FAMILY STUDY

Cardiovascular Disease in American Indians (Phase IV)

Operations Manual - Volume Eight

PSYCHOSOCIAL QUESTIONNAIRES

THE NATIONAL HEART, LUNG AND BLOOD INSTITUTE
OF THE NATIONAL INSTITUTES OF HEALTH
**Table of Contents**

1. Rationale For Psychosocial Questionnaires ................................................................. 1
2. Cultural Factors .................................................................................................................. 2
3. Quality Of Life ................................................................................................................... 3
4. Center For Epidemiological Studies Depression Scale (CES-D) ................................. 4
5. Locus Of Control ............................................................................................................... 6
6. Social Support .................................................................................................................. 8
7. Anger/Hostility - Spielberger -Ax/Cook Medley Scale .................................................. 13
8. Psychosocial Factors Questionnaires Checklist ............................................................. 17
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 outcome. To date, there has been increasing recognition among the medical community that psychosocial factors (e.g., hostility, anger, stress, depression and social isolation) 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. In recent years, it has been found that the personality trait of cynical hostility predisposes individuals for cardiovascular disease. Depression and social support factors are 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). 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 IV 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, but SHS Staff should check all the forms for completeness and ask questions that have not been answered. The following questionnaires are administered to all Phase IV SHS participants: Cultural Factors Questionnaire; Quality of Life – SF-12; CES-D depression scale; Multidimensional Health Locus of Control (MHLC); and Social Support. The Spielberger-Ax/Cook Medley Scale on anger and hostility is an optional form, but will definitely be administered in the Dakota Center.

References:


2. RATIONALE AND INSTRUCTIONS FOR THE CULTURAL FACTORS QUESTIONNAIRE

The terms “cultural factors” and “acculturation” are difficult to define and assess in epidemiologic studies. In the Strong Heart Study, we have had many discussions about the impact of traditional American Indian culture on heart disease and health problems. We have also discussed the dramatic changes that have occurred when younger generations lose many of the old cultural beliefs, values, and traditions and adopt Western beliefs, values, and traditions. This process is usually considered to be one of “acculturation”. The SHS considered many instruments to assess this transition so that we can determine its impact on health and disease. In the interest of simplicity and because there is no universally accepted instrument for this purpose, the cultural factors survey has been used in Phases II, III, and IV of the study. Chani Phillips developed the cultural factors questionnaire used in Phase II. The questionnaire used in Phase II was simplified for Phases III and IV. A brief rationale for inclusion of these questions follows.

There seems to be universal agreement that fluency in native languages is a very objective measure of how well people have retained their culture. Questions 1-3 assess the ability to speak the language and the fluency in the language. Questions 4-7 are self assessments of how well connected the participants feel with tribal tradition and culture and with non-Indian culture.

See Form S10, Volume 3, Appendix D.

REFERENCES

Language


Cultural Identification


Cultural Identification Questions from:

Denver Indian Social Health Survey. Denver Indian Health and Family Services. Denver, CO.
3. QUALITY OF LIFE - SF-12 Form

The SF-12 Health Survey Questionnaire will be used in Phase IV of the Strong Heart Study to replace the SF-36, which was used for the past two examinations (Phases II and III). 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.

See Form S11, Volume 3, Appendix D.
4. 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 screening measure for depression (Radloff, 1977). It is a 20-item self-report instrument designed by the Center for Epidemiologic Studies to measure current level of depressive symptomatology, and especially depressive affect. The items were chosen (from 5 previously used depression scales) to represent all major components of depressive symptomatology. These 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 both adequate test-retest reliability, and internal consistency. The internal reliability (Cronbach’s Alpha) of the CES-D is .89.

Administration Designed for self-administration, or interview format.

Scoring Twenty items are rated on a 4 point likert scale, ranging from “rarely, or not at all” scored as 1, to “most of the time” scored as 4. Four items are reversed when scored: #’s 5, 9, 13, and 17 so that 1 and 2 scores are changed to 4 and 3 respectively (and vice versa). Item scores are then summed for a total depression score (the higher the score, the greater the depression). Item #21 is not a part of the CES-D scale, and so should be scored separately.

