O R I G I N A L   A R T I C L E

Adaptation of the Dartmouth COOP Charts for Use Among American Indian People With Diabetes

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OBJECTIVE — To adapt the Dartmouth COOP Charts for use among American Indians with diabetes and to evaluate the operating characteristics of the adapted charts because measures of health status have not been evaluated for use among American Indians with diabetes.

RESEARCH DESIGN AND METHODS — American Indian adults participated in focus group conferences to adapt and review the Dartmouth COOP Charts for use in American Indian communities. American Indian participants with diabetes were interviewed and administered the adapted charts. The operating characteristics of the charts were evaluated by measuring internal and external consistency, reliability, and acceptability.

RESULTS — Some of the wording and pictures were considered to be offensive and culturally inappropriate in American Indian communities. The adapted charts showed internal consistency in a comparison of interchart variables.

CONCLUSIONS — The adapted Dartmouth COOP Charts are more culturally acceptable than the original charts and appear to measure constructs adequately.

N IDDM is associated with increased mortality and morbidity. Because of the frequency of morbidities associated with diabetes, individuals often have diminished health status, suffering more disabilities than people without diabetes (1). People with diabetes have higher rates of being unable to work, and more frequently are unable to conduct major life activities (1). Assessment of health status may provide useful information about the physical, mental, and social functioning of the individual and can be used as a complement to clinical measures in patient care and research. Traditional western approaches to diabetes education have focused on the assessment of knowledge and clinical measures and often

do not include an assessment of health status (2).

An early hypothesis that diabetes resulted in less morbidity and mortality in American Indians compared with other ethnic groups has been widely refuted (3–11). With the growing public health problem of NIDDM among American Indians nationwide (10) and in New Mexico (12,13), it has become increasingly important to consider health status associated with NIDDM in this population (1). American Indians with diabetes experience high rates of amputations, end-stage renal disease, and retinopathy (14), and while diabetes and it's complications clearly affects health status, few data exist

on the health status of American Indians with diabetes.

Health status assessment is often viewed as too time consuming and too costly to be done (15). The Dartmouth COOP Project, a primary care research network, has developed and validated the COOP Chart system as an efficient way to assess health status in various populations (16). The Dartmouth COOP Charts were developed from the General Health Outcome Standard Form (SF-36), a questionnaire used to assess health status, and were designed for a quick assessment of health status in the clinical setting (15,16). These charts have proven to be easily administered and fully comprehensible and acceptable to both practitioners and patients in non–American Indian populations (15). However, there are no reports of health status measures specific to American Indians with diabetes.

Historically, research with American Indians has been conducted by investigators using a non-Indian viewpoint (17–19). To be successful, research needs to also include an Indian point of view. By including information from both viewpoints, research approaches and instruments can be selected and modified that are both valid and acceptable to the target population. One useful approach to include the viewpoints of participants in research is the use of focus groups (20). We chose to use focus groups to adapt the Dartmouth COOP Charts for use in measuring health status among American Indians in the study.

Before beginning the Native American Diabetes Project (NADP), a lifestyle intervention project, we conducted a study to adapt the Dartmouth COOP Charts for use among American Indians with diabetes, and to evaluate the adapted charts as a health status measure in the target population.

RESEARCH DESIGN AND METHODS

Adaptation of COOP Charts
We used standard focus group methods (21) to establish a planning group and develop a set of open-ended questions to facilitate discussion among focus groups about the

acceptability and applicability of the COOP Charts for use with American Indians with diabetes. Our aim was to determine whether the words and pictures in the charts appeared to relate the same message; whether they conveyed a certain health status concept; whether the participants understood what the charts were trying to measure and whether they thought that members of their communities would understand the charts and find them acceptable; and whether and how the charts should be changed. Permission was obtained from the Dartmouth COOP Chart Project to adapt and utilize the charts. The protocol was approved by the Human Research Review Committee at the University of New Mexico.

