

Working Paper No. 115

**Cultural Conceptions of Illness
and the Measurement of Changes
and Differentials
in Morbidity**

by

P. Stanley Yoder

University of Pennsylvania

1989

This is one of a series of working papers produced by the Center for International, Health, and Development Communication, University of Pennsylvania. The research reported here was done in collaboration with the Fonds National Médico-Sanitaire (FONAMES) of the Zaire Ministry of Health and was supported in part by the Academy for Educational Development through its Communication for Child Survival contract with the U.S. Agency for International Development, Bureau of Science and Technology, Offices of Health and Education (Contract no. DPE-1018-C-00-5036-00). This paper is the responsibility of the author and may not represent the views of those who have supported the research. This paper was presented at the Health Transition Meeting sponsored by the Rockefeller Foundation in London, June 7-9, 1989.

INTRODUCTION

In doing comparative studies of health, morbidity, and mortality, researchers often have to deal with unsatisfactory sources of information and great variety in methods of survey design, data collection, and analysis. Because of the frequent gaps in the data and the inherent biases of service usage reports from health facilities, surveillance data does not often provide a valid picture of changes in morbidity. For those interested primarily in morbidity, large scale surveys of the general population provide an alternative source of information.

However, large-scale surveys ask questions of individuals whose definitions of disease and illness are different from those recognized by biomedicine. How can we ask about diarrhea, or malaria, or pneumonia, if the population does not understand or recognize these diseases as we do? To what degree should we try and take into account local knowledge of illness in planning health surveys? What difference does it make in the nature and quality of the data collected? Isn't translating the questionnaire into the local language sufficient to obtain reliable data?

This paper discusses how anthropological concepts and research techniques can be used to improve the data collection process for surveys of childhood morbidity. In particular, the way in which large-scale surveys may take into account local cultural conceptions of illness in developing a survey instrument and planning the analysis of data will be considered. Demographers, for example, have recently become more aware of the impact of differing cultural conceptions of illness in collecting data on mortality and the cause of death (Zimicki et al. 1985). Many survey researchers have also tried to translate survey questions in ways that are more appropriate in concept and language to the populations surveyed (Vaessen et al. 1987). More and more often questionnaires are translated and printed in local languages.

While the translation into a local language clearly brings a questionnaire closer to local conceptions of illness, it does not solve the issue of how local ethnomedical conceptions of illness should be considered in the formulation of the questionnaire. Some researchers have looked to anthropology for research techniques that will provide the information needed to formulate specific questions in ways that more closely reflect local conceptions of illness. It is primarily scholars doing ethnomedical research who can provide guidelines on how this might be done, for they have found ways to elicit taxonomies of illness and have shown that there are major differences among peoples in how they identify and categorize illnesses.

The purpose of this paper is to identify concepts and research methods from medical anthropology and ethnography that can prove useful in developing surveys for monitoring changes in morbidity. The first section will be devoted to presentations of anthropological approaches to the study of cultural conceptions of illness. The second section discusses research issues in morbidity studies that relate directly to cultural conceptions of illness. The third section discusses different research strategies and presents a research method that has been used successfully to discover taxonomies of illness and develop appropriate survey questions in a short amount of time. The fourth section describes how this

research method was followed in Zaire and outlines some of the results obtained to illustrate what can be accomplished. The fifth and final section examines the implications of ethnomedical studies for questionnaire design and summarizes the ways in which ethnomedical research can be used to improve survey instruments in morbidity studies.

1. THE STUDY OF CULTURAL CONCEPTIONS OF ILLNESS

1.1 Approaches to the Study of Illness

In his comprehensive review of medical anthropology, David Landy (1983:185) remarked that the field "has undergone an explosive growth both in literature and in the number of individuals identifying themselves as medical anthropologists," but that the field has no single theoretical framework. Landy goes on to say that a kind of ecological-evolutionary perspective has achieved fairly wide acceptance among the majority of anthropologists. It is also generally accepted that becoming sick always has social and cultural aspects that cannot be ignored in the study of illness behavior.

A great deal of ambiguity can be seen in the medical anthropology and public health literature when it comes to examining specific conceptions of illness and how to evaluate the impact of these conceptions on the choice of medical treatment. However, certain concepts have been developed and certain conclusions have been drawn that serve to orient much of the research in medical anthropology. Those concepts and conclusions that are pertinent to the study of cultural conceptions of illness as they relate to the measurement of changes in morbidity are discussed below.

1.2 Medical Pluralism

Virtually all populations today live in an environment of medical pluralism, that is, where individuals and groups have a choice of medical treatments from differing traditions. In his introduction to Asian Medical Systems, Charles Leslie discusses medical pluralism and notes that the book amply demonstrates the reality of pluralistic choices in Asia (Leslie 1976). Mark Nichter has clearly shown the process of pluralistic choices for treatment in South India (Nichter 1978). One of the most fruitful and articulate discussions of medical pluralism is found in the work of John Janzen, who analyzes a series of case studies from southwestern Zaire (Bas Zaire) to show the process of multiple consultations of traditional healers, prophets, and medical practitioners (Janzen 1978).

Research on the choice of treatments for illness in pluralistic settings constitutes an important domain of research in medical anthropology today. For many years research was dominated by efforts to evaluate the importance of beliefs in the choice of treatment, a debate most clearly shown in discussions of the importance of hot/cold theories of food, medicine and illness in Latin America (Logan 1973; Rubel 1983). Many scholars sought to explain the differential use of modern medical services by populations that held beliefs about illness and medicine markedly different from biomedical knowledge (cf. Foster &

Anderson 1978). Such research emphasized the cultural barriers to changes in health-related behavior.

In the 1980s the emphasis of ethnomedical research shifted somewhat from the study of beliefs as barriers to change to the study of the form and content of ethnomedical knowledge per se. J. Coreil and D. Mull aptly describe this as a shift from a "conflict model" to an "insight model" (Coreil & Mull 1988). Research in this vein focuses on behavior and conceptions of illness and decisions related to health as seen from the viewpoint of the actors. This perspective uses ethnomedical definitions of what is relevant data as a starting point for examining knowledge and behavior (cf. C. Good 1988).

