# STUDY SERIES (Survey Methodology #2007-17)

# African American Mental Health Module: Final Report

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### AFRICAN AMERICAN MENTAL HEALTH MODULE

Final Report

to

The Census Bureau
U.S. Department of Commerce

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## TABLE OF CONTENTS

		Page			
I.	METHODOLOGY	1			
II.	RESULTS				
	A. RESPONSE TO INDIVIDUAL QUESTIONNAIRES	1			
	B. GENERAL ADVICE AND COMMENTS FROM RESPONDENTS	10			
	C. RESPONSE CATEGORIES	1 1			
III.		13			
$I \lor$ .	REVIEW OF THE LITERATURE				
	A. REVIEW OF ETHNOMEDICAL-MENTAL HEALTH LITERATURE FOR AFRICAN AMERICANS	15			
	B. REVIEW OF OTHER RELEVANT LITERATURE	20			
∨.	BIBLIOGRAPHY	25			
APPENDICES					
	Appendix 1: Copy of Phase I Report (Resubmission)				
	Appendix 2: Demographic Information				
	Appendix 3: Demographic Summary				
	Appendix 4: Range of Responses to "Most, Some, and A Little of the Time" in the Questionnaire				

#### AFRICAN AMERICAN MENTAL HEALTH MODULE FINAL REPORT

#### I. METHODOLOGY

This is an ethnographic study of African American ethnomedical concepts for the purpose of mental health questionnaire development. The in-depth, site specific understanding of cultural phenomena provided by ethnographic methodology is one of the most important contributions of anthropology (Chambers 1987), and the desirability of ethnographic interviewing as a means of informing questionnaire development has been discussed by Bauman and Greenberg (1992). This particular study has proceeded in two phases. In the first phase, ethnographic interviews with twenty-three (23) African American respondents were conducted. These interviews probed for ethnomedical conceptualizations of mental health. The entire Phase 1 report is included here as Appendix 1.

The second phase of this study consists of focused interviews with sixteen (16) African American respondents. These interviews utilized the 45-item schedule of mental health questions provided by the Census Bureau. Appendix 2 (Demographic Information) details the demographic characteristics of the Phase 2 respondents. A summary breakdown of these demographics is provided in Appendix 3 (Demographic Summary) and illustrates that the respondents were selected in an attempt to ensure diversity (by age, gender, SES, rural/urban, and northern/southern).

#### II. RESULTS

# A. RESPONSE TO INDIVIDUAL QUESTIONNAIRES

Only those items with which respondents had some difficulty are included in the following breakdown of the results.

#### DEPRESSED MOOD

The tendency here is for people to see the first three questions as basically the same, but with variations.

you feel happy

you feel sad and blue

you feel depressed

you feel so sad that nothing could cheer you up

Five (5) persons say questions 1, 2, and 3 are the same (#1 SES2; #2 SES4; #8 SES4; #9 SES5; #12 SES5).

One of the five presented an oddity by answering "none" to the question "sad and blue" and "some" to the other two questions while still saying all three were the same.  $(\#8\ SES4)$ 

- Two (2) say questions 1 and 2 are the same (#7 SES1; #1 SES2)
- Two (2) say questions 2 and 3 are the same (#5 SES3; #10 SES5)
- One (1) says questions 1 through 4 are the same (#6 SES3)
- One (1) says question 4 is "almost" the same as 1-3 (#9 SES5)
- One (1) persons stated that you can be "depressed but not be unhappy" [ie. can be depressed and happy] (#1 SES2)

#### EATING

There is some confusion here about "bigger," so that three (3) people seem to see the the term as referring to a normal appetite. In addition, one (1) person said she had a bigger appetite when she felt good.

# you have a much bigger appetite than usual

Three (3) indicate confusion between bigger and normal.

One (1) answers "some" and says "sometimes I'll be thinking I'm getting sick or something ... when I don't eat I'll be wondering what's wrong with me if I don't eat much" ( $\#8\ SES4$ )

Another answered "most" and said "I keeps a good appetite all the time" (#9 SES5)

The third answered "a little" and said he eats more when he's working, especially if it's steady work: "that's where my self-esteem kind of goes up a little bit" (#10 SES5)

One (1) said "a little" and explained that she has a bigger appetite "when I feel good" (#3 SES2)

#### SLEEP

# you sleep much more than usual

One (1) person indicated he slept more because he had been exercising more than usual (#5 SES3)

#### MOTOR AGITATION

# you feel restless and fidgety

One (1) individual sees a definite difference between the two words, "restless and fidgety," stating:

"sometimes I can be restless and not fidgety ... restless is when I'm not able to get to sleep and fidgety is when my heart feels like it's jumping out of my body, but it's really not beating faster, it's jittery on the inside" (#4 SES1)

#### MOTOR RETARDATION

# your thoughts come more slowly than usual

Two (2) individuals seem to confuse this with decision making:

One answers "some" and states "it's difficult for me to make decisions, is that 'thoughts slowly' or what?" (#10 SES5)

The other says "a little" and refers to "thinking about making a decision" (#11 SES5)

- One (1) answers "a little" and associates the question with forgetting: "sometimes I might forget" (#12 SES5)
- One (1) thinks about it as daydreaming: "I think maybe you could relate it a little more to daydreaming" (#7 SES1)
- One (1) is confused by the question and seems to be giving an answer opposite to the that the question intends to ask: she answers "most of the time" and explains: I think thoughts [inaudible], I'm hyper, when you're hyper they just 'ch, ch, ch, ch,' steadily" (#2 SES4)

# you feel like everything was happening in slow motion

There were some problems understanding this question.

Three (3) persons said they did not understand what slow motion meant (#3 SES2; #6 SES3; #5 SES3). One of these said: "I don't know what that means, I've never experienced anything like that" (#5 SES3)

- One (1) asked if it was a physical aspect of retardation: "I don't know if that's a visual question or what? What does that actually mean ... is it talking about somebody that's retarded?" (#1 SES2)
- Two (2) individuals confuse slow motion with the personal "motion" of their own lives (ie. whether they were accomplishing their goals).

One said: "when I first came here, it was like moving real, real slow, like I couldn't get nothing right ... When I tried going forward and I was going backwards, so that's how slow it was" (#8 SES4)

The other said: ""ha, ha, that's my life story til recently, like everything going too slow or that I'm anticipating it too fast" (#10 SES5)

#### FATIGUE

This section received several different responses, including associating fatigue with physical tiredness, answering in terms of physical conditions, and not understanding the word "effort" in Question 2.

# you feel tired out for no good reason

One (1) person says "some people do get tired out for no good reason; it's like a physical problem that they don't know about" (#1 SES2)

# you feel that everything was an effort

- One (1) says "is this a physical effort or a mental effort?" (#1 SES2)
- One (1) answered in terms of her long-standing health problems (#6 SES3)
- One (1) did not understand the word effort: "what does that mean?" (#9 SES5)

#### WORTHLESS GUILT

Here, Question 2 about "ashamed or guilty," elicited some strong responses. In general, ashamed seemed to be a strong word that respondents found uncomfortable, whereas they readily admitted to feeling guilty. Question 3, inferior or not as good as other people, also caused some minor problems of interpretation.

### you feel ashamed or quilty

Four (4) persons indicated feeling guilt, but not shame, and some had strong views on this subject:

One said: "I don't usually feel ashamed ... but I feel guilty"; this individual answered "some" for guilt, not for being ashamed (#2 SES4)

Another answered: "The guilt I feel most of the time. Ashamed, no." (#4 SES1)

Another responded: "no, I think ashamed is ashamed of the way you look, or some action, ashamed of something I have done; guilty would not be looks, but guilty would be of an action, or something I did to someone else" (#7 SES1)

The fourth declared: "ashamed, nah, but guilty, yes. I was raised to never be ashamed ofwhat you do, because you are you and you can't be everybody else ... what you do, if it's wrong or right, be a man and accept that ... Not ashamed, more like worthlessness and uselessness ... I would be ashamed if I was in that jailhouse or in the penitentiary ... or got drunk and fell out there and got hit by a car" (#10 SES5)

# you feel inferior or not as good as other people

- One (1) differentiated between the two terms, saying that he never felt inferior to others, but he did occasionally feel not as good, but in the sense of "accomplishment" (#5 SES3)
- One (1) interpreted the feeling "not as good" as other people as physical: "well, I don't know how other people feel, but I feel good all the time"; he may not have understood the word inferior, or perhaps he was being too literal (#9 SES5)

#### DEATH

# you have thoughts of death or dying

Of those who answered, six (6) seemed to give answers that indicated they were thinking about the death of others or others and themselves. For example, in the group interview of four women (all SES2):

One (1) person said: "I didn't know if it was either friends or yourself or both."