Adult American Indians aged 18 years and older from eight Rio Grande Pueblo communities were eligible to participate in the focus groups. Tribal health workers and public health nurses were asked to invite men and women known to have diabetes and representing a range of age, glucose control, and diabetes duration to participate. A tribal health worker and a tribal leader from each of the communities were also invited to participate. To encourage discussion in the focus groups, we provided a permissive and nonthreatening environment at a nonclinic facility, used a conference format, and invited a keynote speaker. We also provided a luncheon as a form of remuneration.

We conducted two sets of focus group conferences, four focus groups in August 1992 and five focus groups in June 1993. A community advisory group was consulted regarding culturally acceptable methods of conducting the focus groups. When possible, American Indians were trained as facilitators to conduct the focus group interviews and discussions and record responses according to a standard protocol. A conference facilitator and investigator (J.C.) introduced the concept and structure of focus groups to participants, who were assigned to a group using a color name to avoid labeling. Each individual group contained five to six participants who were grouped by the following common characteristics: people with diabetes, tribal health care workers (community health representatives), tribal leaders (governors, council representatives, governor's staff), and Indian Health Services (IHS) professionals (in June 1993). Some variation in focus group participants occurred in the first to second set of focus groups, but many participants were at both sets of focus groups although no attempt was made to ensure the

same participants in both sets. Focus group sessions lasted ~1 h. The focus group discussions were conducted in English. Comments were handwritten by trained recorders as audio or video tapes were not considered to be culturally appropriate by the American Indian planning group. Demographic information was kept to a minimum because it was seen as intrusive or threatening; however, focus group participants included both adult men and women, aged approximately 30–72 years.

Researchers hand-recorded the range of responses elicited during the focus groups and entered these data into a word processing program, organizing entries by type of question and range of responses. Using a computer printout of responses to each question, researchers examined these data to discover common themes. We used this information to redesign the Dartmouth COOP Charts. The redesigned charts were presented at the second focus group conference in June 1993. Comments about the redesigned charts were recorded and were used to make final chart revisions. The final charts were evaluated and approved by a convenience sample of bilingual community members.

Evaluation of adapted charts

The adapted charts were administered as part of the NADP, a community-based lifestyle intervention program. Eight Rio Grande Pueblo communities served by three IHS clinics participated in the project. Through a partnership agreement among IHS, the participating tribes, and the university, a computer-generated list of people with diabetes was obtained from each of the three IHS clinics. Potential participants received an NADP introductory letter. Brochures and posters announcing the project were also displayed in the clinics, post offices, and tribal offices to make the communities aware of the project. Community members were invited and recruited as bilingual interviewers by NADP personnel. The interviewers contacted people in their communities by telephone or in person to ask whether he or she would like to participate in the NADP study. A letter of informed consent was signed by each participant and an appointment was made to administer the questionnaire.

The bilingual community interviewers were trained to administer the adapted charts as part of a 9-day training session. In-person interviews were then conducted in the communities. Although the Dartmouth COOP

Table 1—*Summary of first focus group responses*

Physical fitness
  Need different pictures, show people carrying wood;
  Change facial expressions, show strain, fatigue;
  Picture 3 and 4 are the same, picture 3 needs a larger load.
Feelings
  Words irritable, anxious, depressed not acceptable;
  Don't have tongue hanging out of mouth.
Daily activities
  Pictures 2 and 3 are almost the same;
  People need to be doing something, like chopping wood.
Social activities
  Put some clothes on the people;
  The people aren't doing much, get them active.
Pain
  Pictures and words do not fit the concept;
  Pictures do not show pain;
  Show people doing a range of activities.
Overall health
  People in pictures 2 and 3 have blank stares;
  Don't have tongue hanging out of mouth.
Quality of life
  Problems with words "pretty", "could hardly be...";
  Picture is confusing, use a Pueblo ladder instead;
  Sounds similar to "Change in Health";
  Doesn't ask for anything specific.
Change in health
  It's similar to "Quality of life";
  Symbols are too confusing, don't make sense;
  Words don't make sense;
  Change title to "Health".
Social support
  Have people doing something;
  Assumes elders will ask for assistance, they may not;
  Too many examples in the question;
  Answers are too similar to each other.

Charts have been translated and validated in other languages (22), the Tanoan languages are unwritten and the interviews were conducted in English. The Native languages (Tewa and Tiwa) were, however, used in obtaining informed consent, in general discussion and to answer additional questions.