Evidence of this change in emphasis is varied, but it includes the great attention paid to the semantic interpretation of the experience of illness (B. Good 1977; Kleinman 1980), the numerous studies of specific ethnomedical systems, and the increase in research on health-seeking behavior. Ethnomedical studies have established that particular populations have their own system for identifying and categorizing illness, their own therapy, and their own rules for choosing treatments and evaluating efficacy, even though they now choose treatments from several different traditions. There is far more interest today in both understanding the principles that inform medical choices and in observing how those principles may influence decisions.

1.3 Disease and Illness

The distinction between disease and illness has proved to be a useful heuristic device that enables us to make a contrast between biomedical definitions and local, culturally determined definitions of phenomena. Although disease and illness are usually regarded as synonymous in common English usage, the biomedical paradigm makes a useful distinction between the two concepts. Disease refers to bodily dysfunction, while illness refers to individual experience of disease. Thus physicians diagnose and treat diseases while patients suffer illnesses (Eisenberg 1977). Eisenberg defines diseases as "abnormalities in the structure and function of body organs and systems." Illnesses, on the other hand, are "experiences of disvalued changes in states of being and in social function" (ibid:11). It is, of course, possible to have a disease without being ill or to have an illness with no disease.

In this context illness has both cultural and social aspects. The cultural aspects are those concerned with the ascription of meaning to illness episodes and, as such, are part of a wider symbolic reality that is culturally constructed. In North America the cultural aspects of illness were long obscured by the assumption that everyone accepts the biomedical model of disease as defined by the medical system, for biomedical practitioners defined what was relevant and there was little interest in studying "lay knowledge" or patient experience. That has now changed dramatically.

The social aspects of illness are those concerned with the roles and statuses of sick individuals, with the social networks that participate in health seeking behavior, and with

the social ascription of causality of illness. The roles and statuses of the sick change as they assume and discard the sick role (Mechanic 1978).

While the disease/illness distinction has been criticized as simplistic, too relativistic, or neglecting the social aspects of sickness (Young 1982), it has served to focus research on patient interpretation of the experience of illness and on cultural conceptions of illness per se. The relative usefulness of the distinction will be shown in a later section when local conceptions of illness are discussed.

1.4 Illness Episodes

Illness episodes have now become the standard behavioral units for both observational studies of illness and surveys of morbidity. While epidemiological studies of morbidity have long presented data in terms of frequency and duration of episodes of disease, anthropologists have come more recently to the observational study of episodes of illness. Horacio Fabrega was one of the first to make an articulate case for the use of episodes of illness and demonstrated how such episodes could be observed over time in his research in Mexico (Fabrega & Zucker 1979). Noel Chrisman (1977) has described a fruitful model for the stage by stage analysis of illness episodes to facilitate the study of the process of decision-making by the participants as they perceive symptoms of illness, make a diagnosis, choose a therapy, and evaluate the efficacy of that therapy.

Illness episodes are also the proper contexts for examining the cultural conceptions of illness, for each stage of behavior during an episode (symptom perception, diagnosis, choice of therapy, evaluation of efficacy) is shaped by those concepts. Societies differ in their interpretation of observable symptoms. For example, loose stools during developmental stages such as teething or crawling are often thought of as natural markings of the stage rather than as a symptom of illness. Blood in the urine of young children is not considered as a symptom of illness in some parts of Africa where schistosomiasis is endemic. As for diagnosis, the fact that each ethnic or linguistic group has its own system (ethnomedical system) for classification of illnesses is now generally recognized.

1.5 Belief and the Choice of Treatment

The diagnosis of illness and the choices of treatment cannot necessarily be predicted by invoking beliefs about illness. Although this statement may seem obvious, it is important to note because of the great emphasis placed upon belief in studies of illness causation, treatment choice, and use of medical facilities. Many scholars in the 1960s and 1970s gave the impression that it was belief--in a hot/cold theory, or the evil eye, or sorcerers--that determined both diagnosis and treatment (Harwood 1970; Logan 1973; Foster 1976; Foster & Anderson 1978). This perspective implicitly assumed that belief in the reality of "folk illnesses" would diminish with increasing contact with Western culture.

In the 1970s more studies of specific ethnomedical systems, and about health-seeking behavior as a process, became available in medical anthropology. These studies showed

that beliefs ("knowledge" is preferable) about illness were more systematic and less determinant of actions than was thought earlier (Warren 1974; Bibeau 1979; Leslie 1976). As a case in point, George Foster has recently reinterpreted his own data on treatment choice in Mexico to show that the principles of hot/cold opposition, thought to be fundamental to the humoral theory of Spanish-American medicine, serve a validating function rather than a prescriptive function in the choice of treatment (Foster 1988). James Young (Young 1981) has provided an excellent example of how one can combine the study of beliefs, or knowledge, and behavior regarding illness.

1.6 Qualitative and Quantitative Approaches

Both qualitative studies of the meaning of behavior within illness episodes and quantitative studies of ecological or epidemiological factors are essential to an understanding of behavior related to health, disease, and illness. Qualitative research methods provide a means to examine what has been called "lay knowledge" of disease, illness, and medicine in order to understand illness behavior. This lay knowledge has both observational, or descriptive, and theoretical levels, as people draw on explanatory theories to give meaning to what they observe when they become ill. Arthur Kleinman (1980) has developed a theory of "explanatory models of illness" to encapsulate individual efforts to create order and meaning in illness episodes. In this perspective, the study of illness must always address how individuals make the experience of illness meaningful to themselves, an aspect of illness episodes which involves qualitative research on the process of making decisions within those episodes. The results often show the form of explanatory principles in other domains as well as the logic of knowledge about illness.