Score Interpretation Upon completion of the survey, a staff member will sum the item scores, taking into account the reverse scored items. If the total score of items # 1-20 is above the CES-D cutoff score for indication of depression, the staff member is to ask the participant if they are interested in a referral for follow-up. The staff member then notes in the chart that the verbal offer of a referral had been given to the participant.

Assessment of Depression by Strong Heart Study In Phase II, about 400 SHS participants in Oklahoma and the Dakotas were administered the CES-D questionnaire. In Phase III, all SHS participants in Oklahoma and SHS participants from the Spirit Lake Tribe were administered the CES-
D. Analysis of 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 S12, Volume 3, Appendix D.

References


5. **Multidimensional Health Locus of Control Scale (MHLC)**

**Health Locus of Control**

The construct of Health Locus of Control was derived from the Social Learning Theory developed by Rotter in 1966. This theory states that an individual learns on the basis of his or her history of reinforcement. Health Locus of Control (HLC) is the degree to which individuals believe that their health is controlled by internal or external factors. Whether a person is internal or external is based on a series of statements. The statements are scored and summed to determine whether the individual has internal or external health beliefs.

There have been multiple studies done that have suggested that HLOC can play a major role in health outcome. Individuals who have a more internal HLOC perceive that they retain power over health related rewards are prone to obtain proper nutrition, exercise, rest, stress reduction, and to adopt prevention/enhancement strategies to maintain/improve the state of their health. Those who have a more external HLOC believe that chance, god, or doctors, etc., control their health; they are liable to exhibit behaviors which are less action oriented (more reaction oriented). This can be especially important in diseases that have a strong behavioral component such as diabetes or heart disease.

The MHLC scale has three subscales designed to measure the construct of HLOC.

- Internal HLC (IHLC) is the extent to which one believes that internal factors are responsible for health/illness.
- Powerful Others HLC (PHLC) is the belief that one’s health is determined by powerful others.
- Chance HLC (CHLC) measures the extent to which one believes that health illness is a matter of fate, luck or chance.

**Reliability & Validity**

The MHLC subscales have been shown to be reliable in many studies. They have been shown to have Cronbach alphas in the .60-75 range and test-retest stability coefficients ranging from .60 - .70. The MHLC scale is widely considered to be the instrument of choice when measuring the construct HLC.

**Administration**

This scale was designed for self-administration, or in interview format. Each item is to be answered on a 4 point Likert scale where “Strongly Disagree” is 0, “Disagree” is 1, “Agree” is 2, and “Strongly Agree” is 3.
Scoring

The score on each subscale is the sum of the values for each item on the subscale. All of the subscales are independent of one another, so there is no such thing as a “total” MHLC score. The items for the three subscales are as follows:

Internal: 1, 6, 8, 12, 13, 17
Chance: 2, 4, 9, 11, 15, 16
Powerful Others 3, 5, 7, 10, 14, 18

See Form S13, Volume 3, Appendix D.

References

6. **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 usual cardiovascular risk factors, noted that 5/6 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 a 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 workers 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 others (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, instead of chronic illness in the model, cardiovascular disease was controlled for instead, it yielded a similar risk estimate of 1.37 with p=.07.

Kaplan and workers (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, # 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 and others used a tool that evaluated social network scope, the size of the network, and frequency of contact. Adjusting for age, sex, SES, smoking, 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 author suggested social networks might be more important in supporting recovery than in preventing incidence of new disease.

Penninx and workers evaluated more varied types of social support in 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, perceived emotional support may also play an important role in mediating the reduced risk of mortality in some studies.

