FAMILY STUDY

Cardiovascular Disease in American Indians
(Phase V)

Operations Manual - Volume Eight

PSYCHOSOCIAL QUESTIONNAIRES

THE NATIONAL HEART, LUNG AND BLOOD INSTITUTE
OF THE NATIONAL INSTITUTES OF HEALTH
THE STRONG HEART STUDY

Cardiovascular Disease in American Indians
(Phase V)

Operations Manual

Volume Eight

PSYCHOSOCIAL QUESTIONNAIRES

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# VOLUME VIII

**PSYCHOSOCIAL QUESTIONNAIRES**

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1. RATIONALE FOR PSYCHOSOCIAL QUESTIONNAIRES

Studies of Psychosocial Factors

Over the last twenty years, scientists and clinicians alike have been looking at the relationship between psychosocial factors and health outcomes. To date, there has been increasing recognition among the medical community that psychosocial factors (e.g., depression, anxiety, social isolation, and spirituality) contribute to many forms of disease. One of the most well documented areas in this research has been in the associations between psychosocial variables and cardiovascular disease.

The idea that psychosocial variables could affect health is not a new concept. In 1628, while describing the circulatory system, William Harvey noted that emotions affect the heart. William Osler, often described as the father of internal medicine, described the typical heart disease patient as “a keen and ambitious man, the indicator of whose engine is always at full speed ahead.” (Clay, 2001). Since then, our knowledge of the effects of psychosocial variables and disease outcome has increased considerably. Depression, anxiety, and social support are each related to outcomes after the onset of heart disease, and several intervention studies have shown efficacy in psychosocial intervention improving both the outcome and the quality of life of individuals suffering from heart disease (Clay, 2001) Posttraumatic stress disorder (PTSD) is more common among many American Indian populations (Beals, Manson et al. 2005; Beals, Novins et al. 2005) than others in the U.S.; further, PTSD has been shown to be related to cardiovascular disease among American Indians (Sawchuk, Roy-Byrne et al. 2005). While some of these psychosocial factors appear to be environmentally created, others appear to have a genetic component. Eysenck (1982) concluded through the study of twins separated at birth, “that genetic factors contribute something like two-thirds of the variance in major personality dimensions”. Loehlin and his colleagues followed 400 children who were brought up in either biological or adoptive families and concluded adopted children primarily resembled their biological parents in personality characteristics, even though they had never been in contact (Loehlin, Willerman, & Horn, 1987). These implications both in health outcome and genetic implications justify the use of psychosocial instruments in Phase V of the Strong Heart Study. The Strong Heart Study provides a rare opportunity to continue to look at how these factors contribute to both the physical and psychological outcomes of an American Indian population.

The forms are designed to be self-administered. Participants can choose not to answer specific questions, however, SHS staff should check all the forms to make sure sections have not been inadvertently missed. The following questionnaires are administered to all Phase V SHS participants: Quality of Life – SF-12; CES-D depression scale; Social Support, Posttraumatic Stress Screening Scale, Generalized Anxiety Screening Scale, Spirituality, and Fatalism.

REFERENCES


2. **QUALITY OF LIFE - SF-12 Form**

The SF-12 Health Survey Questionnaire will be used again in Phase V of the Strong Heart Study. The SF-12 replaces the SF-36, which was used in Phases II and III of SHS. The main reason for using the SF-12 instead of the SF-36 is to save time by using this shorter version of the Health Survey questionnaire. The SF-12 version generates two summary measures, physical health and mental health, describing health-related quality of life. These two summary scores, the physical component (PCS-12) and the mental component (MCS-12) outcome scores, are compatible to those generated by the SF-36 and have been validated in various populations.

Analyses of the Phase II SF-36 scale have now been published (Beals, Welty et al. 2006). This was a first step and focused on whether or not the SF-36 worked well in the SHS populations—and it did. Interestingly, however, the physical and mental health dimensions were more highly related to one another than in many other samples; this may reflect a more holistic view of health.