Another responded: "Well, I thought of myself as dying because young people around my age were dying (of aids) and you being to think that you could die anytime too."

When asked directly if they were thinking of themselves or others in this question, they responded as a group:

"It's more less been triggered from people that are close to us dying."

Another older person showed this same confusion:

"It's not so much thinking about yourself, but actually if you hear about it .... I've lost so many people." (#2 SES4)

Finally, another says he thinks about death and dying because the pastor of his church talks about it constantly:

"In church, we talk about death a whole lot in church ...
the decision between going to heaven or hell ... doing
the right things in life to get to heaven." (#11 SES5)

#### ANXIETY

The words nervous and anxiety (Questions 1 and 2) created some confusion. Question 5 (fearful) caused minor difficulties.

#### you feel nervous

One (1) person did not understand the word, and related it to having a cold: "I have been, I've had a cold, I've been nervous ... kind of out of kilter with things, not quick to respond" (#11 SES5)

#### you feel anxious

Two (2) referred to anxiety as a sense of motion, or movement:

One, when asked what "anxious" meant, replied: "ready to go" (#11 SES5)

Another had the same idea, anxious meaning ready "to do something, or what's it mean? I feel anxious about all the time  $\dots$  I'm not a person to sit still" (#9 SES5)

One (1) person interpreted anxious as an "anxiety attack":
"that is, to me ... kind of an anxiety attack"; it
means "afraid, scared of something and you don't know
what it is .... that really scary feeling like going
into a dark cave and you don't know what you're facing
and your breath is quickened and ... it feels like
your heart is beating faster" (#4 SES1)

#### you feel fearful

- One (1) individual did not know the meaning of the word:
  "what that mean, fearful .... I don't know what it
  means" (#9 SES5)
- One (1) asked: "fearful in what sense, fearful from harm, or financial, or spiritual?" (#10 SES5)

#### MOTOR TENSION

The pattern in this section was to interpret both questions almost entirely in physical terms, with a few variations.

# you feel physically tense or shaky

- One (1) person related feeling this way to being diabetic (#11 SES5)
- Two (2) people had strong views about the differences between the two words:

One said: "I think you need to separate ... the shaking and tense, some people can be tense but they're not going to shake .... Being shaky, you're really having a lot of problems" (#7 SES1)

The other said about shaky: "you need to see somebody" (#7 SES1)

# your muscles feel tense, sore, or aching

Interviewees reacted very typically to this question as meaning physical pain of some kind:

Said one: "I have no physical problems" (#12 SES5)

Another: "I've got bad feet ... most of the time" (#1 SES2)

Another mentioned pain from working: "if I'm working and my feet get tired or ache and I get a sore throat or something" ( $\#8\ SES4$ )

One sees it as referring to his arm: "now, this morning, this arm was sore because I laid over and flopped my arm on the bed" (#9 SES5)

Another spoke of his rheumatism (#5 SES3)

Another of his diabetes (#11 SES5)

Another mentioned her physical problems (#6 SES3)

- One (1) found the question "confusing" (#3 SES2)
- One (1) mixed physical and emotional: "I have arthritis ... I have pain pain most of the time," she stated, but added that her muscle tenseness, etc. was also about 50 percent "stress", although "maybe more" than 50 percent was from the arthritis (#2 SES4)
- One (1) offered a more physical answer: "they won't think about the emotional unless you want to separate the tension, soreness and aching, because that's two different things to people" (#7 SES1)

#### HYPERSENSITIVITY

This section prompted many responses, and the overwhelming tendency was to answer the questions as queries about physical status. This appeared in almost all 8 questions.

## your heart pounds or races without exercising

- One (1) mentioned his diabetes (#11 SES5)
- One (1) said it would be "from physical and medical problems" (#7 SES1)

#### your mouth feels dry

- One (1) (an alcoholic) mentioned "probably dehydration from drinking" (#10 SES5)
- One (1) mentioned medication causing dryness (#11 SES5)
- One (1) related it to going outside: "when I go outside or get a cold, like I'm dry now" (#8 SES4)

## you feel short of breath without exercising

- One (1) said "that's a physiological thing" (#7 SES1)
- One (1) related it to ashthma: "I have asthma  $\dots$  That's mostly what I be worried about" (#8 SES4)
- One (1) did not appear to understand the question, saying he felt that way at times because "I walk a lot" (#10 SES5)

# you have indiquestion or an upset stomach

One (1) noted possible confusion between food and emotional upset as causes:

"sometimes people will know that when the eat ... that their seat of emotion is in their stomach .... other people will think it's just a physical thing that they ate something they shouldn't have" (#7 SES1)

- One (1) spoke of problems from food: "one time last week I had indigestion [from] some of the food I was eating" (#12 SES5)
- One (1) said he had indigestion "when I first started having my cold" (#11 SES5)

## you have trouble swallowing

One (1) mentioned illness: "associated with the cold" (#11 SES5)

# your hands feel sweaty or clammy

One (1) mentioned heat: "back in the summer when it was hot" (#9 SES5)

#### you feel dizzy

Three (3) mentioned illness: (#3 SES2); (#4 SES1); (#2 SES4)

One (1) felt dizzy, and attributed it to medication: (#11 SES5)

## your face feels hot and flushed

One (1) mentioned her period: "it all comes from my cycle" (#1 SES2)

Two (2) mentioned menopause:

One asked "something like my hot flashes?"; then said "it's my whole body ... I've never had a problem with just my face, have you?" (#2 SES4)

The other referred to "hot flashes I've had in the past," "the change of life," "surgery" (#4 SES1)

- One (1) says this would stem from physical and medical problems  $(\#7\ SES1)$
- One (1) sees it as related to going out when it's cold: "like when you go outside and you come in" (#8 SES4)

#### VIGILANCE

## you feel keyed up or on edge

One (1) did not understand the question, indicating she did not know what the feelings referred to (#6 SES3)

#### POSITIVE AFFECT

The tendency in this section was for people to regard both questions as the same, although not completely.

#### you feel in a really good mood

#### you feel happy

- One (1) sees them as the "same" (#6 SES3)
- One (1) calls them "about the same" (#4 SES1)
- One (1) says they are "similar" (#7 SES1)
- One (1) is uncertain, but seems to see a difference between Questions 1 and 2. She calls them "pretty similar," because "usually if you're in a good mood you're happy;" but, she adds, "I guess you could be in a good mood and not be real happy" (#1 SES2)

# B. GENERAL ADVICE AND COMMENTS FROM RESPONDENTS

One respondent (#2 SES4), referred to the questions as "heavy" and "very deep" and suggested, not in this context, that the questionnaire be broken down "into a lower-type jargon." Even though other respondents sometimes had difficulties with the meanings of certain words (while respondent #2 did not), she was the only one to mention this as a problem.

Another found that some questions lacked specificity, and in response to Question 2 of the Motor Retardation section (your thoughts come more slowly than usual) stated: "when you say your thoughts come more slowly than usual, then you have to relate that or hook it on to your thoughts about work, your thoughts about home, your thoughts about yourself or your activities, you have to give them some kind of form of reference, a reference point." (#7 SES1).

Several respondents mentioned generally that their particular physical situation might affect their responses to many or all of

the questions. One (#2 SES4) mentioned that she had to keep in mind the difficulties associated with her "disability" (poor eyesight) when answering. Another (#5 SES3) mentioned his rheumatism as something he had to take into consideration.

Specific reference was made by several, but not all, women regarding the possible affect of their menstrual cycles on their responses. One woman (#1 SES2), stated: "I, being a female ... there are so many questions through this questionnaire ... that happen sometimes ... even though you wouldn't normally feel worthless or something."

## C. RESPONSE CATEGORIES

#### Underestimation

In his response to Question 1 of the Worry section (you feel worried about things that were not really important), one respondent answered "every day" but selected only "some" on the questionnaire.

