ILLNESS EXPLANATORY MODELS IN CONTEMPORARY RESEARCH:

A CRITIQUE OF THE EXPLANATORY MODEL INTERVIEW CATALOGUE

by

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The Explanatory Model Interview Catalogue (EMIC) is a semi-structured interview guide used by cultural epidemiologists to collect data on illness representations in different cultural contexts. To facilitate planning of new services for AIDS-affected families, a modified version of the EMIC was employed to study representations of HIV in rural Karagwe, Tanzania. Results of this study are reported here, although research design problems limit the meaningfulness of these findings and raise questions of validity. By reflecting on the shortcomings in my study design as well as published criticisms of the explanatory model framework, I critique several trends in EMIC research. First is the tendency to reduce or even eliminate the preliminary ethnographic phase that precedes interviews. Second is the existence of problematic assumptions about cultural knowledge that characterize many EMIC studies, ignoring cognitive processes and reifying uncertain claims as concrete beliefs. Not all EMIC applications follow these trends, and attention is directed to exemplar studies that demonstrate anthropologically-attuned cultural epidemiological research.

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1.0   INTRODUCTION

This thesis is both a report of my findings from fieldwork on HIV in Karagwe, Tanzania and a critical reflection of my experience conducting research with the explanatory model. During June 2010, I surveyed HIV-positive support group members in rural Tanzania about their experiences, beliefs, and behaviors in regard to *ukimwi* (AIDS). Although the explanatory model framework is traditionally used to collect information for use by clinicians and public health practitioners, I aimed to assist a local cooperative that was preparing to expand its services to AIDS-affected families.

The reflection component of this study was motivated by theoretical questions that arose during data analysis, which prompted a more critical reading of the literature on explanatory models in cultural epidemiology. While many of the shortcomings in this study can be attributed to my inadequate Swahili language skills, insufficient time and resources, and my general inexperience as an undergraduate researcher, certain of my research design errors are indicative of problematic assumptions inherent in the methodologies on which my survey instrument was based. I would have derived little but frustration through this reflection if not for the published contributions of critical authors in medical anthropology. Many clinical anthropologists and cross-cultural psychiatrists also deserve credit for turning the critical lens on their own work, as I am attempting to do here.

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As this thesis aims to contribute to the ongoing constructive dialogue about research using the explanatory model framework, I will recognize studies that demonstrate current methodological or theoretical problems as well as exemplary cases of research that transcend these problems. While it is necessary to identity problematic assumptions, it is also important to recognize those researchers who are demonstrating a way forward.

The explanatory model framework has influenced many theories, methods, and approaches in health-related research, leaving its mark on a broad swath of academia. I use the remainder of this chapter to provide an overview of the explanatory model framework. I also define the subset of methodologies and research trends toward which my comments are directed. I provide a brief overview of the Explanatory Model Interview Catalogue (EMIC), which is the focus of this thesis, as well as the Barts Explanatory Model Interview (BEMI), which was influential on my 2010 case study.

In the next chapter, I describe my field study in rural Karagwe, Tanzania. I recall the design process through which I formulated the survey instrument, which was a balancing act among three priorities: academic questions about illness representations of HIV, the information needs of the local cooperative, and the limitations of time, money, and language skill. Data and results are reported at the end of the chapter, as well as some basic conclusions that will be communicated with the cooperative.

Chapter 3 examines my research experiences and reflects on the assumptions underlying my choices during the design phase. This chapter is divided into two parts, the first dealing mostly with methodology and the second with theory. The first part discusses the importance of preliminary ethnographic work, which I could not carry out for this study. The second deals more fundamentally with the concept of an illness explanatory model, which some researchers

have applied without attention to cognitive processes. For each point, I review related criticisms from published articles as well as example studies in academic journals. All of my critiques are targeted at community-level and public health research, although they are relevant for clinical applications of the EMIC, too.