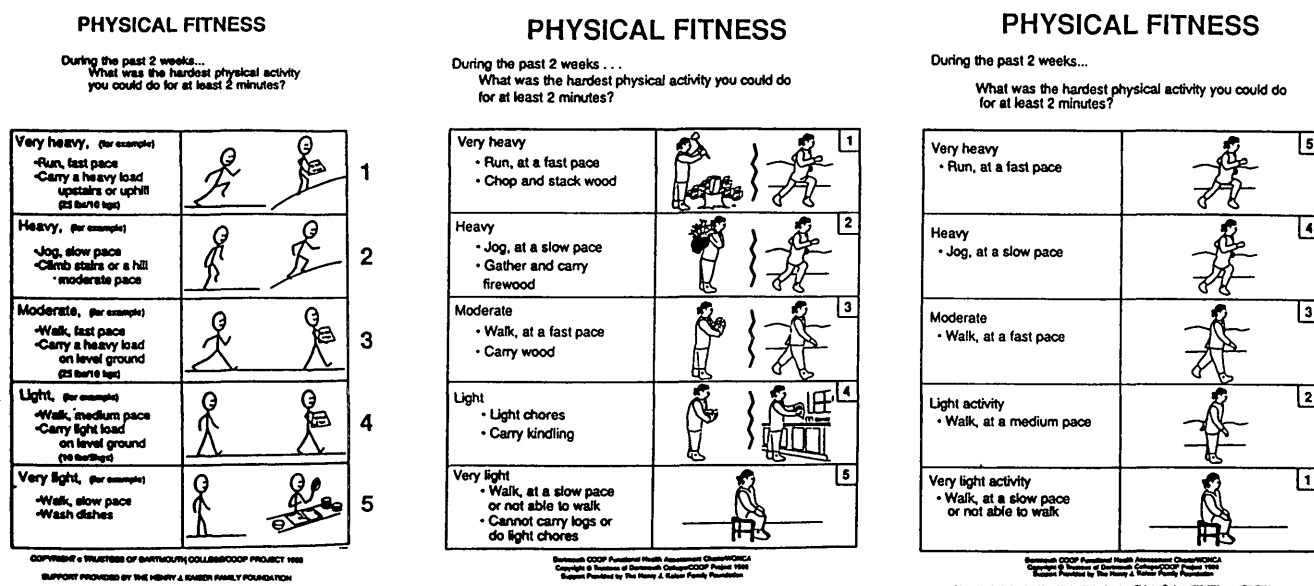The adapted Dartmouth COOP Charts made up a small portion of a longer NADP

PHYSICAL FITNESS

During the past 2 weeks...
What was the hardest physical activity
you could do for at least 2 minutes?

PHYSICAL FITNESS

During the past 2 weeks . . .
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PHYSICAL FITNESS

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Figure 1—*Adaptation of the physical activity chart through focus group interviews among American Indian people.*

questionnaire, which took approximately an hour to administer. Administration of the adapted charts consisted of showing the six charts, one at a time. Each chart consisted of a simple title and five response choices that were each illustrated by a picture. A 5-point ordinal scale was used to indicate the level of functioning. As each chart was shown, the interviewer carefully read the corresponding question aloud. The participants indicated the answer that best depicted their health status. The interviews were performed in one of three project offices located in or near the target communities. All participants were paid $10 for their time and cooperation.

To determine reliability, a retest was made by a repeat administration of the questionnaire 2–7 days after the initial administration to a computer-generated random sample of participants ($n = 30$). At that time, additional questions were asked to evaluate participant acceptance of the adapted charts.