On the other hand, studies that examine the influence of specific variables on illness behavior are crucial to an understanding of the relative importance of different factors in the response to disease. These studies demand quantitative analysis of survey data and may include environmental, physiological, or behavioral factors. Results can often show the relative importance of factors such as age, education, and access (geographic, economic, social) in explaining specific behaviors.

Many anthropologists today assume that research on illness necessarily involves both qualitative and quantitative techniques for data collection and analysis. This is well illustrated in the outstanding overview of anthropological methodology for research on diarrhea by P. Pelto, M. Bentley, and G. Pelto (Pelto et al. in press). These authors stress the importance of examining folk taxonomies of illness before conducting observations and household surveys. In order to take into account cultural conceptions of illness in the measurement of morbidity, local ethnomedical classifications of illness must be taken at face value initially and ways found to elicit and use the appropriate terms. That is, what people "believe" about illness is really what they know from their own ethnomedical system. As social scientists, we face the challenge of discovering what that knowledge is and how it enters into making decisions about health and illness.

2. APPROACHES TO THE MEASUREMENT OF MORBIDITY

2.1 Surveys of Morbidity

The measurement of morbidity relies largely on three types of data: routine surveillance data, sentinel surveillance data, and survey data. In his review of the causes of diarrhea and issues in the measurement of diarrheal morbidity and mortality, Robert Black (1984) discusses the merits of different sources of morbidity data. With regard to routine surveillance data, Black notes that information is often deficient because diarrhea may not be a reportable disease, because the completeness and accuracy of the data are influenced by the distribution of health facilities and other resources, and because many cases are not brought to health facilities. He concludes by saying that "diarrheal incidence rates based on health service statistics are not useful indicators of the actual level of diarrheal morbidity" (Black 1984:151). He also mentions that prospective, or longitudinal, studies are the best means for estimating diarrheal morbidity, but that the number of regular observations required and the need for close supervision make such studies too expensive for many countries.

The review of longitudinal studies of diarrheal morbidity and mortality conducted by John Snyder and Michael Merson reveal other problems in the use of longitudinal data (Snyder & Merson 1982). They considered twenty-two studies conducted for at least one year and two multi-country studies for a total of twenty-four studies. Except for the latter two, each of the studies conducted morbidity observations every two weeks. The data were used to calculate the annual number of actual diarrheal episodes for children under five years of age in Asia, Africa and Latin America. They concluded that because of the relatively uniform results in these three regions of the world, the morbidity and mortality figures are probably fairly accurate.

However, the authors mention two main problems with these data. First, the frequency of the observations and the size of the sample population affected the estimates of incidence. Second, only ten of those studies presented definitions of diarrhea and eight different definitions, including two formulated by mothers, were used. Thus we are uncertain of the equivalence of the phenomena being observed. These problems suggest that rates of morbidity from such surveys should be used with great caution. In fact, all of these studies (with the two exceptions mentioned) begin with the assumption that the definition of diarrhea or other illnesses and symptoms are biomedical and uniform. It turns out that the actual operational definitions used for relevant data in these surveys vary widely, which makes valid comparisons difficult.

The importance of making explicit the operational definitions used to define relevant data are valid for most syndromes or groups of diseases. A review of health interview surveys carried out in developing countries conducted by David Ross and Patrick Vaughan reveals problems in comparability similar to those cited above (Ross & Vaughan 1986). The surveys varied widely in their definitions of illness, in sampling design, in interviewing training and techniques, in proxy versus self-reporting, and in recall periods. Symptoms

of morbidity were reported as specific symptoms, as dysfunctions of organic systems, or as medical diagnoses.

The authors conclude that these cross-sectional surveys differed widely in their reported morbidity prevalence and in their assessment of the use of health care facilities, differences that are reflections of major contrasts in methodology. While more consistency in all aspects of survey design would improve comparability, the most pertinent issue for our discussion is the development of more consistency in the way diseases under study are defined and data are collected about their prevalence.

2.2 Surveys and Local Knowledge of Illness

The importance of considering just how well a survey population has understood the survey questions asked is beginning to receive attention. This issue was confronted in a study of the cause of death in Bangladesh where it became clear that misclassifications of the cause of death occurred because of inconsistencies in the eliciting and recording of information (Zimicki et al. 1985). As the authors note, "one of the most important reasons for misclassification is the lack of fit between local and medical notions of why people die" (ibid:9). The example provided is that of neonatal tetanus. An examination of the day of death and the sex ratios of deaths suggested that deaths caused by other factors (prematurity, congenital defects, hyaline membrane disease) may have been included in the category of tetanus because of similarity in the observed symptoms.

This returns us to the central questions of this paper. How can recognition of local knowledge of cultural conceptions of illness be used to improve data collection for surveys of morbidity? To what extent should local knowledge of illness be taken at face value in developing questionnaires? Are local diagnoses ever sufficiently clear and reliable to form the basis of questioning? Should questions be asked about symptoms, or illnesses, or diseases, or all of them? At what point and in what way should the translation be made from ethnomedical into biomedical terms?

To respond to these questions and evaluate the pros and cons of different solutions, I shall use data from ethnomedical studies of diarrheal disorders. Diarrheal disorders have been chosen mainly because there is more information available about those disorders than about others, for a great deal has been learned about local knowledge of diarrheal disorders as well as about the choice of treatment. There is very clear evidence available about the nature of differing diagnoses of diarrheal disorders and about how those diagnoses differ from biomedical definitions. However, the same principles can be applied to the study of other syndromes or groups of disorders (acute respiratory infections, fevers and malaria, etc.). I shall then present recent qualitative and quantitative data from Zaire about the diagnosis of diarrheal disorders in Swahili to illustrate the main methodological points and to show patterns in local diagnoses.