Also, in answering Question 2 of the Worry section (you worry about things that were not likely to happen), this respondent offered "all the time" but selected only "a little" on the questionnaire. As in Question 1, he appears to be underestimating the degree of his worry. (#5 SES3)

Another respondent replied "half the time" to Question 1 of the Motor Tension section (you feel physically tense or shaky), but selected "a little" on the questionnaire (#12 SES5)

#### Overestimation

A respondent stated "some of the time" in Question 6 of the Hypersensitivity section (your hands feel sweaty or clammy), but said "I never really noticed that ..., not enough for me to really pay attention" (#2 SES4)

# An unusually strict interpretation of "a little of the time"

In response to a general question (at the end of the entire interview) about the meaning of "a little of the time," one respondent replied: "seems like none." In the course of responding to the entire questionnaire, he actually used this category only once, when answering in reference to an event that had occured only once. (#9 SES5)

# The meaning of "none of the time" to one respondent

In response to Question 2 of the Motor Retardation section (you feel like everything was happening in slow motion), this respondent answered "none," but stated "I have felt that feeling (in

the last month), you know, when everything was slowing down, but it's not a daily ...." When asked about the "none" response, she explained she said none "because I think that happens to everybody." (#2 SES4)

In her response to Question 4 of the Anxiety section (you get upset by little things), she stated "none," but went on to discuss actually being upset by little things when someone else spoke to her about them, such as on the phone. She also indicated that she worried about falling and about stepping on her cat because of her bad eyesight. On being asked about the "none" response, she insisted on "none" as her answer.

While answering concluding questions, she offered a very idiosyncratic explanation for the meaning of the category "none of the time" on the questionnaire. Asked what "none" meant, she replied "a fifth or a half of a day" each month, and elaborated stating: "you're gonna feel something ... because I'm only human."

## range of responses for all participants

	Most	Some	A Little
Indiv.*	16-30 days***	1-30 days	1-8 days
End**	20-30 days	1-24 days	1-10 days

- \*refers to answers given to individual questions in the context of administering and discussing the questionnaire
- \*\*refers to responses given at the end of the questionnaire when asked what the terms "most, some, a little, and none of the time" meant to them
- \*\*\*one person actually gave an answer as low as 4 days, but because this was an unusually low number, it has been discarded

A more detailed breakdown of these responses is available in Appendix 4 (Range of Responses). The differences between the individual and end-of-questionnaire definitions of responses do not seem significant. What is notable, however, is that the "some" category responses show numbers as low as one (1) day in each case.

Also, it appears that the size (in days) of the three categories is not equal. While both the "most" and "a little" categories seem to encompass a time period slightly larger than a week (at 10 to 14 days and 8 to 10 days, respectively), the "some" category seems to be much larger (at 24-30 days). This suggests that respondents are using "some" as a catch-all category for a very wide range of frequencies, and saving the "most" and "a little" categories for smaller ranges of frequencies at either end.

## III. DISCUSSION AND RECOMMENDATIONS

This section is an overview of the most important findings of Part II (Results) of this report. If only one person demonstrated difficulty with a particular question, that response was dropped from this analysis on the assumption that the interpretation may have been idiosyncratic. (These responses, however, are still listed in the Results section for reference). While it is notable that even one person in a such a small sample (N=16) had problems with interpretation, in a sample this small there is no way to know what such a response might mean. An exception to this rule was made if the respondent did not know the meaning of a particular word.

In general, the language of this sample questionnaire did not appear to create serious difficulties of interpretation among the respondents, possibly because the questionnaire itself provides context and suggests at least a general kind of meaning for the words used. However, because problems of definition involve the most elemental levels of communication, all examples of not knowing the meaning of a particular word have been included.

In conclusion, the following points are noted, with accompanying recommendations, if any:

- 1. DEPRESSED MOOD Most saw Qs 1-3 as similar to each other and different from Q4, with two (2) exceptions.
- EATING bigger appetite than usual Three (3) gave positive answers confusing bigger with normal or good.

Recommendation: add a clarifying phrase.

3. MOTOR RETARDATION - thoughts come more slowly There were substantial problems of understanding here by five (5) people, with associations to decision making, forgetting, daydreaming, and confusion to the point of giving the exact opposite answer.

Recommendation: reword question.

4. MOTOR RETARDATION - slow motion Again, there was substantial confusion. Three (3) did not understand the question at all, one (1) confused slow motion with mental retardation, and two (2) confused slow motion with an understanding of the personal motion (direction) of their own lives.

Recommendation: reword question.

5. FATIGUE - everything was an effort
Two (2) people confused this with ongoing physical problems
and one (1) person did not know the meaning of the word
effort.

Recommendation: reword question.

6. WORTHLESS GUILT - ashamed or guilty Four (4) very strongly stated that they felt guilty, but not ashamed.

Recommendation: drop the word ashamed from the question.

- 7. WORTHLESS GUILT inferior or not as good
  One (1) person did not know what the word inferior meant.
- B. DEATH thoughts of death or dying Six (6) persons either thought only of other people's death (5) or thought of death only because it was raised by their church's pastor (1).

Recommendation: reword question.

- 9. ANXIETY nervous One (1) person did not understand the word nervous.
- 10. ANXIETY anxious
  Three people had difficulty. Two (2) confused anxious with a sense of motion or movement and one (1) defined anxious as "anxiety attack."

Recommendation: reword question.

- 11. ANXIETY fearful
  Two people had difficulty. One (1) was confused about
  the kind of fear being referred to, and one (1) did not
  know the meaning of the word fearful.
- 12. MOTOR TENSION physically tense or shaky
  Three had difficulty. One (1) answered in terms of his
  diabetic condition, and two (2) objected to shaky as being
  too serious to be included in the same sentence with tense.

Recommendation: drop the word shaky, consider rewording.

13. MOTOR TENSION - tense, sore, or aching A total of ten people had problems with this question. Seven (7) associated their answers with physical conditions, one (1) gave an answer that mixed physical and mental conditions, and two (2) were confused.

Recommendation: drop this question.

#### 14. HYPERSENSITIVITY

There were at least some problems with every category, with people giving answers that indicated associations to physical conditions or problems:

-heart pound or race: 8

-mouth feel dry: 3

-short of breath: 3

-indigestion: 3

-swallowing: 1

-sweaty or clammy: 1

-dizzy: 4

-hot and flushed: 5

Recommendation: explain at the beginning of this section that respondent should not answer in terms of any physical or illness related condition.

#### 15. RESPONSE CATEGORIES

It appears that respondents are using "some" as a catch-all category for a very wide range of frequencies (ranging all the way down to one (1) day a month), and saving the "most" and "a little" categories for smaller ranges of frequencies at e i t h e r

Recommendation: consider providing the respondent with definitions for each response category.

end.

### IV. REVIEW OF THE LITERATURE

A. REVIEW OF ETHNOMEDICAL-MENTAL HEALTH LITERATURE FOR AFRICAN AMERICANS

#### Introduction

The existence of a traditional system of African American folk medicine has been well documented (Bestman 1986; Golden 1977; Hall and Bourne 1973; Hill and Mathews 1981; Jordan 1975; Mathews 1987; Rocereta 1973; Scott 1978; Snow 1974, 1983; Stewart 1971; Weidman et al. 1978). This ethnomedical system is usually

referred to by anthropologists and other researchers as "root-work," or as conjure medicine, hoodoo and voodoo. The term root-work derives from the fact that magical spells or hexes believed to cause illness are made from plant roots and can be treated by healers known as root doctors. Belief in magic, or "unnatural illness," is paralleled by a concept of "natural" illness and its cure with herbs and other natural substances. An essential characteristic of the rootwork system is the absence of boundaries between physical and mental concepts of health and illness. As Mathews notes: "the system is based on a view of life as a union of body, mind, and soul, and a definition of health as the blending of physical, social, and spiritual well-being" (1987:885). Within this system, treatment for illness may be sought from a variety of practitioners, including root doctors, conjurers, herbalists, spiritualists, faith healers, bone setters, prophetesses, granny midwives, and chiropractors.