Data analysis
We evaluated the adapted Dartmouth COOP Charts for 1) internal consistency, 2) external consistency, 3) reliability, and 4) acceptance by participants.
Internal consistency. A Spearman correlation coefficient (23,24) between different measures of the adapted charts was used to determine whether the charts had internal consistency. Two of the investigators (A.J.W., M.E.H.) decided a priori on items that would be expected to correlate based on

clinical experience and data presented in slides that used the original COOP Charts (16). Interrelated activities were expected to have a high correlation (i.e., feelings and social activities, physical fitness and daily activities, pain and overall health, feelings and overall health, physical fitness and overall health). Conversely, less-related items were expected to have a lower correlation (i.e., feelings and daily activities, pain and physical fitness, pain and daily activities). The scores from the six charts were compared in order to determine whether there was supporting evidence in the hypothesized direction. A χ^2 test was performed and an analysis of residuals was performed to determine the significance of the χ^2 test (23,24).
External consistency. To evaluate external consistency, the adapted charts were compared with measures that were constructed from the past-week physical exercise section of the full questionnaire utilized in the NADP study. The results from the past-week physical exercise section were quantified in terms of metabolic equivalent (MET) hours per week, and used for comparison. We hypothesized that people who scored low on the physical fitness chart would also have low MET hours per week. An analysis of variance (ANOVA) was used to determine whether there was consistency in the hypothesized direction.
Reliability. Cohen's κ statistic (24,25) and Spearman's correlation coefficient (23) were used to assess reliability of the adapted charts. To provide consistency with

Dartmouth published data, we used the κ reliability correlation ranges provided by Fleiss (25,26): excellent (>0.74), good (0.74–0.40), and poor (<0.4).
Acceptability. Data gathered from the focus groups showed that the adapted COOP Charts were appropriate to use in the target communities; we wanted to reassess acceptability of the charts in their final form. Three additional questions were asked of 30 randomly selected participants for repeat administration of the charts:

1. Were any of the questions confusing?
2. Are the questions easy to answer?
3. Does each question apply to your life?

Qualitative analysis methods were used to determine acceptability.

RESULTS

Adapation of COOP Charts
Table 1 summarizes the responses of the 46 people who participated in the focus groups during the two conferences. The use of charts to assess health status was found to be culturally acceptable. Although the Dartmouth COOP Charts were generally satisfactory, some changes in wording and pictures were recommended to improve comprehension and cultural acceptability (Fig. 1). The COOP Chart stick figures were found to be inappropriate and offensive as they implied poor health, and the participants thought the figures would be more acceptable if they

Table 2—*Internal consistency: Spearman's correlation of NADP-adapted COOP Chart*

	Physical fitness	Daily activity	Social activity	Feelings	Pain	Health
Physical fitness	1.0	—	—	—	—	—
Daily activity	0.38	1.0	—	—	—	—
Social activity	0.32	0.19	1.0	—	—	—
Feelings	0.06	0.17	0.12	1.0	—	—
Pain	0.23	0.40	0.17	0.39	1.0	—
Health	0.27	0.37	0.31	0.29	0.40	1.0

Correlations: excellent, ≥0.4; good, 0.25–0.39; poor, <0.25.

looked like Indian people. The consensus was that the stick figures should be changed to more realistic figures and their activities should be more common to those of American Indian people, such as chopping wood. Because the 4-week recall time period was perceived to be too long and vague, it was changed to a 2-week period to make recall over time easier. The order of the numbers on each chart was reversed as participants thought higher numbers meant you were doing better (Fig. 1).

The COOP Charts are based on the following nine domains of health: *1*) physical condition, *2*) daily work, *3*) social activities, *4*) emotional condition, *5*) quality of life, *6*) overall condition, *7*) change in condition, *8*) pain, and *9*) social support. Three domains (quality of life, change in health, social support) were not understood or were confusing and were changed or dropped. The quality of life concept was deleted as it was perceived as identical to change in health, did not ask anything specific, and contained words that were confusing and could be

misinterpreted (e.g., "pretty" used as an adverb, as in pretty good and pretty bad, and the phrase "could hardly be," as in could hardly be better). The change in health domain in conjunction with the overall health domain was seen as redundant; the pictures conveyed ideas different from those intended and did not fit with the words. Therefore, change in health was combined with overall health into one domain called health. Social support was dropped because the pictures and words did not fit well with each other, too many examples were used, too many questions were asked at one time, it assumed older people would ask for support, the people were too skinny and were not doing anything, and the overall domain did not connote social support.