3. RESEARCH STRATEGIES FOR DIARRHEAL DISORDERS

3.1 Taxonomies of Diarrheal Disorders

A number of anthropologists have recently published findings on the classification of diarrheal disorders into different illnesses and on common beliefs and practices. These data come from many countries (Honduras, Peru, South India, Sri Lanka, Costa Rica, Pakistan and Swaziland) and were generated with qualitative research methods. In most cases, data collection was related to a primary health care project of some kind. The authors have all presented a taxonomy of types of diarrheal disorders as well as descriptions of beliefs associated with several kinds of diarrheal illnesses and options for treatment. In most cases mention is made of an illness that we would gloss as diarrhea with dehydration but that is locally considered to be an illness distinct from diarrhea.

Susan Scrimshaw and Elena Hurtado have reported on the typologies of diarrheal disorders in Guatemala, Nicaragua and Costa Rica in an article describing how anthropologists can work with primary health care projects (Scrimshaw & Hurtado 1988). Carl Kendall and colleagues contrasted ordinary diarrhea with that associated with empacho and "fallen fontanelle" in Honduras (Kendall et al. 1984).

Following research that focused on feeding and nutritional issues during diarrhea, Margaret Bentley has reported on different types of diarrhea in Peru (Bentley n.d.). Research in Swaziland by Ted Greene showed three main types of diarrheal disorders, including diarrhea with dehydration (Greene 1985). Extensive research by Dennis Mull and Dorothy Mull in Pakistan showed a similar typology (Mull & Mull 1988). Finally, Mark Nichter discussed Sinhalese conceptions of diarrhea, dehydration, and the response to ORT (Nichter 1988).

In research conducted in three language groups (Hassaniya, Ffulde, Fulani) in Mauritania, and in three language groups (Nupe, Hausa, Gwari) in Nigeria, very similar results were obtained (Yoder 1985). In all six cases several kinds of diarrheal disorders were identified and characteristic symptoms were given. In all cases diarrhea associated with dehydration was diagnosed as an illness separate from diarrhea and one that required a very different sort of treatment.

While still other research could be cited, these authors share a concern for collecting and analyzing data that can be used in the planning and implementing of improved care of diarrheal disorders, most often by the promotion of some kind of oral rehydration therapy. It is also worth noting that these data were collected in a relatively short amount of time, often by a team of researchers, rather than by a single anthropologist working for many months.

The results from all of these studies have several points in common. First, they all show that a number of illnesses (from four to eight) whose symptoms include loose/frequent stools are identified in the local language. Second, that these illnesses are labelled, or diagnosed, according to symptoms, causes, or both. Third, that diarrhea accompanied by

what biomedicine regards as signs of dehydration is identified as an illness distinct from diarrhea and usually as unrelated to diarrhea. In short, one does not usually find a single term that groups diarrheal disorders into one category of illness as we do.

This evidence indicates that the choice of terms used for diarrhea in a survey may have a large impact on the data collected. Suppose, for example, that we conduct a survey of morbidity due to diarrhea in a context in which there are four different types of diarrhea as locally defined, plus an illness we would gloss as dysentery, and another we would gloss as diarrhea with dehydration. How should the questions on diarrhea be formulated? If we ask only about diarrhea per se, how many of the cases of dysentery and dehydration will be included?

While the answers to these questions remain incomplete, it is clear that some qualitative research on local identification of diarrheal disorders should precede the development of survey instruments. It is less clear that research projects have the time, funds, or personnel to conduct such research as part of developing a questionnaire. The next section considers various strategies to accomplish that task.

3.2 Rapid Research Strategies

Anthropologists have made very few attempts to develop a research strategy that can rapidly provide ethnographic data useful to primary health care projects or to survey researchers. Some anthropologists would even insist that such efforts betray basic tenets of ethnographic research (cf. Alland 1988). Yet there is growing evidence that it is possible, and that many types of survey research might profit from the development of explicit research guides or manuals for the study of health-related behavior.

The most comprehensive guide available is the product of several years of collaboration among many individuals in research and testing under the direction of Susan Scrimshaw and Elena Hurtado. Sponsored by the United Nations University, this is a field guide for "conducting rapid assessments of health-seeking behavior, behavior involved in maintaining health and overcoming illness, including the use of both traditional and modern health services" (Scrimshaw & Hurtado 1987:1). The manual contains directions to cover many aspects of research, from design to developing protocols, from analysis to presentation of final reports. Qualitative research methods are emphasized.

The manual was developed so it could be used by anyone with some training and experience in the social sciences. While the scope of this guide is far wider than is needed for ethnomedical research in preparation for a morbidity survey, the section on focus groups will be helpful in situations where all that is desired is identifying the local names of illnesses.

A second example of a guide more focused on the questions we are pursuing is the one developed by the Dietary Management of Diarrhea project (DMD) as recently reported by Margaret Bentley and her colleagues (Bentley et al. 1988). Bentley wrote a field guide for qualitative research on beliefs about diarrhea and feeding practices for use in Peru and

in Nigeria (Bentley 1986). Called a "rapid ethnographic assessment" (REA) methodology, the guide provides simple and systematic directions for choosing field research sites, eliciting illness taxonomies, and collecting data on symptoms, causes, and treatments of illness. The core activity is the interviewing of several dozen individuals with a flexible and open-ended protocol.

The key to the success of this method lies in the selection of informants to be interviewed and in the skill and training of the interviewers. With so few interviews it is crucial that time be spent in selecting a wide range of persons willing and able to talk, in order to capture the variations in cultural conceptions of illness. It also takes a very skilled person to conduct open-ended interviews. It is unclear how the symptoms and treatments of specific illnesses are used in the research results.

3.3 A Rapid Research Strategy in Ethnomedical Studies

In the context of working with several primary health care projects, the author developed a methodology that fits the needs of survey researchers for assistance in collecting and analyzing ethnomedical data for survey purposes. This methodology was first pursued in three language groups in Mauritania, then three languages in Nigeria, and most recently, in Lubumbashi, Zaire. This model of research provides a way to collect ethnomedical data that shows how illnesses are classified, how symptoms are grouped according to illness, and what causes and options for treatment are known. It consists essentially of interviewing a number of small groups of women (3-5), asking questions about common illnesses in local terms. The questioning is always open-ended and moves from the general to the specific within each session, so that the persons interviewed provide the terms for subsequent questions.