# Rootwork: Prevalence and Utilization

Rootwork is believed to have originated in the slave culture of the antebellum South, as slaves continued to use medical practices they had known in Africa. These original ideas were influenced in ensuing years by Catholicism, Native American beliefs, self-care techniques of European settlers and possibly even European ideas about witchcraft (Mathews 1987). Some researchers hypothesize that rootwork has continued as a form of medical care for blacks because, as a group subject to constant racism, they perceive themselves to be helpless in the face of a hostile and unpredictable environment and thus attempt to gain some measure of control through magic (Mathews 1987; Snow 1974). Other researchers emphasize the high relative cost and lack of access to orthodox medicine as important factors in the perpetuation of traditional medicine (Scott 1978; Mathews 1987; Hall and Bourne A final important reason, Scott adds, is that the system is functional: "these beliefs and therapies ... may indeed be measurably effective." (Scott 1978:69)

It is easier to document the existence of traditional African American forms of folk medicine than to determine prevalence or utilization patterns. Part of the explanation here may be that the use of roots is often "hidden" because of shame, fear of criticism, or fear of violating laws against practicing medicine without a license. Both patients (Golden 1977: Rocereto 1973) and therapists (Hall and Bourne 1973; Stewart 1971) have been reported as unwilling to discuss these traditional folk systems. Stewart (1971), for example, was refused interviews by over 50 percent of the indigenous healers he had located for his study. The Miami Health Ecology Project encountered similar difficulties. Although able to interview 20 folk healers, it required special "courage and determination" among their assistants, and they still experienced resistance from informants when discussing unnatural illnesses (1978).

Root medicine is not the exclusive preserve of Southern African Americans, since some Hispanics, Haitians, Bahamians, whites and African Americans outside the South also utilize this system (Bestman 1986; Rocereto 1973; Snow 1974; Hill and Mathews 1981). The complexity of traditional folk medicine is evident in the Miami Health Ecology Project findings in which similar, but identical, systems are detailed for African Americans, Bahamians, and Haitians (Weidman et al. 1978). They conclude that characteristics such as "Black" and "Spanish-speaking" are not adequate for identification of folk beliefs (Bestman 1986). all African Americans, for example, believe in folk medical cures (Rocereto 1973). A study of the folk medical system in Atlanta revealed that young people in the community did not use indigenous healers and actually viewed them as "quacks;" most of the support for folk medicine came from older residents (Hall and Bourne 1973).

The Miami Health Ecology Project presents a different view. In examining the health cultures of five of the largest ethnic groups in Miami, Florida, including southern U.S. blacks, they found community members were "not moving resolutely away" from traditional beliefs and practices toward scientific medicine (Scott 1978:61). In fact, "many" were reported to be "completely alienated" from modern medicine, while others used it "serially or in tandem with folk care systems" (Scott 1978:69). In observing the practices of 20 traditional healers, these researchers found that women consistently outnumbered male clients and that the majority were in their 30s to 50s, with a few younger women, and fewer still older women (Weidman et al. 1978).

Research by Kronefeld and Wasner indicates that a large proportion of the American population may utilize elements of folk medicine. In their study of 96 sufferers of rheumatic disorders (nearly 70 percent female and about 75 percent white), they discovered that 94 percent had employed an unorthodox remedy or practitioner (1982). Arthritis, they caution, may be an unusual case in that there is no clear cure. Hill and Mathews, however, point out that folk systems may be more commonly used for chronic illness, while scientific practitioners are consulted for acute illnesses (1981). It is clear from virtually all of the folk medical literature that many individuals turn to rootwork and biomedical systems simultaneously, creating a kind of medical syncretism. As Snow states: clients "weave in ad out of both systems" (quoted in Hill and Mathews, 1981:309). Unfortunately, utilization patterns are not clear from existing research, and the extent of such interweaving is never formally measured.

Nursing research has indicated that while some differences in perception and management of problematic behavior between mental health professionals and minority group members were related to differing levels of education, most differences were related to cultural influences (Flaskerud 1984). In contrast, a more recent investigation by Capers found that those with higher levels of education were more likely to view behaviors as mental illness and to recommend psychiatric treatment (1991).

It may be that some of the difficulties of delineating separate traditional and modern medical systems can be explained by an argument advanced by Hill and Mathews, that as biomedical concepts and information spread, we are dealing with one belief system, not two (1981). While it is clear that health practices are changing over time, the manner or direction of change is as yet unarticulated. Hall and Bourne see confused misunderstandings of biomedical mental health as being the most resistant to change: "While explanations of physical illness are increasingly accepted in scientific terms," they note, "mental illness as a concept in this culture remains poorly perceived" (1973:142).

# Rootwork: Mental Health

The traditional healing system of African Americans does not distinguish between problems or illnesses of the mind and of the body in the manner common to orthodox medicine. Instead, ill-nesses are treated simulataneously on physical, psychological, and social levels (Hill and Mathews 1981). For example, as Hall and Bourne note in their study of indigenous Southern therapists in an urban community: "psychiatric problems were frequently couched in somatic terms and, even when a problem was clearly identified as psychological, herbs or potions were frequently sought as the most appropriate treatment. Similarly, spiritual cures were frequently the treatment of choice for physical ail-ments" (1973:141).

This blending of physical and mental categories presents a research problem when trying to understand folk categories of mental illness and, although information about mental health problems appears in the literature, it tends to be conveyed in a very confusing manner. For example, Hall and Bourne mention three to five persons with "nerve problems" who visit a particular root doctor weekly, but they provide no further definition of this condition (1973). Hill and Mathews note that traditional healers may diagnose cases as "overwork, 'nerves,' (1981:311-312) when confronted with such symptoms as "headaches, backaches, occasional loss of memory, tiredness, thinking about a particular subject or person too much, and sexual impotency" (1981:311); again, however, they provide no information specific enough to allow definition of the category of "nerves." Hill and Mathews point the finger of blame for missing specificity to the generalized notions of disease causation that result in illnesses not being given specific names but being "lumped together under a more general term such as 'misery' or 'nerves'" (1981:313). Finally, even terms such as "hysterics" or "nerves" which to those accustomed to orthodox medicine may appear to involve mental health can be classified as both mind and body problems (Hill and Mathews 1981).

Another problem of interpretation lies in the fact that detailed case studies of conditions such as "nerves" are lacking.

Snow mentions the case of a 42-year old woman from Tucson, Arizona with a high school education and nurses' aid training who was hospitalized for "'nerves' (professional diagnosis, acute anxiety state)" (1979:86). She believed she had been hexed and felt herself to be cured afterwards when she dug up a pair of underpants which had been buried along with a snapshot of herself (which had the date she was to die printed on the back). No symptom list or course of illness information is given for this case. In such a vacuum, we do not have a precise understanding of what is meant by terms such as "nerves." A good example of how muddied the waters can be appears in the statement by Hill and Mathews that headaches and nerves are considered "illnesses of the lungs" (1981:316).

A final example of the confusion that arises in searching the folk medical literature for issues relevant to mental illness and health is illustrated by apparent contradictions between the findings of Mathews (1987) and Weidman et al. (1978). discusses illnesses of the mind, declaring that natural illnesses of the mind are caused by disobedience to God's laws and that unnatural illnesses of the mind are the result of root magic. This argument runs counter to two cases discussed by Weidman in the Miami Health Ecology Project. In the first, Weidman notes in her discussion of sysmptoms a link between high blood (the folk schema of blood has been delineated as bitter/low or high/sweet, thin or thick, and dirty or normal/clean (Mathews 1987)) mental illness in the report that an informant's brother had strangled his wife: "'His blood was way up, and she said it caused his mind to snap'" (1978:543). Later, in making additional comments about natural illness, Weidman et al. outline the risks in not discussing "marital" woes. "The danger in keeping it all in," they explain, "lies in the accompanying turbulence or movement of the blood and the consequences of high blood in the form of mental disorder. If sexual intercourse has diminished or ceased during extended conflictful periods, then 'blocked' nature is another complicating factor with a potential to cause mental illness" (1978, 561-562). Not only is this interpretation not linked to a taxonomy any more detailed than the difference between natural and unnatural illness, it also seems to contradict Mathews' assertion that natural illnesses of the mind caused by disobedience to God's laws.

#### Conclusion

Perhaps the only uncontestable statement about traditional systems of African American health in the United States is that they do exist. Beyond that, detailed understandings of the conceptualization of these systems are difficult to locate. We do not know, for example, the prevalence or incidence of utilization of folk medicine. Some researchers suggest it is dying, others claim it to be alive and well, yet hard data to corroborate either position is lacking. While all investigators agree that

African American folk medicine does not differentiate between mental and physical illness in the same manner as orthodox biomedicine, there is often disagreement on the classification of illnesses. There is no clearly defined "mental" folk illness, and it is difficult, if not impossible, to determine precise definitions and understandings of many of the illnesses that do exist within this system. It may be that some reports in the literature are not accurate, or that they are accurate, but not comparable. The research populations from which the research was drawn may vary in some unknown manner. For whatever reason, the resulting picture of folk medical mental health concepts is unclear. Consequently, it is presently impossible to determine what, if any, are the points of overlap or contact between the traditional African American mental health ethnomedical system and orthodox biomedicine.