The second set of focus groups, conducted to evaluate the modified charts, confirmed the need for changes, but considered some of the revised pictures to be stereotypical of sex and culture, for example, dish washing and carrying wood (Fig. 1), respectively. Suggestions included mak-

ing the figures and activities more neutral, using more descriptive facial expressions, and using one set of pictures across domains whenever possible. The suggested changes were made, and the charts evaluated a final time by another sample of six bilingual community members who approved the charts as appropriate for use in their communities.

Evaluation of adapted charts

The participants were American Indian adults ranging in age from 18 to 88 years, with a mean age of 58.2 years. Of the 211 participants, 68.2% ($n = 144$) were women and 31.8% ($n = 67$) men. Only 206 of the 211 participants were used in the analysis because four did not have a diagnosis of diabetes and one was found not to be American Indian. The mean duration of diabetes was 9.2 years.

Internal consistency. Table 2 shows the results of the Spearman's correlation between the NADP-adapted COOP Chart variables. Table 3 demonstrates that the variables hypothesized to be related had good correlation and were statistically significant, except for feelings and social activities, which correlated poorly. In addition, variables hypothesized to be less related had lower correlation.

External consistency. To measure external consistency, an ANOVA showed that the physical fitness chart was significantly related to self-reported MET h/week (physical activity) for men and women ($P = 0.001$ and $P = 0.0001$, respectively). For participants who reported a high score on physical fitness (participation in heavy to very heavy activity), the calculated MET scores had corresponding high values. As expected, the reverse was also true; when the participants reported a low level of

Table 3—*Correlation between variables of the adapted COOP charts that are hypothesized to be related versus less related*

Variables	r	P value
Variables hypothesized to be related		
Pain versus daily activities	0.40	<0.001
Pain versus health	0.39	<0.001
Physical fitness versus daily activities	0.38	<0.001
Feelings versus health	0.29	<0.001
Physical fitness versus health	0.27	<0.001
Feelings versus social activities	0.12	0.136
Variables hypothesized to be less related		
Pain versus physical fitness	0.23	<0.001
Social activities versus daily activities	0.19	0.008
Pain versus social activities	0.17	0.013
Feelings versus daily activities	0.17	0.022

Correlations: excellent, ≥0.4; good, 0.25–0.39; poor, <0.25.

Table 4—*Reliability of the NADP-adapted COOP charts*

	κ	Spearman's coefficient
Physical fitness	0.16	0.18
Social activity	0.37	0.42
Feelings	0.48	0.52
Health	0.76	0.78
Pain	0.46	0.47
Daily activity	0.66	0.70

κ correlation: excellent, >0.74; good, 0.74–0.40; poor, <0.4. Spearman's correlation: excellent, ≥0.4; good, 0.25–0.39; poor, ≤0.25.

PHYSICAL FITNESS

During the past 2 weeks . . .
What was the hardest physical activity you could do
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PHYSICAL FITNESS

During the past 2 weeks...

What was the hardest physical activity you could do
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PHYSICAL FITNESS