Interviewing several persons in a group rather than one person at a time has two advantages: there are always one or two persons willing and able to answer questions, and it makes it possible to obtain answers from a wider range of individuals in a short amount of time. One can easily interview four or five groups per day in one village or neighborhood, which makes it possible to interview 35 or 40 groups in 10 different areas in two weeks. Having that number of groups makes possible a comparison of the responses about specific symptoms of the illnesses of primary interest.

One first asks for the names of common illnesses, or for illnesses that strike a certain group (children, women, men, very young children) according to the focus of the research. Once the names of illnesses provided are largely known and further questioning gives little or no new information, one selects those illnesses of particular interest and asks about their symptoms, possible causes, and treatments. Although it is a good idea to always begin with several general questions, the sessions that occur later in the two weeks of data collection focus more on specifics than do the early ones.

The key to the success of this model is the way the process of questioning is constructed, both with each group and during the period of fieldwork. The questioning of the first two days is largely devoted to asking about illness lexemes in order to get a

comprehensive list. Once the responses begin to become repetitious, one begins to ask about the specific symptoms, causes, and possible treatments of the illnesses of interest. It is always the persons interviewed who provide the terms and concepts to be used in subsequent discussions.

In the analysis, the information collected on specific illnesses (symptoms, causes, treatments) is grouped into tables that make it possible to compare the answers of each group to the same questions. This allows the analyst to evaluate the relative consistency of the symptoms given for a particular illness as well as to make a judgment about the range of treatment possibilities.

The main advantages to this strategy are the short amount of time required, the fact that informants provide all terms and categories for questioning, and the way symptoms can be grouped according to specific illnesses to estimate the consistency of knowledge about symptoms. Research can be completed in five weeks, with one week of preparation, two weeks of fieldwork, and two weeks for analysis and report writing. Results from the use of the research methodology in Swahili in Lubumbashi, Zaire, are provided in the next section.

4. ETHNOMEDICAL DATA FROM ZAIRE

4.1 The Ethnomedical Study

In November 1988, following the model developed in Mauritania and Nigeria, an ethnomedical study was conducted concerning the most common childhood illnesses in the city of Lubumbashi, Zaire. The study was part of a series of research activities conducted by the Annenberg School of Communications in order to evaluate the HEALTHCOM project in Zaire that had been designed and implemented by the Academy for Educational Development with funds from USAID. Since the purpose of the study was to provide information for an oral rehydration therapy (ORT) promotion campaign and for developing a questionnaire on diarrhea and vaccinations, diarrheal disorders were given high priority. Swahili is the language spoken by nearly everyone in Lubumbashi.

In addition to the names of diarrheal disorders in Swahili, information was needed about what symptoms were associated with each illness characterized by diarrhea, in order to understand what women observe when they identify particular illnesses. The process of data collection will be briefly described and the results summarized to serve as an example of what can be accomplished with the research strategy outlined above.

The study was conducted in Swahili by a Zairian anthropologist from the University of Lubumbashi, and two assistants, after he and I had spent one week in examining written materials and practice interviewing. A total of 35 groups of three to five women per group were interviewed in three different zones of the city over a period of two weeks.

The average time spent with each group was about 45 minutes. Questions asked were always open-ended and progressed from general to specific within sessions. Once a list of common childhood illnesses was established and further questions did not reveal new information, the investigations concentrated on soliciting the symptoms, treatments and possible causes for each illness associated with diarrhea.

It was found that people spoke of five different illnesses which generally included frequent and/or watery stools as characteristic symptoms: maladi ya kuhara, kilonda ntumbo, lukunga, kasumbi, and buse. That is, for Swahili speakers in Lubumbashi, a child with frequent/watery stools may have had one of five illnesses. To analyze the data, the symptoms, causes, and treatments mentioned for each illness were arranged in tabular fashion to permit comparison of the common symptoms of each illness as well as the responses of each group to the elements related to each illness. Table 1 shows four examples of what was recorded for two illnesses, maladi ya kuhara and lukunga, responses of four different groups of women who were asked about the symptoms, treatments, and possible causes for lukunga and for maladi ya kuhara. More than twenty groups were asked about each of these illnesses and the table shows examples from those responses.

The table should be read in two ways. One, a horizontal reading provides the answers to what each group said about the illness. Thus one can compare the symptoms given with the causes and treatments given by each group in order to understand the kinds of logical links that are made between symptoms, causes, and treatments. Two, a vertical reading of each column permits a comparison of what symptoms, treatments, and causes the groups gave for each illness. This provides an estimate of the relative consistency of the responses for each illness.

A consideration of this table suggests that maladi ya kuhara might be glossed as diarrhea, while lukunga might be glossed as diarrhea with dehydration. The symptoms, treatments, and causes are remarkably different for the two illnesses. Similarly, by comparison of the symptoms named for each illness, we find that from a biomedical point of view, kilonda ntumbo can be glossed as dysentery or amebiasis, kasumbi as diarrhea with a diaper rash, and buse as diarrhea in a nursing child which occurs when the mother becomes pregnant. Are these all different kinds of diarrhea in Swahili?

A careful study of tables constructed in the same manner as Table 1, but using five different illnesses, showed the following: first, that there is a high level of consistency in the symptoms, the causes, and the treatments mentioned for each of these illnesses, and second, that there are major differences among the five illnesses in terms of symptoms, causes, and treatments. This indicates that in Swahili, these five illnesses are not different kinds of diarrhea. They are, rather, five illnesses that happen to include loose stools as one of a series of symptoms. The degree to which mothers see relationships among these five illnesses is not clear, but it is clear that they are distinct illnesses. Nevertheless, since the illnesses all include loose or frequent stools as symptoms, a survey on morbidity due to diarrhea would want information on all five illnesses.