# B. REVIEW OF OTHER RELEVANT LITERATURE

#### Incidence Studies

An historical glance at the incidence of mental illness among African Americans is revealing for the widely ranging conclusions presented, all supposedly documented by epidemiological research. For example, before and just after the Civil War, high rates of mental illness were reported as justication that freedom was a deranging experience for African Americans. Earlier this century, lower rates of depression were reported, with an accompanying picture of African Americans as "happy-go-lucky" people who did not experience loss in the same manner as whites (Adebimpe 1984; Thomas and Sillen 1972). More recently, African Americans have been hypothesized to have higher rates of depression as a consequence of the brutality they endure in a deeply racist society. Such sweeping generalizations, Thomas and Sillen have pointed out, have been based on skimpy evidence (1972).

Psychological literature on African Americans documents their experience with both anxiety and depression. A study of psychiatrists who treat, or have treated, African Americans in psychotherapy indicates that depression is the most frequent presenting problem of both males and females, although females are most often diagnosed with anxiety disorders (Gray and Jones 1987), and males with affective disorders (followed by anxiety and adjustment disorders) (Jones et al. 1982). It should be noted, however, that in this, as in other research, a major conceptual and methodological criticism is that studies of African Americans almost always use standard conceptualizations, procedures, and instruments, usually developed by and on whites (Jackson et al. 1982).

In an overview of African Americans and psychiatry, Adebimpe (1984) argues that schizophrenia has often been overdiagnosed and affective disorders underdiagnosed for African Americans. He

states that these differences decrease when patients' age, sex and socioeconomic status are controlled, that socioeconomic status is often more important than race, and that when structural diagnostic categories are used and socioeconomic factors controlled, apparent differences in prevalence and symptomology are minimal. Epidemiological research on African American-white differences has been an area of controversy that will probably not be settled for some time. Neighbors, et.al. have argued that researchers should not assume that there are no differences between African Americans and white any more than they should assume African Americans to be unique. They assert that concerns about differences in symptomology and dignosis will not be resolved until systematic research utilizing structured instruments is carried out (1989).

A brief review of some of the most important recent findings of epidemiological research will highlight current understandings of African American and white differences in psychological distress. Kessler's and Neighbors' review of eight epidemiological surveys in an investigation of the relationship between income level and psychologic distress concludes that rates are similar for upper income respondents, while for those in lower social classes, race differences are pronounced (1986). Somervell examined the prevalence of major depression in African American ans and whites in the Epidemiological Catchment Area Study (5 U.S. sites) using DSM-based diagnostic criteria. They reported that, although evidence to date from symptom scores consistently demonstrates an excess of African American depression, when prevalence of diagnosis is examined, they do not have higher rates of depression than whites.

Finally, in a study conducted in a psychiatric clinic, Fabrega et. al. examined African American—white differences in psychopathology within relatively pure diagnostic groups, including affective and anxiety disorders. They found variation in psychopathology associated with ethnicity when controlling for education, gender and age, and excluding any subjects with secondary diagnoses. However, in only a few instances did these variations apear to be "criterial" in establishing the original diagnosis. They concluded that differences in psychopathology among unipolar depression patients were substantial, and argued that the typical African American patient "looks different" (1988:294). They also noted that their study provided no empirical support for somatic or neurovegetative differences.

#### "Black" Mental Health

"Black Psychology" seems to have been born in the 1960s and bred by the dissatisfaction that African Americans felt when they examined their involvement in, and treatment by, the mental health care system. A good example of the literature generated during this period is  $Black\ Psychology$ ," edited by Jones (1972).

Some of the historial issues mentioned in the previous section on the epidemiological research record offer some rather dramatic examples of what African Americans were upset and even angry about. These were the years in which books such as <u>Black Rage</u> (1969) and <u>The Death of White Sociology</u> (1973) were published. Thomas and Sillen, who examined closely the impact of "white racism" on the theory and practice of psychiatry, objected to, among other things, the tendency to regard the African American personality as being deformed by racism (1972), an idea that Jones has referred to as "the psychological cripple theme" (1972: 111).

Although some of the angriest criticism has diminished over time, it seems clear that problems of racism still exist in the area of African American mental health and in American society at large. As Neighbors notes, there are still difficulties with access to, and quality of, mental health care for African Americans (1987), and a recent and distressing example of research reported in the <u>Journal of Social Science and Medicine</u> demonstrates all too clearly that so-called "scientific" research is not immune from racism (Leslie 1990).

The subfield of black psychology, then, seems to have been an only partially successful attempt to counteract racist approaches. Unfortunately, much of this literature does not provide a sufficiently deep understanding of the psychological functioning of African Americans. Most of the writing is both soft and general. An example is an article by Jones (1985), logical Functioning in Black Americans: A Conceptual Guide for Use in Psychotherapy," in which the conceptual framework is a discussion of the four psychological tasks facing all African Americans. While such an article provides a general and flexible approach to dealing with African American patients, it is overly simplistic and provides no hard research on the existence or nonexistence of actual pyschological differences. If analyses such as this are not totally without merit, they are also too diffuse and too general. Part of the problem may be that, since the 60s, we have experienced not so much a revolution in the subject content of psychology as a changing of the psychological guard. White psychologists and psychiatrists may have been replaced by their African American counterparts, but the result is still a top-down view of providers by professionals.

A final example of some of the difficulties in dealing with professional assumptions about mental health functioning is demonstrated in McGoldrick and Rohrbaugh's investigation of ethnic family stereotypes among mental health professionals. They found that when mental health professionals from ethnic backgrounds (including blacks) were presented with lists of family-based stereotypes, the professionals themselves shared many of the stereotypes (1987). The question that remains unanswered is whether these stereotypes are reality based, or whether ethnic mental health professionals are just as stereotypical in their assumptions as the general population.

There is very little information about mental health or illness as it is actually experienced by African Americans, although a few exceptions to this can be noted. Estroff et al. (1991) study those who suffer from severe and persistent mental illness by focusing on self-labeling and on five kinds of illnessidentity accounts. They report that African Americans, especially men, are less likely to hold medical-clinical accounts of their illness and less likely to self label as mentally ill. Although they do not indicate the existence of accounts that ightharpoonupcould be clearly labeled as folk medical, this is probably the result of a research population with fairly extensive mental health contact, as all respondents had been clinically diagnosed as mentally ill. Another example is the research of Barbee (1989), who examines the interplay of biological and social forces in the differential experience of aging for African American and white cohorts. Barbee uses a structured interview and, although she discusses how African Americans and whites "age in different ways," her research is more suggestive than definitive.

#### Language

Studies of language provide an important means of investigating social phenomena, and the examination of language is often an integral part of ethnographic research (Bauman and Greenberg 1992). Unfortunately, ethnographies of African Americans have not dealt with issues of mental pathology and mental health. Black Vernacular English (BVE) has been extensively analyzed (Spindler and Spindler 1983), but most of this work has been concerned with the development of educational policies. In addition, a problem with studies of BVE has been that African Americans do not constitute a single speech community (Baugh 1983).

Language has not been an issue of concern to most researchers who develop or use questionnaires: researchers have tended to simply assume that all respondents would understand any given question and interpret it as the researcher intended (Jackson et.al. 1982).

When speaking of difficulties in communication and understanding, it can be useful to discuss cultural features that operate across ethnic lines. Several researchers have noted communication problems with lower socio-economic classes, defining these people as more concrete and less able to abstract and analyze information in the self-conscious manner typical of members of upper socio-economic classes (Schatzman and Strauss 1955; Gans 1972). Some researchers have postulated that these differences are linked to the media habits of the lower socio-economic classes. Childers' literature review indicates that the "information poor" or "disadvantaged" American watches a lot of television, very seldom reads newspapers, and never reads books (1975). Others, however, suggest that the fact that certain groups do not respond in the manner expected by researchers does not mean they

are uncooperative or unreachable (Freimuth and Mettger 1990). Discussions such as these possibly provide one of the strongest arguments for ethnographic research: if informants are not verbalizing information in a manner that is understandable to more sociologically inclinded researchers, an anthropologist who utilizes participant observation is in a prime position to gather social information in context and therefore to gain cultural knowledge of the group being studied.