During the past 2 weeks...
What was the hardest physical activity
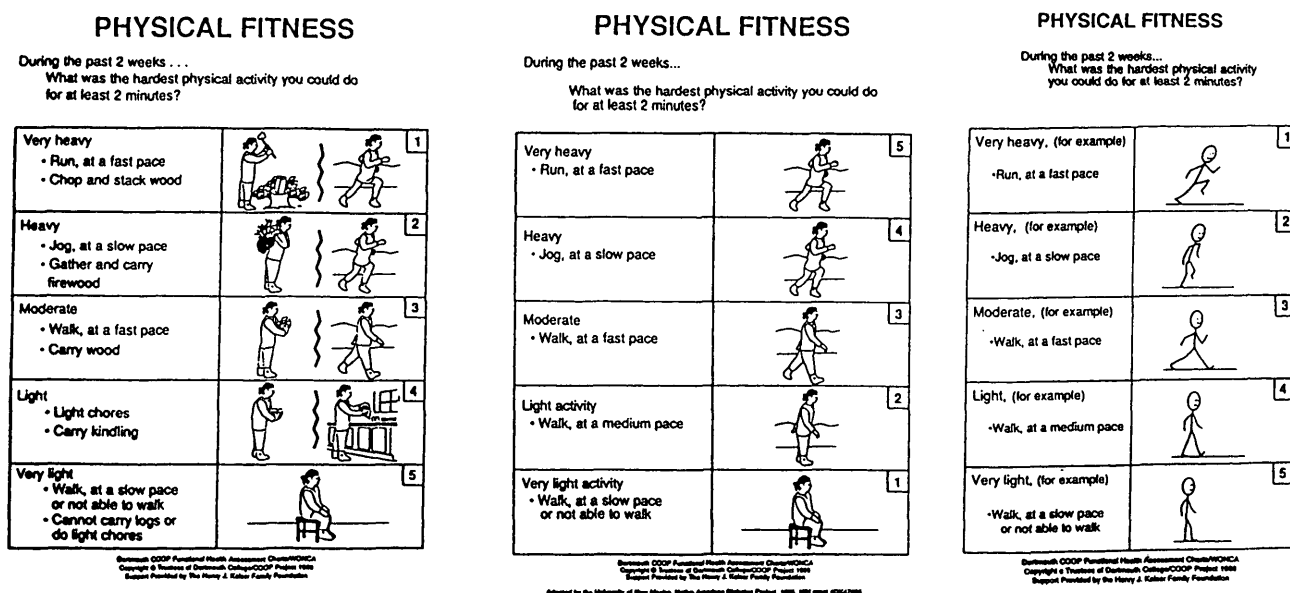you could do for at least 2 minutes?

Figure 2—*COOP/WONCA functional assessment charts compared with the first and second versions of the NADP-adapted Dartmouth COOP charts.*

physical fitness, their MET scores were low. **Reliability.** The test/retest reliability results suggest that the adapted charts are reliable for all of the charts except two charts (Table 4). The intraclass Spearman's correlation coefficients ranged from 0.18 to 0.78, with a mean of 0.51. If the physical fitness variable was excluded due to low reliability, the mean intraclass correlation rose to 0.58. The Cohen's κ statistic shows similar results with a range of 0.16–0.76, mean 0.48. Physical fitness and social activity charts both have poor reliability (κ = 0.16 and 0.37, respectively).

Acceptability. Data assessing participant acceptability of the adapted charts showed that the charts were regarded as highly acceptable. More than 93% of the participants said the charts were easy to answer. Only two people thought the charts were confusing: one person found the pain chart difficult to answer because her/his pain changed from day to day; the second person said the charts were confusing because she/he became nervous during the interview process; in addition, she/he had become increasingly confused in the past few days because of a recent illness.

CONCLUSIONS — The adapted Dartmouth COOP Charts appear to be an acceptable instrument for use in Rio Grande Pueblo American Indians and a good instrument to measure health status in this American Indian population. The ability to assess health status among American Indian people with diabetes may pro-

vide useful information to health care providers interested in improving diabetes care and also the quality and applicability of behavioral diabetes research in general. Assessing health status may have a secondary effect on glycemic control as health care providers have additional information about patients' physical, mental, and social functioning and can work together with diabetes patients to achieve and maintain better health (27).

Focus group interviews were a good method and source of information to adapt the Dartmouth COOP Charts in this population. By including the participants in the process, we were able to produce a more culturally acceptable measure of health status. Our approach to adapting the instrument is supported by the comparability of our revisions to the Dartmouth COOP Charts with the revisions made to those charts by the World Organization of General Practitioners/Family Physicians

(WONCA) Functional Status Classification Committee to develop a system to measure health status in an international research setting (28) (Fig. 2).