138
LUKUNGA

<u>Symptoms</u>	<u>Treatments</u>	<u>Causes</u>
diarrhea; sunken font., sunken palate; small bumps on palate; puckered up mouth.	mix burned banana leaves in palm oil & local salt; mix Vicks with local salt; apply to fontanelle and palate.	some are born with the illness.
vomiting; diarrhea; puckered up mouth; unable to nurse well; sunken fontanelle; depressed palate.	mix Vicks & local salt to rub on palate and fontanelle; burn sugar cane leaves & mix with oil & salt.	nipple from bottle that irritates palate.
dry mouth; sunken font. line on the head; diarrhea; depressed palate; puckered up mouth.	burn up trash from market, mix with palm oil & local salt, rub on fontanelle & on palate.	heat of the sun; lack of water in body.
diarrhea & vomiting; red line on palate; sunken fontanelle; puckered up mouth; green stools.	burn green beans, peanuts & fish head, mix with palm oil & local salt, rub on palate & fontanelle.	no cause identified.

MALADI YA KUHARA

<u>Symptoms</u>	<u>Treatments</u>	<u>Causes</u>
very frequent stools; no appetite; crying; very thirsty.	give rice water; give SSS to drink.	drinking non-boiled water; eating many different foods; bad milk; intestinal worms.
frequent stools; no appetite; weakness; getting thin.	give rice water to drink; give carrot water; give SSS to drink.	dirty water; too many kinds of food eaten; microbes.
weakness; no appetite; great thirst; frequent stools.	give carrot water to drink; give SSS to drink; give rice water; give vermifuge.	intestinal worms; dirty water; poorly prepared food.
watery stools; frequent stools; general weakness; intense thirst.	give rice water to drink; give SSS and ORS packets; give rice water; give carrot water; Terramycine.	teething; eating dirt; intestinal worms; too many kinds of foods.

4.2 Survey on Diarrheal Disorders

The information from the ethnomedical study was used in formulating questions for a large-scale sample survey conducted in March 1989 in the city of Lubumbashi. Eighteen female interviewers were trained in the use of a questionnaire developed with their assistance in Swahili. The sample was 1125 mothers of children under three years of age who were asked a series of questions concerning recent cases of diarrheal disorders in their children and the treatments they gave or sought. The main purpose of the survey was to provide baseline data on knowledge of diarrhea and on ORT use for the evaluation of a health program.

Drawing on the ethnomedical study, we decided to collect data on all five illnesses rather than ask about diarrhea only. Therefore, mothers were told that we were interested in all five illnesses (identified by name), and then the mothers were asked if any of their children had one of those illnesses that day. If she said "no," then she was asked which child had been ill with one of the diarrheal illnesses recently. Mothers with a child currently or recently ill with a diarrheal disorder were asked to name the symptoms of illness that they recalled. No symptoms were suggested by the interviewers. Then the women were asked which illness the child had.

This set of questions provided data on the relative frequency of these illnesses among themselves and on the list of symptoms given for each illness. Using data from all current and past cases of diarrheal disorders mentioned (N=918), we found that the percentage of the cases of each type of illness was the following:

TABLE 2

Percentage of Cases of Illness

<u>maladi ya kuhara</u>	48%
<u>kilonda ntumbo</u>	25%
<u>lukunga</u>	15%
<u>kasumbi</u>	4%
<u>buse</u>	4%
other	<u>4%</u>
	100%

This means that of all the cases of diarrheal disorders mentioned, 48% of them were diagnosed as maladi ya kuhara, 25% were called kilonda ntumbo, and 15% were known as lukunga. Thus 88% of the episodes were identified as being one of the three main illnesses. From the point of view of relative frequency, kasumbi and buse are far less important and thus may deserve less attention than the other three illnesses. An examination of the symptoms cited in the ethnomedical study had shown that the symptoms were less serious than those of the other three illnesses.

Evidence from the symptoms associated with each of the illnesses identified by mothers shows somewhat different patterns for each illness. Using only data from current and recent (within two weeks) cases, for instance, we found that the main symptoms for kuhara were frequent and liquid stools, for kilonda ntumbo they were frequent stools and mucus, and for lukunga they were a clacking of the tongue (sign of extreme thirst) and frequent stools. The differences in symptoms mentioned in the survey results confirmed the results of the ethnomedical study.

The survey also showed that the choice of treatments given for these five types of diarrheal disorders differed markedly, namely, that cases of kuhara were four times as likely to be given ORT as those diagnosed as lukunga. Cases of lukunga were three times as likely to be treated with traditional medicine at home as cases of kuhara. The local diagnosis in Swahili clearly had an impact on the choice of treatment.

While the survey results tended to confirm the conclusions of the ethnomedical study, most importantly, it demonstrates that a survey in Swahili that asks only about diarrhea (maladi ya kuhara) will certainly miss a great deal of pertinent information. One can get some idea of the proportion of diarrheal cases that might be missed by examining the frequency of the five types of diarrheal disorders shown in Table 2. About one-half (52%) of all cases were diagnosed by mothers as some illness other than kuhara. While this frequency distribution may be seasonal, and some of the cases of illness other than maladi ya kuhara may be picked up anyway, certainly an important proportion of the cases would not be mentioned by asking about diarrhea only.

5. IMPLICATIONS FOR QUESTIONNAIRE DESIGN

Ethnomedical studies have demonstrated that illnesses, including diarrheal disorders, are diagnosed differently by different societies or language groups. To what extent can researchers who design survey instruments take account of these differing cultural conceptions of illness in questionnaire design and analysis? How can one make questionnaires more culturally specific without sacrificing comparability?

While the way the main questions are asked in a morbidity survey certainly affects what data will be collected as well as its validity, describing an ideal strategy for developing questions that reflect local knowledge of illness is no easy task. There are four obvious ways that language and concepts can be used in morbidity surveys to formulate questions about the incidence of diarrhea (or any illness or syndrome).

- 1) the questionnaire is developed in English or another official language different from the local language; interviewers are trained in English but are asked to translate each question into the local language as needed.
- 2) the questionnaire is translated into the local language and it uses a term that informants say translates diarrhea adequately to ask about the illness.