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Appendix 1

### REPORT ON ANXIETY AND DEPRESSION SYMPTOMS AND CATEGORIES OF AFRICAN-AMERICANS

Linda C. Illingworth August 1992

#### I. METHODOLOGY

Appendix 1 (Demographic Information) details the demographic characteristics of the 23 African-American respondents interviewed in this study. A summary breakdown of these demographics is provided in Appendix 2 (Demographic Summary), showing that the respondents were selected in an attempt to ensure diversity (in the categories of age, sex, SES, rural/urban, and northern/southern).

A copy of the interview schedule is enclosed in Appendix 3 (Anxiety/Depression Exploratory Questionnaire). This schedule was used as a loose guide in stimulating open-ended discussion of the respondent's view of the general areas of anxiety and depression. Respondents were encouraged to name and define categories (if any) which they viewed as important (and separate) parts of anxiety and depression. The interviews were taped, and selected portions were transcribed in order to develop anxiety and depression categories (by interview) and symptom lists (of anxiety and of depression).

The analysis which follows is divided into four sections: symptom list results, category list results, and discussion of language for "an ordinary person" (#11, SES5) and final recommendations. As the final discussion of language focuses on SES level, all quotes will be identified by interview number and level of SES.

## II. SYMPTOM LIST RESULTS

The complete symptom lists are included in Appendix 4 (Symptom Lists). These lists do not include the words depression and anxiety (as these were introduced by the interviewer), or any of the category names listed by the respondent (see Appendix 6, these will be analyzed in Section III). The following words were also introduced by the interviewer, but were included on the symptoms list if the respondent acknowledged using them: blue, sad, down, nerves, panic, phobia.

In a search for the diversity and flavor of language used by respondents, no attempt was made to ensure that the symptoms listed by a given respondent were mutually exclusive. In other words, if the respondent mentioned the word "sad" more than once, it was listed only once, but if they also mentioned two other colloquial expressions for the word sad (ie. "unhappy" and "melancholy"), both were listed.

For purposes of analysis, the symptoms lists were divided into the subcategories of Cognitive, Physiological, Social and Emotional symptoms of anxiety and of depression. Within these subcategories, similar ways of saying the same thing were grouped together; for example, "bogged down" and "overloaded".

## Analysis of Symptom Lists

Analysis of the Symptom Lists allows us the opportunity to see the particular language used in describing anxiety and depressive states, and to achieve a basic conceptual understanding of these two states by comparing the content of the categories. In examining the Symptom List Summary (see Appendix 5), we see very clear differences in the manner in which respondents view depression and anxiety. As these are lay views of mental health states, they are not necessarily the same as the conceptualizations of mental health professionals.

In terms of cognitive symptoms, depression is viewed as a state in which the sufferer is "overloaded," can't think straight, and can see no solution. Similarly, the cognitive state of anxiety is also seen as confused, but with a slightly different bent: the sufferer is "unsure," doesn't know what to expect, and can't decide what to do.

Physiologically, depression is viewed in terms of "feeling bad," "tired," "crying," and appetite and sleep changes (direction unspecified). Those who suffer from anxiety are also thought to have appetite and sleep problems (they "can't" eat or sleep), to cry (only 1 mention of this), and to have many additional symptoms of "sweat," "headache," "other pain," "hyperventilation," "heart of pulse pounding," "cold feet," "stomach problems," "breathing problems," and "pacing."

Interestingly, the social symptoms of depression reveal that a significant number of people (5) see "loneliness" as a cause of depression, while there are also numerous categories mentioned which describe the result of depression in terms of social withdrawal. While social withdrawal is sometimes mentioned in connection with anxiety, there are many fewer examples of this (7 as compared to 15) and loneliness is never mentioned as a cause of anxiety.

Finally, the emotional symptoms lists for anxiety and depression reveal the use of totally different terms: for anxiety, there is "nervous," "nerves are shot," "nerves," "stressed

out," "upset," "jittery," "fidgety," "hyper," "scared," "fear," and "afraid," while for depression there is "down," "sad," "low," "blue," "unhappy," anger, "feel like giving up," and "helpless." (See Appendix 5 for the number of mentions of all the symptoms discussed in this section). At worst, anxiety is seen as "uncontrollable," and depression as "inability to cope" or "feel like killing yourself."

# Summary of Symptom List Analysis

For the respondents, both anxiety and depression are seen as two distinct states. Depression, in particular, is viewed in terms (both causative and consequent) of social isolation. It is also seen as more serious, in that in it's most extreme form, sufferers may try to kill themselves and/or others.

In sum, depression, consisting largely of problems of isolation and withdrawal, can be contrasted with anxiety. Anxiety seems to involve emotional sins of commission ("jittery," "fidgety," and "hyper," for example), paired with numerous physiological symptoms which do not necessarily isolate a person socially. On the other hand, the emotional symptoms of depression ("low," "down," and "unhappy") result in sins of ommission (avoidance) which do socially isolate the sufferer.

### III. CATEGORY LIST RESULTS

Appendix 6 (Categories List for Anxiety and Depression) details the categories listed by interview. Close examination of this summarizing list reveals the following points:

- 1. There is a large range in the number of categories listed, from interview #4 (SES5) in which no terms were listed for either anxiety or depression to interview #5 (SES4) in which 5 anxiety and 4 depression categories were identified.
- Everyone recognized the categories of anxiety and depression, even if they listed no particular category names.
- 3. Most respondents ordered their categories of depression and anxiety by level of severity. Four of the five exceptions to this rule (all noted in Appendix 6) involved anxiety categories.
- 4. There was no hesitation on the part of respondents to view categories of anxiety and depression as mental illness. (Also noted in Appendix 6).

5. Most of the interviewees with SES5 suggested fewer categories than those of higher SES. For example, #4 had no term for either anxiety or depression, #9 (4 people) had 1 term each, and #11 had 1 term for anxiety and no terms for depression (all 6 interviewees are SES5). (The only exception to this rule was interview #12, a woman with extensive Adult Children of Alcoholics involvement).

It is this final point #5 which brings us to the following discussion of language as a function of SES.

# IV. LANGUAGE for "AN ORDINARY PERSON"

To this point, we have defined the categories and symptoms of depression and anxiety as described in the interviews. We have demonstrated order within the diversity of symptoms (Appendix 4) and categories (Appendix 6), and shown that composite understandings of both anxiety and depression do exist (Appendix 5). We have also established, in some detail, the language used to describe these understandings. However, it is also useful to consider language not used by SES5 respondents, in contradistinction to our previous examination of language used. This can be done by discussing what, in SES5 interviews, is missing or different from those of higher SES interviews (1 though 4).

For example, interview #9 included 4 elderly, rural women who were participating in a senior citizen lunch-program (see Appendix 1 for further demographic information). In comparison to other interviewees, these women had remarkably simple understandings of depression and anxiety. For depression, they had one category, that of "sad," which they defined as "you are sitting at home by yourself and you feel sad, you know". Their anxiety category was "nervous": when they have to speak in public, they feel "scared".

When asked whether he had a name for the category of depression which he was currently discussing, interview #11 (a retired janitor) ventured: "I wouldn't think of trying to have a name for it, to call it. I'm just an ordinary person." The category for anxiety he named was that of "scared or frightened."

Interview #4 (a 36 year old homeless man from a rural area) had no term for either anxiety of depression. When pressed on this point, and asked what words he thought others might use, he stated:

If something is getting ready to happen to you and you're aware of it, it would upset you a little bit, but as far as some of them using these phrases to change their life, I don't think that some of them are aware of it.

All three of these interviews indicated a lack of exposure to mental health systems or ideas of mental health, nor did they display an abstract understanding of the world of mental health (at least as we of higher SES are educated to see it). All three consistently revealed a very basic level of knowledge. The 6 respondents involved tend to be older and tend to come from rural areas. They were very concrete in their answers and used fewer, simpler words. By breaking the interviews into higher and lower SES levels, we reflect the fact that SES is based on higher education levels and, consequently, on increased exposure to educated people through the workplace.

Using the same three interviews (6 respondents), we can discuss their understanding of the terms "depression" and "anxiety" (and "anxious"). We will follow this with a consideration of the treatment of the term "blue" by all interviewees. We will conclude, in light of this, with recommendations for questionnaire wording.

### Use of the Term "Depression"

The four elderly lunch-program participants admitted to knowing the term "depression," stating that it is at its worst when "it gets the upper hand. I have been tooken, and I know." However, they believe that there is no special name for this or any other depressive condition, and that people would not use the word depression, but would use the word "sad" instead. The retired janitor said, "I think it would be a different word (than depression)," but did not know what that word might be. The homeless man, when asked for other words, stated: "just bad, not good, it wouldn't be word of depression... some people you might be able to mention word of depression, they wouldn't be able to understand what that is."