As a test of the utility of the adapted Dartmouth COOP Charts as a health status instrument in this American Indian population, we found good correlation between variables thought a priori to be related, except for social activities versus feelings. A comparison of our results with previously published data from six of the nine original Dartmouth COOP Charts (16) showed similar findings. The majority of the variables coincide and have a good or excellent correlation in a comparison of the two versions of the COOP Charts (Tables 2 and 5); however, the construct of social activities differs between the two. The following are two possible reasons for this difference: 1) the adaptation of the Charts changed the operating features for this parameter, or 2) this American Indian population's percep-

Table 5—*Internal consistency: Spearman's correlation of original COOP Chart variables*

	Physical fitness	Daily activity	Social activity	Feelings	Pain	Health
Physical fitness	1.0	—	—	—	—	—
Daily activity	0.35	1.0	—	—	—	—
Social activity	0.23	0.59	1.0	—	—	—
Feelings	0.02	0.39	0.53	1.0	—	—
Pain	0.25	0.44	0.36	0.26	1.0	—
Health	0.36	0.57	0.50	0.48	0.38	1.0

Correlations: excellent, ≥0.4; good, 0.25–0.39; poor, <0.25.

tion and participation in social activities differs from those of non–American Indian populations. The latter conclusion is likely because American Indians have different community and social obligations. For example, their attendance at social activities (such as feast days and/or traditional dances) is expected, and is defined by distinct cultural and societal expectations. The difference in reliability between the adapted social activities chart versus the original also suggests that this chart may be interpreted differently in this population.

Results from the physical fitness chart show a possible interpretive difference when comparing the original and adapted COOP Chart. In this study, the close association between the physical fitness and self-reported MET h/week, the poor reliability of this chart, and the poor correlation between physical fitness and pain could all be explained by participants interpreting physical fitness as physical activity. In addition, while the original charts showed a good correlation between feelings and daily activities ($r = 0.39$), the adapted charts showed a poor correlation (0.17), indicating that these charts may have a different meaning in our study population.

We assessed the acceptability of the adapted charts and determined that community members considered the adapted charts to be acceptable measures of health status in addition to finding them to be culturally appropriate to their communities. The acceptability of the adapted charts was overwhelmingly positive. More than 93% of the participants found the charts easy to understand and answer and said they pertain to their lives.

This study has several limitations. First, we were unable to assess validity of the adapted charts at this time. Previous studies have documented the validity of the original Dartmouth COOP Charts (16) in non–American Indian populations by comparing the charts to previously validated measures such as the RAND short-form health status questionnaire. We could not validate the adapted COOP Charts in this manner because a "gold standard" for measuring health status in American Indian populations does not exist, and we believe the SF-36 would need to be adapted for this population. We attempted an external validity approach using diabetic complications (comorbid factors) as health-related indicator variables to determine severity groupings (27). Unfortunately, we did not have a sufficient number of patients within

each comorbid category and could not validate by groupings for severity of disease.

Second, correlations between unrelated items may have appeared related because of response bias. In the adapted charts, the positions of the ordinate scale were always in the same direction, so that the highest level of function was indicated by the number 5 and listed at the top of the chart. This was done in response to focus-group feedback in which tribal members noted confusion when a better outcome was given a smaller number or located in a different position on different charts. Therefore, it was decided that this confusion provided greater risk to interpretation of the adapted charts than response bias.

It is not clear whether the Dartmouth COOP Charts can be implemented cross-culturally and still accurately help physicians to assess changes in health status associated with chronic disease. A preliminary trial has been completed in seven other countries to determine the international applicability of the WONCA/COOP Charts (23). The only change made to the charts was the translation into the respective languages. Landgraf et al. (22) concluded that the WONCA/COOP Charts were an acceptable instrument to evaluate health status and that they continue to have clinical utility (15). Because the adapted COOP Charts in our study are similar to the WONCA version evaluated by Landgraf et al. (22), subsequent longitudinal data from the Native American Diabetes Project may contribute to the findings of those researchers.

Third, bias may have been introduced in the data collection during the focus groups as handwritten notes were taken instead of taped recordings. The conference facilitator and the recorders were all researchers or health professionals trained in the focus group process, which may address the concern for bias.

Lastly, by changing or deleting three of the domains of health status charts (quality of life, change in health, social support), we may not have captured other components of health that are valued in the Pueblo community. In future research studies, researchers may want to include a qualitative study before the adaptation of health assessment instruments to understand cultural concepts of "health," thereby replacing culturally inappropriate categories with the culturally appropriate categories rather than just deleting the ones found to be inappropriate.

The methods of adaptation described in this study may provide a useful model for future use in adapting additional instruments and materials for American Indian people with diabetes and other chronic conditions.

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