- 3) the questionnaire is translated into the local language but questions are asked primarily about various symptoms rather than about illnesses per se.
- 4) the questionnaire asks, in the local language, about each of the types of diarrheal disorders according to their ethnomedical diagnosis.

The first option, having each interviewer translate questions into local languages, may produce a great amount of interviewer bias since interviewers will vary in how they ask questions. This option may be appropriate only in environments where a survey is being conducted in many languages simultaneously, when research into many local terms would be too costly and time consuming. This option is being used less and less in survey research.

Judging from manuals and directions that accompany major survey efforts such as the World Fertility Survey (WFS) and the Demographic and Health Survey, the second option is currently widely used. The use of a local term for diarrhea is a reasonable option for surveys that are conducted in a number of different languages, since several days of qualitative research can establish the appropriate term to be used in each language. Several scholars who worked on the World Fertility Survey have written an excellent overview of the problems of translation of survey questionnaires and WFS policy in this regard (Vaessen et al. 1987).

It is unclear to what extent the third or fourth options are being used for morbidity or other types of surveys. However, there has been some effort recently to develop structured interviews to ask about signs and symptoms associated with the cause of death, a method known as "verbal autopsies." For example, researchers in Bangladesh tested several versions of questionnaires in Bengali asking about symptoms related to neonatal tetanus and associated diseases (Zimicki 1986). The questionnaires were designed to improve upon a system of "lay reporting" first proposed by the World Health Organization (WHO 1978) and used by the Matlab Demographic Surveillance System (DSS). Sets of rules or guidelines ("decision rules") were developed to properly interpret or recode Bengali symptoms into biomedical diagnoses.

Asking about specific symptoms or locally defined illnesses directly requires more qualitative research than most surveys usually conduct. These two options also require rules for translation of ethnomedical data into biomedical terms. In the example from Bangladesh, the "decision rules" developed provided the translation of ethnomedical data into biomedical terms, for while the discussions of the causes of death used ethnomedical (Bengali) terms for symptoms and illnesses, the rules developed provided data in terms and categories relevant to biomedicine.

Whether one should ask mainly about symptoms or mainly about illnesses depends upon the clarity of the diagnostic categories, for while the distinction between the two is somewhat arbitrary, some illnesses (measles, dysentery) are easily recognized, while others are not. In the research strategy outlined earlier, a way is suggested to compare the set of symptoms given by different groups for each illness. That comparison gives an estimate of the relative consistency or variations in how the illnesses are identified. Thus, if it was

found that the symptoms mentioned for the illnesses targeted by a morbidity survey vary tremendously according to the groups of persons interviewed, it would be best to ask questions about those symptoms rather than about the illnesses themselves.

Using options three or four in developing questionnaires for morbidity surveys has both advantages and drawbacks. Three major advantages of these options should be noted. First, if local ethnomedical terms are used to identify the illnesses of interest, one is far less likely to miss relevant data because of differences in perceptions or diagnoses. Examining the example from Lubumbashi, Zaire, it seems clear that a substantial number of diarrheal disorders would not have been mentioned if the survey questionnaire had asked only about maladi ya kuhara, or diarrhea, rather than asking specifically about the five illnesses earlier identified, for one-half of all cases of diarrheal disorders had a diagnoses other than simple diarrhea. Second, using these options increases the validity of the variables, for there is a far higher congruence between what is being asked (viewpoint of the researchers) and what those interviewed are answering (viewpoint of those interviewed). This can only improve the quality of the data. And third, the results of the research conducted to discover ethnomedical terms will suggest other ways to analyze the data and often provide reasons for current behavior related to health and illness.

There are, however, certain costs or disadvantages to using these options. First, the survey will require some additional time (six weeks), money (variable), and personnel (researcher) before finalizing the questionnaire. Second, the writing of rules to go from ethnomedical terms back to biomedical terms will require more time and an understanding of how individuals categorize signs and symptoms to make diagnoses, and that process is sometimes complex. Third, using local terms initially may complicate the comparison of the results with other surveys.

It may not always be possible to use ethnomedical knowledge in the process of instrument development for morbidity surveys. In order for knowledge of local conceptions of illness to be useful, at least three conditions must be met. A simple and rapid research strategy must be available for obtaining ethnomedical knowledge about the illnesses of interest, for survey researchers do not normally have the time and other resources to conduct extensive ethnographic research in local knowledge of illness before doing each survey. The evidence of local knowledge of illness must be clear and must include details about both symptoms and ethnomedical diagnosis. And a system must be devised to translate local, ethnomedical data into biomedical language.

The first two conditions can be met with simple qualitative research focused on locally defined illnesses and the key symptoms used to make those diagnoses. To satisfy the third condition, rules must be written based on the ethnomedical research to translate the illnesses and the groups of symptoms into biomedical diagnoses. The rules must be systematic and explicit and must state how each illness and each symptom recorded in the survey will be interpreted. This process is roughly the same as the writing of "decision rules" being developed for mortality surveys that rely on verbal autopsies. The use of such rules will help assure comparability in morbidity surveys, comparability that would otherwise be compromised by the use of local conceptions of illness in survey data.

Whether cultural conceptions of illness are recognized and used in the preparation of survey instruments or not, the choices that are made about terms and language affect the nature and the quality of the data collected. No matter what set of diseases or syndromes are targeted, it is clear that the persons interviewed have their own system of identifying illnesses, and we should expect to find important differences between that system and the biomedical one. Asking questions about illnesses that may not be well understood places the onus of interpretation on the person interviewed. The burden of interpreting questions should, rather, be assumed by the interviewer, and that is accomplished by finding appropriate ways to formulate the questions.

In short, while the consideration of local knowledge of illness in the formulation of survey questionnaires requires more resources, it provides a means of improving the quality of the data collected. One cannot give guidelines for choosing the right strategy that will fit all contexts, given the limited resources and the linguistic complexity that must often be confronted. One can, however, say that researchers should expect contrasts in cultural conceptions of illness and should always make explicit their strategy for addressing that fact. If an explicit strategy is presented, other scholars can better assess the quality of the data and the analysis that follow the questionnaire.