Subjective health, or how people see their own health, is increasingly recognized as an important factor in whether people take the necessary steps to either prevent health problems or to seek services for such problems. The SF-12 is an important measure of subjective health. Further, recent research has suggested that, to some degree, measures such as the SF-12 may tap genetic predispositions (Romeis, Heath et al. 2005).

*See Form S9, Volume 3, Appendix C.*

**REFERENCES**

3. CENTER FOR EPIDEMIOLOGICAL STUDIES DEPRESSION SCALE (CES-D)

Depression and Health  A vast research literature exists establishing to varying extents the relationship between depression and health. Measurements of depression can be useful to assess the association of depressive symptoms with health risk behavior, prevalence and incidence of cardiovascular disease, and also to evaluate the effect of health status or CHD on mood states.

Assessment of Depression  The Center for Epidemiologic Studies of Depression Scale (CES-D) scale was originally developed as a general measure of depression (Radloff, 1977). It is a 20-item self-report instrument designed by the National Institute of Mental Health to measure current level of depressive symptomatology, and especially depressive feelings. While the items were chosen (from 5 previously used depression scales) to represent all major components of depressive symptomatology, the CES-D measures demoralization and psychologic distress, as well as depression. The major components of depressive symptomatology include: depressed mood, feelings of guilt and worthlessness, feelings of helplessness and hopelessness, loss of appetite, sleep disturbance, and psychomotor retardation. Items are rated on a 4-point scale indicating the degree of their occurrence during the last week. The scales range from “rarely or not at all” to “most of the time.” The scale can distinguish between clinical groups and general community groups. Although it is usually scored continuously, there are various cutoff scores for clinical depression, with reasonable associations between cutoff scores and a clinical diagnosis (Beals et al, 1991).

CES-D Utilized by Similar Studies  The CES-D is the standard scale used in numerous large-scale studies including the Honolulu Heart Program, the Inter-Tribal Heart Project (Menominee, Red Lake & White Earth), Cardia, and the Stanford Coronary Prevention Project.

Reliability and Validity  The CES-D has been found to have both adequate test-retest reliability, and internal consistency. The internal reliability (Cronbach’s Alpha) of the CES-D is 0.89 (Radloff, 1977).

Administration  Designed for self-administration or interview format.

Caveat:  As with any SHS data, the user should carefully consult the manual and forms for the phase(s) of SHS involved. The SHS website provides online forms (annotated with variable names) and manuals for each phase showing how the data were scored. Please note that for the CES-D form, the numbering of questions differed slightly in the early phases compared to the later phases.
CES-D Scoring

The original CES-D is a 20-item form. Please note that the first question on the SHS Phase V CES-D form is NOT a CES-D question, per se. This question is un-numbered, asks “How is this questionnaire administered?”, and is NOT included when computing the CES-D score for a participant. In the cohort exams, this item was numbered question 1, thus changing the SHS CES-D question numbers relative to the original 20-item CES-D questionnaire. Note also that the question “During the past year, I have felt depressed or sad” was added by SHS to this form. This added question (question number 21 in the Family study and number 22 in the cohort exams) also must NOT be included when computing the total score for the CES-D form.

To date, SHS investigators using the CES-D data limited their analyses to complete forms only (no skipped, refused, missing answers). Instructions in the literature indicate that no CES-D form having more than one missing answer should be used. It should be noted that the SHS CES-D form data entry included entry into the database of the number 9 as an indicator for a missing, etc answer.

Inspection of the CES-D form from any phase of SHS will demonstrate that the answers to each of the 20 CES-D items are always scored as follows:
- Rarely or none of the time (less than 1 day) = 1
- Some or a little of the time (1-2 days) = 2
- Occasionally or a more moderate amount of the time (3-4 days) = 3
- More or all of the time (5-7 days) = 4
- Not applicable = 9

Once all records including the number 9 for any question are eliminated (or addressed according to the analysis plan), there are three additional steps to scoring the 20-item version of the CES-D:

1. The scores 1 through 4 in the data file for each of the 20 items in this instrument should be transformed to the traditional CES-D form values of 0, 1, 2 or 3. There are four exceptions (nos. 4, 8, 12, and 16) which are “reverse-scored” items where the transformation must be 1 to 3, 2 to 2, 3 to 1, and 4 to 0.