**Recommendations for a social support scale for Phase IV of the SHS**

In phase II of the SHS, a social support scale, the interpersonal support evaluation list (ISEL), was piloted in about 500 participants. Initial analyses showed elements of convergent/divergent validity and good reliability coefficients; however, on further analysis, it did not break down into the expected factors of tangible, appraisal, belonging and self-esteem. This is concerning, as others have noted that when using psychological tests in other cultures, a similar factor structure across cultures is a necessary but not sufficient component of validity. However, the Strong Heart Study – ISEL was a shortened version of the original and some items were altered, which conceivably might account for the lack of expected factors. Given this, we examined other alternatives.

Dr. Jan Beals, a colleague of Dr. Spero Manson from the National Center for American Indian and Native Alaska Mental Health Research, suggested a series of social support questions from the American Indian Service Utilization, Psychiatric Epidemiology, Risk and Protective Factors Project (AI-SUPERPFP).

The social support questions for AI-SUPERPFP were derived from two sources: the National Comorbidity Study (NCS; Kessler et al., 1994) and the American Indian Vietnam Veterans Project (AIVVP). 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 a integrated quantitative/qualitative approach to measure.

The SHS Psychosocial Committee felt that AI-SUPERPFP questions 32-47 would provide the most appropriate assessment of social support for the SHS Family Study. The questions encompass various types of social support, including what appears to include perceived emotional support, social networks, tangible and negative social support. Negative social support may be contributory to poor health outcomes in many Indian communities. Analyses in a family study may include hierarchical linear modeling analyses where one can differentiate the impact of social support of the individual and family levels -- examining their impact on outcomes, along with structural equation methods to model the common variance and unique variances from different levels of analysis to examine family/environmental contributions.

*See Form S14, Volume 3, Appendix D.*

**REFERENCES**


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


Source Documents:


7. ANGER/HOSTILITY

Spielberger -Ax/Cook Medley Scale
(This form is optional, but will definitely be used in the Dakota Center)

**Definitions of Anger and Hostility** Anger is defined as “an emotional state that consists of feelings that vary in intensity, from mild irritation or annoyance to fury and rage” (Spielberger et al 1985). Spielberger also suggested the closely related construct of hostility. Hostility’s central feature is a complex set of negative attitudes towards others, such as distrust. These attitudes are intertwined with emotions such as cynicism, resentment, vengeance, and alienation, which tend to have complex cognitive features, thereby differentiating them from emotions such as anger, which are definable more in terms of affect.

**History of Anger and Hostility in Health Research** The Type-A behavior pattern has received much attention since it was identified by Friedman and Rosenman (1974). The idea that psychologically related factors could be risk factors for various health outcomes was not completely new, but Type A behavior made sense to many people. Who among us does not know someone who meets the criteria for “Type A behavior” and worry somewhat about their health? An expert review panel convened by the National Institute of Health (NIH) asserted that Type A behavior is an independent risk factor for the development of coronary heart disease equivalent in power to smoking or hypertension (Review Panel 1981).

As the traits of Type A behavior were broken down, anger and hostility were shown to be major risk factors for coronary heart disease (Dembroski and Costa 1987, Spielber and London 1982, and Williams 1989, and his colleagues Barefoot, Dahlstrom, & Williams, 1983, Williams et al., 1988, Williams et al., 1980). Williams (1980) measured Type A behavior and hostility in a group of heart patients. Findings were that the hostility levels were better predictors of coronary blockage than the overall Type A behavioral pattern. These findings have been extended in three other studies (Barefoot, Dahlstrom, &Williams, 1983; Barefoot et al. 1987; & Shekelle et al. 1983), all indicating that hostility scores predicted both coronary heart disease morbidity and total mortality. Also, in a meta-analysis of studies on type A behavior, Matthews (1988) concludes that hostility is a reliable predictor of events of coronary heart disease in population-based prospective studies. Correctional studies and reanalysis of the two major prospective studies, the WCGS and MRFIT, found significant relationships between clinical ratings of the potential for hostility and coronary artery disease (CAD) and CHD endpoints in the absence of significant relationships between global Type A and disease endpoints. (Matthews et al., 1977; Shekelle et al., 1985; Hecker et al., 1988; Dembroski et al., 1989).