# Use of the Term "Anxiety" and "Anxious"

When asked what the word anxiety brought to mind, the homeless man answered: "It makes me think of how I'm feeling on the inside, but as far as knowing the meaning of the word anxiety, I don't know." The retired janitor responded to the word anxiety: "I've heard of it, but the relative full meanings of it, I don't understand." When then asked about the word anxious, he said: "I think maybe that both of them apply to some of the same things." The lunch-program women did not know what either anxiety or anxious meant.

### Use of the Term "Blue"

There was some controversy regarding the use of this word. One respondent (#8 SES4) stated strongly: "Blacks wouldn't hardly say 'blue.' They might say 'sad,' 'mad,' 'angry,' all of those turned inward can become depression." She went on to suggest, "'Do you feel like you got the blues?', they might deal with that better than saying, 'Do you feel blue?'"

Yet another respondent, interview #5 SES4, when asked whether anxiety terms might mean the same thing to everyone, stated equally strongly:

There's no color barrier with this. I mean, it come in all colors, all shapes, all sizes. I mean, you know, you got blacks, whites, hispanics, whatever, you hyperactive, normally active, overactive, overhyped, whatever, it's just a mental thing, you know, there's no color in your mind ... no certain color has a different word for it.

He said that he would use the term blue, and gave the following example: "All this sadness and blueness has just come to a head and just took you straight down."

Another respondent also stated that African-Americans do not use the word "blue," while yet others stated that they knew the word, but would not use it themselves. One of those who said he would not use the term "blue" was interview #13, a shelter manager (SES2) who stated that the proper street term for depression is "Down and out, that's the word we usually use on the block." In contrast, it should also be noted that 9 people (Appendix 5) actually used the term "blue" in their symptom lists.

#### V. FINAL RECOMMENDATIONS

If the authors of a questionnaire intend to reach all respondents, the issues raised in Section IV must be carefully considered. Interviewee #8 SES4 remarks:

They (African-Americans) will hear a big word and rather than raise their hand and say, "Would you break that word down to a lower jargon?" or something, they might go ahead and vote on something without understanding, rather than question. (She feels much of this is "done deliberately by whites.")

A way to avoid this problem is suggested by Interviewee #4, our homeless respondent: "I think a person would use a word that's very small, a very small word."

In keeping with this spirit, I would conclude this report by suggesting the following word usage:

	Anxie	ety	Depression		
Don't Use: Do Use:	·	anxious afraid/scared	depression, blue down, sad		

In order to measure the incidence of mental health problems at lower, as well as higher levels of SES, the language chosen for questionnaires should be the absolutely simplest possible.

APPENDIX 1
DEMOGRAPHIC INFORMATION

No.	Age 	Sex	SES	rural/ urban	Northern/ Southern	Comments
1	54	M	1	rural	No.	
2	45	F	1	rural	No.	
3	63	F	2	urban	No.	hospitalized 3 times for depression
4	36	M	5	rural	So.	homeless
5	33	М	4	urban	So.	worked several years as hospital aide
6	21	M	1	urban	So.	,
7	24	M	2	urban	So .	black muslim
8	54	F	4	urban	So.	disability since 1974 (retinosa pigmentosa) 7 months weekly therapy
9a	67	F	5	rural	So.	, months weekly therapy
9b	83	F	5	rural	So.	
9c	80	F	5	rural	So.	
9d	75	F	5	rural	So.	
10	55	M	1	urban	So.	
1 1	80	M	5	rural	So.	
12	70	F	5	rural	So.	ACOA participation
13	28	M	2	urban	So.	
14	45	F	1	urban	So.	disability since 1986 (meningioma)
15a	50s	F	2	rural	So.	
15b	33	F	2	urban	So.	
15c	35	F	2	urban	No.	
16a	48	F	1	urban	No.	
16b	50	M	1	urban	No.	
17	36	F	2	rural	So.	

TOTAL = 23 interviewees 17 interviews

#### APPENDIX 2

#### DEMOGRAPHIC SUMMARY

Total = 23 interviewees 17 interviews

#### SUMMARY

14 Female 9 Male 11 rural 12 urban 6 Northern 17 Southern

3 age 20s 5 " 30s 3 " 40s 5 " 50s 7 " 60s+

# ANXIETY/DEPRESSION EXPLORATORY QUESTIONNAIRE: for use with a research population of African-American people LINDA ILLINGWORTH July, 1992

#### A. DEMOGRAPHIC INFORMATION:

Name
Age
Years of Schooling (Highest Degree)
Occupation
Rural/Urban
Northern/Southern

# B. ESTABLISHMENT OF TERMS, DEFINITION AND MEANING

- 1a. When I use the word ANXIETY (A), what do you think
   of: what does that word mean to you?
- 1b. Would you use a different word than A or is that a word you use?

  (Note: The Questions are used first to establish terms for A, the repeated for depression (D).
- 2. How does a person know when they are A? (SYMPTOM)
- 3. What do you think makes people A? (CAUSE)
- 4. How common is A? (INCIDENCE)
- 5. How much trouble does A cause people? (QUALITY OF LIFE)
- 6. Is there anything a person can do to help A? (CURE)
- 7. How long does A last? (DURATION)
- 8. Do people ever get over A? (PROGNOSIS)
- 9. Does the word A mean the same thing to everyone? (VARIATION)

- C. ALTERNATE TERMS/RANGE OF CATEGORIES If positive response to any Questions 10-13, repeat Qs 1-9.
  - 10. What kind of different problems might people have with A?
  - 11. What happens when people have very bad problems with A, the very worst kind of problems a person can have? Does this ever happen?
  - 12. Are there any other words people use or ways people have problems with A?

#### D. MEDICALIZATION

- 14. Do you think of any of the kinds of A we've talked about as a mental or physical illness?
- 15. If not, what would you call (name) them?

# E. PERSONAL EXPERIENCE WITH A/D

- 16. Have you ever had any problems with A?
- 17. Did you ever have any treatment for A?
   (M.D.
   mental health prof.
   hospital < or > 2mo)?
- 18. Have any of your friends or family had problems with A?

Repeat entire Q for Depression (D).

DEPRESSION: COGNITIVE

worried a lot on their mind

in a daze can't reason loose focus

bogged down overloaded don't have the motivation or resources to deal with certain things

don't have anything really to go on not being able to deal with it lost their way in life

never catch up
never get out of it
don't know how to get out of it
can't see a way out
no way out of here
can't put things together

can't come to any decisions or solutions

"hallucinive"

ANXIETY: COGNITIVE

worried (4) chronic worries

anticipation
apprehension
not knowing what you're going to face or how you're going to react
don't really know what to expect
high degree of concern about something that's going to happen

unsure undecided emotional uncertainty

got a lot of problems but you don't have no solutions don't know what to do next don't feel confident your not knowing but wanting to know don't know anything about . . . emotionally insecure

not accomplishing anything

too much on my mind too many things going on

see stuff that's actually not there

DEPRESSION: PHYSIOLOGICAL

feeling bad (3)

worn out tired (2) loss of energy

crying (3) teary

appetite changes
won't eat (2)

sleeping a lot sleeping habits poor

under the weather

take to drinking

ANXIETY: PHYSIOLOGICAL

sweat (3)
sweating (2)
palms sweat
hot sweats
kind of warm

headaches (3)

back pains

physical pains you can't explain

don't feel good at all

everything revs up

hyperventilation

heart rate speeds up heart palpitations pulse starts racing heart pounds

cold feet stage fright

crying for no reason

butterflies in their stomachs tense feeling in your stomach usually stomach ache

don't tend to sleep
can't sleep

loss of appetite can't eat

choking
couldn't breathe
smothering
suffocating

pacing

smoking drinking too much drugs

DEPRESSION: SOCIAL

lonely (5)

want to be alone
being by yourself
stay to themselves
loss of desire to be sociable
cut themselves off from people
retreat from things
shut themselves off
withdrawn
go into their own world
isolate themselves
not feel like bothering with people
don't want to be bothered
don't even go out of the house
poor relationships with people
without a friend

don't communicate well
not responsive

not as responsible as they usually are

problems dealing with life
can't function
don't do their job

not being their normal selves differentiation from the norm change of habits character traits change changing in dress

ANXIETY: SOCIAL

withdrawn (3)
act somewhat differently
not quite as friendly
prefer not to be in crowds
gotta go

inability to carry out a function that you would normally carry out can no longer function forget appointments can't work

DEPRESSION: EMOTIONAL down (10) down and out (2) below what you ordinarily feel down to a low point, where nothing makes you feel good emotional low sad (13) blue (9) unhappy (3) melancholy heavy, terrible feeling anger (3) mad ugly more vocal upset unsettled mood swings (changes) despairing frustration taken out of the regular way they feel problems with self confidence problems with self esteem (3) problems with self image trouble coping inability to cope things don't work out look at things on the negative side negative outlook on everything why try feel like giving up (3) life not worth living helpless (2) hopeless feel like killing yourself

try to harm yourself

ANXIETY: EMOTIONAL nervous (10) nerves are shot (3) nerve problem don't have any nerves anymore a person gets on someone's nerves problems with their nerves stressed out (3) stress related problem stressful jittery (4) jumpy skittish upset (3) tense overly anxious . pressure edgy agitated high strung excited easily excited excitable race ahead of themselves fidgety (2) hyper (2) hyperactive hyped hyped up quick fast act out confrontational panic panic button go to pieces breaking up hysterical scared (2) fear (3) fearful fear of the unknown frightened afraid, really afraid extreme fear of something (continued...)

