comments after the interview is over, to explain what happened.

When the interview is over, give the respondent the demographics form, and ask them to fill it out. You will have previously filled in the top with interview number etc., and the first name only of the respondent. This is also the time when you can answer their questions in more detail, explaining what the information we are collecting will be used for. Don't do this at the beginning!

7/6/92: The following are terms selected for use in the symptom card sort. The first set of terms was taken from the first few pages of the CB handout "Mental Health Screening Scale Items". After testing them on four persons, I added the second set of terms. The second set ensures that the five issues CB particularly wanted studied are present by term, to see if people sort them regularly with terms that mental health workers would sort them with, and also, to see if these terms result in different responses from respondents than the descriptors. That is, there are now both 'labels' from the psychotherapeutic model (eg., 'anxiety'), and 'descriptors' used to diagnose in that model and used in daily speech ('anxious'). Some of the terms are more or less technical, while others are commonplace language or even mildly dialectal. No-one in the first few interviews objected to any of the terms as being not understandable, or esoteric, or obsolete. Some perhaps more slangy terms are present in the second set.

First Set

Worried Anxious Blue
Irritable Depressed
Down in the Dumps
Tense Jumpy Jittery
Sad Tired Worn Out
Fatigued Angry
Hopeless Despairing
Stressed Out
Excitable Unstable
Unbalanced Nervous
Downhearted
Impatient Confused
Frustrated
Flustered Restless
Breathless Lazy
Procrastinating
Trapped
Scared for no reason
Unpleasant thoughts that won't stop
Feelings easily hurt
Weak Sleepless

Second Set NOT USED

Anxiety Panic Fear Phobia Fearful Afraid
Out of Control Lethargic Grouchy Crabby
Out of Touch Gloomy Over the Edge Hysterical
Freaked Out Paranoid Disconnected Buzzed
Frenetic
In Limbo

CHECK-OFF SHEET--CB INTERVIEWEES

Interview #: _____

Date: _____

Interviewer: _____

Your Sex: _____ Age: _____

Religious Affiliation: _____

Occupation: _____

Education: Some highschool Highschool graduate

Some college College Graduate

Technical Degree (specify): _____

Graduate/Professional Degree (specify): _____

You live (circle one): in the city suburbs rural area

What kinds of health care have you ever used? (check as many as needed)

- acupuncture
- chiropractic
- dance or art therapy
- herbal therapy
- homeopathy
- massage/manipulation/physical therapy
- osteopathy
- psychotherapy
- 'regular' medicine with an MD
- surgery
- twelve-step program
- other(s) (please list):

Compared to most people your age and sex, how would you say your health is? (Circle one)

- Much better
- Somewhat better
- About the same
- Somewhat worse
- Much worse

QUESTIONNAIRE PROVIDED FOR RESPONDENT

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	____	____	____	____

APPENDIX 3

QUESTIONS ASKED OF RESPONDENTS ASSESSING CB-PROVIDED SURVEY QUESTIONNAIRE MOCK-UP (See Appendix 2)

The following open-ended question format was developed to help respondents comment on the test questionnaire.

1. The respondent was handed the 45-question questionnaire and asked to look it over. When they stated that they were ready for the interview to start
2. They were asked if I had their permission to tape record.
3. Those who wanted simply to respond, were permitted to do that, without my asking any questions initially. Once they had completed their comments, I continued the interview with further questions intended to clarify their comments or to cover all the characteristics of the test questionnaire.
4. At the end they were asked to complete a simple one-page "demographics" check-off form.
5. The basic questions to assess the test questionnaire were:

--What can you tell me when you look at this questionnaire?
  --How do you feel about it?
  --What does it make you think of?
--What does this questionnaire seem to be about?
  --Can you tell me more about that? or
  --What kind of health issues?
    --What tipped you off that this was about [use their term]
    --Ask them to define any mental health terms they use, especially depression, anxiety, panic, or phobia.
--How would you set about answering this questionnaire?
  --Is it clear to you that the first half of the basic question is asked on page one, and all the rest of the questionnaire asks you to respond to that same question? Is that arrangement OK with you?
  --How about these answer terms "some of the time" "most of the time"--what do you think of that?
    --Could you use these categories yourself?
    --Can you put a specific time in days on how often a person would have to be experiencing a symptom to make it "most of the time"?
      (Repeat question for all four time frames)
  --Supposing a person did have some of these symptoms, and they happened maybe one or two hours on most days, but not all the time. How would you answer in that situation?
  --Now consider the 30 day time period. Do you think that's long enough to know that something wasn't quite right with someone? How about in yourself?
  --Notice that the questions are separated by words

like section headings. What do you feel about this?
--the use of section headings?
--the words themselves?

--Are there any words in the questions themselves
--which you don't understand?
--which you don't use?
--which you don't like for some reason?
--which seem old-fashioned, or maybe slangy, or ambiguous, or anything like that?

--Are there any ideas missing from this questionnaire? For example, if you were looking at a friend or a relative, and you were wondering if maybe they had some [problems/issues] like these, are there any other things or behaviors you'd look for that would tell you that this person wasn't doing so well?

--Is there anything in this questionnaire that would make you not want to fill it out?
--the format might be hard to understand
--you might feel irritated or suspicious or frightened...any sense of negativity?
--you might feel it was not important or worth doing...

--[If they object to aspects of the questionnaire]--Do you have any suggestions for dealing with that?

--Is there anything else that occurs to you, that you'd like to tell me about this questionnaire?