Numerous studies have pointed to anger and hostility as playing a significant role in mortality from coronary heart disease (CHD) as well as mortality from all causes (Barefoot, Dahlstrom & Williams, 1983; Helmers, Posluszy & Krantz, 1994; Miller, Smith, Turner, Guijarro & Hallet, 1996; Siegman & Smith, 1994). Also, research has shown that mortality rates from all causes are higher for individuals scoring high on hostility (Barefoot et al., 1983; Miller et al., 1996). As such it is clear that anger and hostility play an important role in physical health. Unfortunately, most of this research has been conducted on Caucasian, middle aged men. There is very little published research found across different genders, ages or cultures.
Anger and hostility will be measured in the Dakota Center (and in the other two centers, if opting to do so) during Phase IV of the Strong Heart Study in order to determine how these traits affect health outcomes in Northern Plains Indians (and in the Tribes in Oklahoma and Arizona, if used in those field centers) using the Spielberger Anger Expression Scale and the brief Cook Medley Hostility Scale. These instruments can both be administered in under two minutes, either by interview or self-administration. Both of these instruments have been used with Native populations in previous studies and are known to have stable reliability and validity characteristics. The potential findings could be useful to both mental health and medical providers working with this population in developing interventions that could improve the overall quality of life for the proposed population.

**Administration:** Can be self-administered or in a interview format. If a participant asks for clarification, the response should be that there are no right or wrong answers and they should answer it the best they can.

**Scoring:** The scoring of the Spielberger -AX/Cook Medley Scale is broken into several steps. This instrument is actually a combination of two separate instruments. Items 1 - 20 are from the Spielberger - AX which are designed to measure the construct of anger, while items 21-28 are the Cook-Medley scale.

The AX scales yields three scales: an Anger Expression score based on all 20 items, and scores for the 8-item Anger-In and Anger-Out subscales. Some of the AX items are worded in a manner such that a high rating indicates that anger is frequently expressed. Other items are worded so that a high rating indicates that anger is experienced but not expressed.

In calculating the AX total score, the score weights for items on which high ratings indicate the expression of anger correspond to the direct score. For items on which high ratings indicate that anger is not expressed, the scoring weights are reversed, i.e., the scores for responses marked 1, 2, 3, or 4, are changed to 4, 3, 2, & 1 respectively. To obtain the AX-Total score, simply sum the weighted scores for all 20 items, making sure to take the direction of scoring into account. In calculating the AX-Total score, the 9 directly scored items and the 11 reversed scored items are:

- Directly scored items: 2, 4, 7, 9, 11, 13, 17, 19, 20
- Reversed scored items: 1, 3, 5, 6, 8, 10, 12, 14, 15, 16, 18

The Anger-In and Anger-Out scores are obtained by summing the weighted scores for the 8 items that comprise each subscale. The scoring weight for each item corresponds to the number circled on the answer sheet; all 8 items are scored directly in calculating the subscale scores. The items which comprise the AX subscales are:

- Anger-In: 3, 5, 6, 10, 12, 14, 15, 18
- Anger-Out: 2, 7, 9, 11, 13, 17, 19, 20
The range of possible scores on the AX-Total can vary from a minimum of 20 to a maximum of 80. The range of possible scores on the Anger-In and Anger-Out subscales can vary from a minimum of 8 to maximum of 32.

Items 21-28 comprise the Cook Medley scale (HO). These items are to be answered true (1), false (0) or don’t know (N/A, if the participant is not willing to answer the question). The score on the scale is the total number of items marked true (indicating hostile direction).

See Form S15, Volume 3, Appendix D.

References:


8. PSYCHOSOCIAL FACTORS QUESTIONNAIRES CHECKLIST

Reason for Incomplete Psychosocial Instruments Form

Rationale: There has been some concern that the administration of psychosocial questionnaires during Phase IV 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 S16, Volume 3, Appendix D.