ANXIETY: EMOTIONAL (continued)

obsess

uncontrollable anxiety have no control lack of control

lose your ability to cope whole system breaks down

irritated

being impatient

uncomfortability

projecting negativeness or viewing a situation as a problem

give up trying

disgusted

# APPENDIX 5: SYMPTOM LIST SUMMARY

### ANXIETY SYMPTOMS

COGNITIVE	PHYSIOLOGICAL
don't know what to expect ("unsure") can't decide what to do  .	"sweat" (8) "headache" (3) other pain (2) "hyperventilate" "heart or pulse pounding" (4 "cold feet" "crying" "stomach" problems (3) "can't eat" (2) "can't sleep" (2) "breathing" problems (4) "pacing"
SOCIAL	EMOTIONAL
withdrawal descriptions (7)	"nervous" (10) "nerves are shot" (3) "nerves" (4) "stressed out" (3) "upset" (3) "jittery" (4) "fidgety" (2) "hyper" (2)

"fear" (6) "afraid" (2)

at worst = "uncontrollable"

### APPENDIX 5: SYMPTOM LIST SUMMARY

#### DEPRESSION SYMPTOMS

# COGNITIVE PHYSIOLOGICAL

can't think straight
("overloaded")
can see no solution

"feeling bad" (3)
"tired" (4)
"crying" (4)
appetite changes (2)
sleep changes (2)

SOCIAL EMOTIONAL

lonely (cause) (5)
withdrawal (result)
-large number of withdrawal
descriptions (15)

"down" (11)
"sad" (13)
"low" (3)
"blue" (9)
"unhappy" (3)
anger (7)
"feel like giving up" (3)
"helpless" (2)
at worst = "inability to cope"
"feel like killing
yourself"

#### APPENDIX 6

CATEGORIES LIST FOR ANXIETY AND DEPRESSION -listed in order of severity

Note: ( ) = sublevels, not official enough to be considered as separate subcategories

MI = Mental Illness

cbMI = can be mental illness

	ANXIETY	DEPRESSION
#1	minor anxiety problems with anxiety nervous breakdown (MI)	depression depression with a small "d" (MI) Depression with a capital "D" (MI)
#2	anxiety	when I'm down semi-depression severe depression
#3	mild anxiety anxiety phobia (MI) nervous breakdown (MI)	small depression big depression (MI)
#4	(has no term)	(has no term) (cbMI)
#5	normal hype (cbMI) hidden something (cbMI) over-hyped (cbMI) hyperactive (cbMI) nervous breakdown (cbMI)	normal (cbMI) step 1 depression (cbMI) the borderline (cbMI) the down syndrome (cbMI)
#6	<pre>anxious (MI)   (uncomfortability or nervousness)   (high levels of anxiety)</pre>	mild depression (MI) depression (MI) chronically depressed (MI)
#7	wouldn't separate A & D because "in a depression" (MI) (emotional uncertainty)	way anxiety is (emotional blurring)

(emotional self-destruction)

(emotional futurism)

# APPENDIX 6 (continued, p.2)

nervous (cbMI)

phobia (MI)

# CATEGORIES LIST FOR ANXIETY AND DEPRESSION

#8 (without special order) depression (MI) panic attack (MI) stress attack (MI) phobic attack (MI)

#9 nervous sad (MI)

#10 anxious (MI)

(known: long-term = anxiety (treatable: reaction to loss

unknown = phobia)

depression (MI)

(treatable: reaction to loss

organic: genetic defect, treatable but not cur-

able)

#11 scared or frightened (has no term) (MI)

#12 (no order) depression (cbMI) tied up in knots (cbMI) keyed up (cbMI)

#13 anxiety down and out

#14 (no order) (no order)
anxiety (panic) attack regular depression
nervous and jittery depression as a disease
hysteria (MI)

#15 panic attack passing depression pressure-release anxiety depression terminal depression (cbMI) phobia

APPENDIX 6 (continued, p.3)

CATEGORIES LIST FOR ANXIETY AND DEPRESSION

#16 anxiety attack/phobia

16a short-term depression
16b temporary self-indulgent depression (cbMI)
chronic depression
debilitating type of
depression (MI)

nervous breakdown (MI)

#17 (no order)
anxiety
anxiety attack

depression more severe depression (MI)

APPENDIX 2
DEMOGRAPHIC INFORMATION

No.	Age	Sex	SES	rural/ urban	Northern/ Southern	Comments
1 a 1 b	50s 35	F F	5	rural urban	So. No.	repeat interview (RI) (RI)
1 c 1 d	26 49	F F	<i>ا</i> م	rural rural	So. So.	
2	54	F	4	urban	So.	(RI) disability since 1974 (retinosa pig- mentosa)
3	38	F	2	rural	So.	
4	45	F	1	urban	·So.	(RI) disability since 1986 (menengioma)
5	40	M	3	rural	No.	<b>3</b> ··· <b></b> ,
6	70	F	3	rural	No.	
7a	48	F	1	urban	No.	(RI)
7b	50	Μ	1	urban	No.	(RI)
8	21	F	4	urban	So.	homeless
9	54	M	5	rural	So.	homeless
10	39	M	5	urban	So.	homeless/alcoholic
11	37	M	5	urban	So.	homeless
12	23	M	5	urban	No.	homeless

TOTAL = 16 interviewees 12 interviews

#### APPENDIX 3

#### DEMOGRAPHIC SUMMARY

Total = 16 interviewees
12 interviews

#### SUMMARY

10 female 7 rural 6 Northern

6 male 9 urban 10 Southern

3 age 20s 4 " 30s 4 " 40s 4 " 50s 1 " 60s+

#### APPENDIX 4

RANGE OF RESPONSES TO "MOST," "SOME," AND "A LITTLE" OF THE TIME IN QUESTIONNAIRE

Abbreviations: D = Day

W = Week / = per ~ = approx.

Note: Where days are indicated alone (ie. 2D) this refers to days per month (2D = 2 of 30 days)

Each column follows the descending order of highest frequency to lowest. Where no particular number of days could be attached to a word or phrase, they were listed at the bottom of the column.

	MOST	SOME	A LITTLE
Range (indiv.)*	all 30D 20D 18D 4/W (16D) 1/W (4D) majority	2/D daily all but 2-3D 25D 6-23D 3-4D/W (16D) 1/2 (15D) 3D/W (12D) 1-3D/W (12D) 1/3 (10D) 2/W (8D) 1-2D once	all the time pt ea. day 2/W (8D) 1 W (7D) ~1/4 (7D) 20% (6D) 1-5D 1/W (4D) 2-4D 2D 1-2D once rarely
Range (end):**	30D 29D 28D 25D 6/7 (24D) 80% (24D) 20D quite often frequently all majority almost always about ev. day day after day	20-80% (24D) 15-20D 1/2 (15D) 14D 10-12D 8-10D 1/3 (10D) 1/W (4D) 1-2D you wonder it speaks for itself	10D ~1/4 (7D) under 7 20% (6D) 2-5D 1/W (4D) 2-3D 2D 1D occasionally very unusual often seems like none not much

<sup>\*</sup>refers to answers given to individual questions, in the context of administering and discussing the questionnaire.

<sup>\*\*</sup>refers to responses given at the end of the questionnaire, when asked what the terms "most, some, and a little, and none of the time" meant to them