   Specifically, the four items requiring reverse-scoring transformation are:
   4. I felt that I was just as good as other people.
   8. I felt hopeful about the future.
   12. I was happy.
   16. I enjoyed life.

2. Once you have transformed the value for each item, compute a total, adding the values for each of the 20 items. The resulting score should range between 0 and 60. (Reminder: Do not compute a total if there is more than one missing answer (blank entry or 9) (blanks and 9s must be removed from the data file). However, computer programs to impute missing data can be used.)
3. A high score on the CES-D indicates a high level of distress. A score of 16 may suggest a clinically significant level of psychological distress. It does not necessarily mean that the participant has a clinical diagnosis of depression. In a general population, about 20% would be expected to score in this range (16 or higher). (Reminder: Item #21 (“During the past year, I have felt depressed or sad”) on the SHS form is not a part of the CES-D scale and must be interpreted separately.)

**Score Interpretation:** The CES-D is a general measure of depression. It has been used as a screening measure in some studies (e.g., Lyness et al, 1999). However, Lyness used a scoring system of 1-4 (instead of the usual 0-3), with a score of 36, 41, and 43 having been used as markers for possible major depression. Comparable scores would be 16, 21, and 23 when using the traditional 0-3 scoring system. None of this work has been done with American Indians.

Rather than asking staff to score the CES-D, we suggest that each participant be given a referral list. Those listed on the referral list should be available locally, have expertise in mental health, and have agreed to be listed. Participants can then decide for themselves whether or not to approach those on the referral list. In very rare cases, a participant may appear visibly distressed in answering these questions; in such circumstances, the staff member should cease asking the questions and offer the referral list immediately. The staff member should then note in the chart that the referral list and a verbal offer of a referral had been given to the participant.

**Assessment of Depression by the Strong Heart Study** In a pilot test of the psychosocial forms performed in Phase II, the CES-D questionnaire was administered to about 200 SHS participants in Oklahoma and about 350 in the Dakotas. In Phase III, the CES-D was only administered to SHS participants in Oklahoma. Analysis of the Phase II CES-D data from one of the Dakota Center Tribes showed that males and females were similar on psychological, health-related, and cultural behaviors (Plaud et al, 1998). Family history of diabetes was associated with depression (Plaud et al, 1997). Further analyses of the results of SHS data on depression are planned.

*See Form S10, Volume 3, Appendix C.*

**REFERENCES**


4. SOCIAL SUPPORT

Definition of Social Support

Definitions of social support include objective and subjective elements of social support from the ability to gain tangible (instrumental) support from friends (such as a car ride), to appraisal or advice and also emotional support. Cobb emphasizes that the individual believes he/she is esteemed, cared for and loved and belongs to a network that fosters communication and mutual obligation.

Early Work on Social Support

Some of the early work on social support focused on communities in transition. Cassel notes that individuals involved in rapid change of culture or stress (change in social support) may be more susceptible to disease. One study by Cassel and Tyroler noted that 1st generation workers who moved from rural communities had more health problems than second generation workers, who they theorized were not so much in transition and were more familiar with life in a factory town. Marmot, studying Japanese men and controlling for the usual cardiovascular risk factors, noted that 5 out of 6 measures of social assimilation with western culture correlated with increased prevalence of CHD (controlling also for culture of upbringing). However, there were some limitations with this study as it was cross-sectional. Bruhn, Phillips and Wolf noted members of the community of Roseto Pennsylvania in the years 1955-1965 had low rates of CVD compared to other surrounding communities. These lower rates of CVD were felt to be related to differences in communities and social cohesion; it was predicted that loosening of family ties and community cohesion would be accompanied by an increase in CVD - and this is exactly what happened.