Acknowledgements--I would like to thank Douglas Ewbank for his insightful comments on an earlier version of this paper.

BIBLIOGRAPHY

- Alland, Alexander 1988. Looking backward: an autocritique. Medical Anthropology Quarterly 1(4):424-431.
- Bentley, Margaret et al. 1988. Rapid ethnographic assessment: applications in a diarrhea management program. Social Science & Medicine 27(1):107-116.
- Bibeau, Gilles 1979. De la maladie à la guérison. Essai d'analyse systématique de la médecine des Angbandi du Zaïre. Doctoral Dissertation. Laval University.
- Black, Robert 1984. Diarrheal diseases and child morbidity and mortality. Population and Development Review suppl. 10: 141-161.
- Browner, C.H., B.R. de Montellano & A. Rubel 1988. A methodology for cross-cultural ethnomedical research. Current Anthropology 29(5):681-702.
- Chrisman, Noel 1977. The health seeking process: an approach to the natural history of illness. Culture, Medicine & Psychiatry 1:351-377.
- Coreil, Jeannine & Dennis Mull eds. (in press). Anthropology and Primary Health Care. Boston: Kluwer Academic Publishers.
- Coreil, Jeannine & Dennis Mull 1988. Introduction: Anthropological studies of diarrheal illness. Social Science & Medicine 27(1):1-3.
- Eisenberg, Leon 1977. Disease and illness. Culture, Medicine & Psychiatry 1:9-23.
- Fabrega, Horacio & Martine Zucker 1979. Components of illness and type of medical practitioner: a comparative study. Social Science & Medicine 13A:13-23.
- Foster, George 1976. Disease etiologies in non-Western systems. American Anthropologist 78:773-782.
- Foster, George & Barbara Anderson 1978. Medical Anthropology. New York: John Wiley & Sons.
- Foster, George 1988. The validating role of humoral theory in traditional Spanish-American therapeutics. American Ethnologist 15(1):120-135.
- Good, Byron 1977. The heart of what's the matter: The semantics of illness in Iran. Culture, Medicine & Psychiatry 1:25-58.
- Good, Charles 1987. Ethnomedical Systems in Africa. New York: Guilford Press.

- Greene, Ted 1985. Traditional healers, mothers and childhood diarrheal disease in Swaziland. Social Science & Medicine 20:277-285.
- Harwood, Alan 1970. Witchcraft, Sorcery and Social Categories Among the Safwa. London: Oxford University Press.
- Janzen, John 1978. The Quest for Therapy in Lower Zaire. Berkeley: University of California Press.
- Kendall, Carl et al. 1984. Ethnomedicine and oral rehydration therapy: A case of ethnomedical investigation and program planning. Social Science & Medicine 19:253-260.
- Kleinman, Arthur 1980. Patients and Healers in the Context of Culture. Berkeley: University of California Press.
- Landy, David 1983. Medical anthropology: a critical appraisal. In J. Ruffino (ed). Advances in Medical Science Vol.1. New York: Gordon & Breach.
- Mechanic, David 1978. Medical Sociology. Second Edition. New York: The Free Press.
- Mull, Dennis & Dorothy Mull 1988. Mothers' concepts of childhood diarrhea in rural Pakistan: What ORT program planners should know. Social Science & Medicine 27(1):53-67.
- Nichter, Mark 1978. Patterns of resort in the use of therapy systems and their significance for health planning in South Asia. Medical Anthropology 2(2):29-58.
- Nichter, Mark 1988. From aralu to ORS: Sinhalese perceptions of digestion, diarrhea and dehydration. Social Science & Medicine 27(1):39-52.
- Pelto, P., M. Bentley & G. Pelto (in press). Anthropological research on diarrhea: methodology. In Anthropology and Primary Health Care. *ibid.*
- Ross, David & Patrick Vaughan 1986. Health interview surveys in developing countries: A methodological review. Studies in Family Planning 17(2):78-94.
- Rubel, Art 1983. Mexican American Folk Healing. Reviews in Anthropology 10:65-71.
- Scrimshaw, Susan & Elena Hurtado 1987. Rapid Assessment Procedures for Nutrition and Primary Health Care. UCLA Latin American Center and United Nations University.
- Scrimshaw, Susan & Elena Hurtado 1988. Anthropological involvement in the Central American diarrheal disease control project. Social Science & Medicine 27(1):97-105.

- Snyder, John & Michael Merson 1982. The magnitude of the global problem of acute diarrheal disease: A review of active surveillance data. Bulletin of WHO 60(4): 605-613.
- Vaessen, M., C. Scott, J. Verrall & S. Coulibaly 1987. In J. Cleland & C. Scott(eds), The World Fertility Survey: an assessment. Oxford: Oxford University Press.
- Warren, Michael 1974. Disease, Medicine and Religion Among the Techiman Bono of Ghana. Doctoral Dissertation. Indiana University.
- Yoder, P. Stanley 1985. Enquête ethnomédicale dans le Trarza et le Guidimaka (Mauritanie). American Public Health Association & USAID Mission/Mauritania.
- Young, Allan 1982. The anthropology of illness and sickness. In Annual Review of Anthropology Vol. 11. Palo Alto: Annual Reviews Inc.
- Young, James 1981. Medical Choice in a Mexican Village. New Brunswick: Rutgers University Press.
- Zimicki, Susan 1986. Approaches to assessment of the cause of mortality: A case study from Bangladesh. IUSSP Seminar on Comparative Studies of Mortality and Morbidity, Siena, July 1986.
- Zimicki, Susan et al. 1985. Cause of death reporting in MATLAB. Source Book of Cause-Specific Mortality Rates. Demographic Surveillance System - MATLAB Vol. 13. ICDRB Scientific Report No. 63