Given the social disruption endured by American Indian tribes over the last few hundred years, it would not be surprising that changes in social support/culture may contribute to health problems. However, there are few such studies examining the relationship between social support and health in American Indians. A number have addressed the issues in non-Indians, indicating a correlation of social support to later CVD or mortality.

Social Support and Mortality

Berkman and Syme examined mortality in 6928 people in the Alameda County study. They used a social network index based on general categories of marriage, contacts, church membership, and membership in other groups and weighted questions to form an index score. The age adjusted relative (mortality) risk for those who had the fewest social connections (based on their social network index score) was 2.3 for men and 2.8 for women.
House and colleagues in 1982 in the Tecumseh Study (N=2554) looked at different types of social contacts and assessed overall mortality. They prospectively examined categories of social contact, involvement in organizations, social activities, and passive solitary pursuits. Results controlled for age, CAD, FEV1 and smoking and appeared significant primarily in men, with protective factors being marriage, frequency of meeting of volunteer organizations, and frequency of attending social activities-sporting events/lectures.

Orth-Gomer and Johnson (1987) in Sweden used a social interaction index, which encompassed frequency and type of visits with family members, friends, neighbors and coworkers to prospectively assess mortality and CVD mortality in 17,433 people. Controlling for age, smoking, exercise and chronic illness yielded a risk estimate of 1.36 (p=.024) for increased mortality with a low social interaction score. When controlling for cardiovascular disease instead of chronic illness in the model, the analysis yielded a similar risk estimate of 1.37 with p=.07.

Kaplan et al (1998) studied 13,301 people from North Karelia, Kuopio and Eastern Finland using a social connections index that yielded a score and included categories of marital status, frequency of visiting friends/relatives, number of homes visited, meetings, clubs, with the dependent variable being all-cause death or CVD/IHD. Adjusting for age, geographic location, cholesterol, blood pressure, BMI, smoking, family history of CVD, urban/rural and education, and comparing the lowest quintile to all others, all-cause death revealed an OR of 2.0, death from CVD an OR of 1.8, and IHD an OR of 1.72.

Hanson and others in studying "Men born in 1914 in Malmo Sweden" examined an N=621 with univariate results indicating an elevated mortality risk in three categories: adequacy of social support, availability of emotional support and marital status but not for material or informational support, adequacy of emotional support, adequacy of social influence, contact frequency or social anchorage.

In an HMO study of 2603 that examined mortality along with incidence of disease, Vogt et al used a tool that evaluated social network scope, the size of the network, and frequency of contact. Adjusting for age, sex, SES, smoking, and subjective health at baseline, they found that decreased mortality was strongly associated with network scope and different network domains, i.e., different types of relationships; also, size of network and frequency of contact were significantly associated with decreased risk. When examining IHD, network scope was correlated with decreased risk but otherwise none of the social support measures correlated with rates of IHD, HTN, CA, or CVA. The authors suggested social networks might be more important in supporting recovery than in preventing incidence of new disease.

Penninx et al evaluated more varied types of social support in a longitudinal study of mortality that included structural support networks and functional receipt of social support (including two subcategories, one of instrumental social support - help with meals, chores, rides etc., and one of emotional support received - how often during the previous year they talked to a network member about personal experiences and feelings). Also, perceived support - sense of loneliness was measured. With an N=2829, and adjusting for age, sex, education, specific
diseases, physical limitation, self rated health, alcohol and smoking, they found that high instrumental support actually predicted a higher risk of mortality; those with emotional support had about 1/2 the risk of dying and those with the highest levels of loneliness had 1.89 higher risk of death.

These results suggest that social networks or types of social contacts seem to be important in relation to health, and that instrumental support (loans, car rides) may not be a major contributor to ameliorating health risks. Furthermore, some studies indicated that perceived emotional support may also play an important role in mediating the reduced risk of mortality.

The social support questions here were used in the American Indian Service Utilization, Psychiatric Epidemiology, Risk and Protective Factors Project (AI-SUPERPFP). This large study was conducted in both the Northern Plains and in the Southwest (Beals, Manson et al. 2003); tribal confidentiality promises do not allow the tribes to be publicly mentioned. This measure derived from two sources: the National Comorbidity Study (NCS; Kessler et al., 1994) and the American Indian Vietnam Veterans Project (AIVVP) (National Center for Posttraumatic Stress Disorder and the National Center for American Indian and Alaska Native Mental Health Research 1996; Beals, Manson et al. 2002). The NCS measures were selected, in large part, so that one could compare data to that of a national sample. The AIVVP measures, on the other hand, are more reflective of an integrated quantitative/qualitative approach to measure. All items were reviewed and edited by focus groups of American Indian participants.

The questions selected encompass various types of social support, including perceived emotional support, social networks, tangible and negative social support. Negative social support may be contributory to poor health outcomes in many Indian communities.

See Form S11, Volume 3, Appendix C.

REFERENCES


Social Support – background material for questions from the AI-SUPERPFP


Source Documents:


5. POSTTRAUMATIC STRESS DISORDER (PTSD)

American Indian populations are exposed to more trauma than many other Americans. For instance, mortality statistics indicate greater risk for these populations than others for death from unintentional injuries and violence (U. S. Department of Health and Human Services 2001). Indian participants report both more types of traumatic events and greater frequency of events (Manson, Beals et al. 1996; National Center for Posttraumatic Stress Disorder and the National Center for American Indian and Alaska Native Mental Health Research 1996; Ritsher, Struening et al. 2002; Manson, Beals et al. 2005). Therefore, it is not surprising that the constellation of problems associated with such events, encapsulated by the DSM diagnosis(American Psychiatric Association 1994) of PTSD is found at higher rates in some Indian populations.(Manson, Beals et al. 1996; Beals, Manson et al. 2002; Beals, Manson et al. 2005; Beals, Novins et al. 2005)
Recent research has indicated that psychiatric disorders such as major depression are risk factors for cardiovascular disease (Bankier and Littman 2002; Schnittker 2005; Simon and Von Korf 2006). More recently the role of PTSD and cardiovascular diseases has also received attention (Sawchuk, Roy-Byrne et al. 2005). Given the symptoms of hyper-excitability, increased vigilance, and overall anxiety associated with this disorder, PTSD promises to be an important risk factor for cardiovascular disease. Preliminary analyses of data collected by the American Indian and Alaska Native Programs at the University of Colorado support this hypothesis (Sawchuk, Roy-Byrne et al. 2005) and additional research is in progress. However, this research is all cross-sectional, thus, addition of PTSD items to Phase V of the SHS will provide a critical next step in understanding the relationship between PTSD and cardiovascular disease.

PTSD describes the symptoms some people have after experiencing or witnessing a horrible event. The symptoms are broken out into 3 types: re-experiencing or reliving the event; avoidance of places, people or things that might remind the person of the trauma, and increased vigilance or arousal. These reactions have to last at least a month to qualify as being PTSD.

The measure being used here comes from the same study as the anxiety measure to be used in Phase V of SHS. The PTSD measure has 6 items. The first asks whether or not the person has experienced a trauma. While examples of possible traumas are provided (victim of violent crime, seriously injured in an accident, being assaulted, seeing someone seriously injured or killed, or being the victim of a natural disaster), the participant is not asked to describe the event at all. If they have experienced a trauma, the remaining 5 questions ask about: 1) reliving the experience, 2) being less interested in things, 3) problems sleeping or concentrating, 4) avoiding places or things that remind one of the trauma, and 5) whether some of these problems have lasted more than 1 month.

Staff may be worried about a participant’s reactions to these questions. Most people, even those with PTSD, will answer them with no problem. However, staff should be prepared with a list of referrals (see example) in case a participant wants to talk to someone about their trauma and symptoms.

See Form S12, Volume 3, Appendix C.

REFERENCES


6. ANXIETY

Generalized Anxiety Disorder is commonly associated with stress and, although the research is still formative, anxiety is thought to increase the risk for cardiovascular disease. Furthermore, those with CVD are thought to be at increased risk for Generalized Anxiety Disorder (Bankier and Littman 2002; Bankier, Januzzi et al. 2004; Barger and Sydeman 2005).

Generalized Anxiety Disorder is the label given to those who worry excessively most of the time. Furthermore, people with Generalized Anxiety Disorder feel that they cannot control
this worry, and many are fatigued, irritable, have difficulty concentrating, muscle tension, and disturbed sleep. Finally, in order to receive a formal diagnosis of Generalized Anxiety Disorder, the affected person must describe his/her daily life as being affected (impaired) by the symptoms (American Psychiatric Association 1994).

We ask only 3 questions about anxiety, tapping the essential components: persistent worry, difficulty controlling anxiety, and impairment due to the anxiety. This measure was developed in the context of a large study that included American Indians – and it worked well in that sample (Ritsher, Struening et al. 2002).

See Form S12, Volume 3, Appendix C.

REFERENCES


7. SPIRITUALITY

Research in the general population has described prospective relationships between religious affiliation and religiosity with mortality, morbidity, and coping with physical illness (Jarvis and Northcott 1987; Levin and Schiller 1986; Idler and Benyamini 1997; Koenig, Hays et al. 1999; Koenig, Larson et al. 2001). Work from the University of Colorado has demonstrated the importance of broadening the conceptualization of religiosity in Indian communities to a more general measure of spirituality. This research has shown that the general spirituality measure is related to the SF-36 (Beals, Welty et al. 2006) and help-seeking behaviors for alcohol and drug problems (Beals, Novins et al. 2006) The inclusion of this measure in SHS V allows important extensions of this research into understanding the role of spirituality in the treatment of physical illnesses.

Four questions are asked about spirituality. The first asks generally how important spirituality is in one’s life. Another asks about the amount of time spent on spiritual or religious
practices, while a third asks how important it is to the participant that his or her child participates in religious or spiritual practices (for those without children, this question asks them to answer as if they had children). The final question is about seeking comfort through spiritual or religious means.

A couple of comments are in order about these questions. Once again, focus groups of American Indian people helped develop them. They do not require someone to believe in the Christian God, for example, but are also appropriate for Christians. Also, these questions are quite general and do not ask anything specific about the person’s religious or spiritual practices. But, given the sensitivity of this type of question, we remind participants that they can skip over anything they want to.

See Form S12, Volume 3, Appendix C.

REFERENCES


8. FATALISM

Sometimes people feel that, regardless of what they do, things are going to happen to them. This sense of “what’s going to happen, will happen” is called fatalism. Although one can be fatalistic about both positive and negative things, recent research has focused on the role of
fatalism in health, and in particular, if one thinks that, regardless of what one does, s/he will get diabetes or heart disease, that person is likely to be less motivated to exercise, watch their diet, etc. (Davison, Frankel et al. 1992; Mayo, Ureda et al. 2001; Egede and Bonadonna 2003).

Three questions are included here on fatalism about diabetes were recommended by Dr. Felicia Hodge. She conducted a study of Diabetes Wellness Talking Circles in four Northern Plains Indian communities, which found that diabetes fatalism decreased among Northern Plains American Indians who participated in Talking Circles, compared with those who did not. In order to prevent diabetes and CVD, it is important to assess fatalism and overcome it at both the individual and community levels.

See Form S12, Volume 3, Appendix C.

REFERENCES


9. PSYCHOSOCIAL FACTORS QUESTIONNAIRES CHECKLIST

Reason for Incomplete Psychosocial Instruments Form

Rationale: There has been some concern that the administration of psychosocial questionnaires during Phase V will make participants uncomfortable, or not be understood, or stress the time resources of the Strong Heart Study field staff. This form is to be completed for all participants in regard to their completion of the battery of psychosocial questionnaires, in order to improve understanding of the barriers to doing this type of research in the field with American Indians.

See Form S13, Volume 3, Appendix C.