In Chapter 4, I consider my critiques in light of a larger discourse in medical anthropology: the critical vs. clinical debate. As indicated above, my research was negatively affected by my inexperience and theoretical naivety as an undergraduate researcher. Nonetheless, the pressures to which I was subjected while conducting research for my contacts in Karagwe mirrors the relationship that many clinical anthropologists have to biomedical and public health "clients." I conclude with suggestions for future research using the EMIC framework.

As an undergraduate student, my first attempts at independent research were formative in my understanding of anthropological concepts and theories. Particularly, designing and employing a survey based on the EMIC and BEMI methodologies forced me to question my elementary conception of "culture." In so far as these two methodologies may have initially led me astray, there is room for discussion about their language and theoretical premises. Indeed, older and more experienced anthropologists may be less easily swayed by the assumptions inherent in the methods that they employ. But cultural epidemiology is a multidisciplinary enterprise involving different researchers with diverse backgrounds and disciplinary perspectives. For such research groups to work together, it is best if potentially problematic assumptions are made explicit.

1.1   THE EXPLANATORY MODEL OF ILLNESS

Although the foundations of the framework were laid earlier, Arthur Kleinman (1980) provided a comprehensive overview of the explanatory model of illness and its implications for research in his influential publication *Patients and Healers*. Defined as "the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process" (Kleinman 1980:105), explanatory models were presented as conceptual tools to understand how different cultural and social contexts affect the ways that people negotiate their experiences with illness. Explanatory models are created and recreated by individuals living within a cultural matrix of social values, expectations, beliefs, and relationships. These matrices comprise what Kleinman defines as social or cultural reality, which is distinguished from the physical reality of the environment and the biological reality of the body. Furthermore, symbolic reality is "a bridging reality that links the social and cultural world with psychobiological and biological reality" (1980:41), and it acts as a filter through which individuals can perceive and interpret the social matrix in which they reside.

For any particular episode with sickness, a person attaches meaning to the experience of illness by creating narratives describing *its causes* (etiology), *how it is manifested* (symptoms), *how it affects the body or person* (pathophysiology), *how it is expected to proceed* (course), and *what should be done about it* (treatment) (Kleinman 1980). People apply content from their cultural reality to define each of these five categories in a creative process that is motivated by the need to make sense of dysfunction. Connections among the five concepts form a semantic network, guided by symbolic reality.

Explanatory models, as originally conceived, are basically schematics of these semantic networks. For Kleinman, these tools presented a theoretical basis for comparative studies to be

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carried out across cultures as well as within health care systems. He designated three domains present within most pluralist systems: the popular, professional, and folk sectors. Each sector consists of its own social reality through which individuals can formulate and modify explanatory models pertaining to particular illness episodes.

In time, Kleinman moved away from his original conceptions of the explanatory model framework, instead embracing subjective studies of illness that were more in line with post-modernism. He recognized his previous attention to cognitive models and distinct cultural boundaries as uncomfortably structuralist, and he instead concentrated on illness narratives to tell the stories of particular experiences with sickness (1995). In his own words:

> Today, I am uncomfortable with the style and even the preoccupation of "models," ethnocultural or other, which imply too much formalism, specificity, and authorial certainty, but models were definitely in my mind in the 1970s, a residue of symbolic and structuralist readings… I, like many others…have become less impressed by systematic connections and more by differences, absences, gaps, contradictions, and uncertainties. [1995:7-8]

Despite the shortcomings of the explanatory model in the era of postmodernism, Kleinman's designation of the popular, professional, and folk sectors was important in the movement to recognize biomedicine as an ethnocentric cultural perspective (Kleinman 1995). Rebuking the biased dichotomization of healthcare activities into either the cultural practices of traditional healers or the non-cultural and scientifically legitimized practices of biomedicine, Kleinman broadened the definition of an ethnomedical health care system to include biomedicine as a cultural institution within the professional sector (1980). Additionally, he recognized the popular sector as the busiest place in the healthcare system. This remains true even to this day in Dar es Salaam, where diabetics among the urban poor were found to depend primarily on their families for support and care (Kolling, et al. 2010), and in Kenya, where even children missing

school due to an illness or injury were found to manage a vast majority of their ailments alone, some with the use of herbal or pharmaceutical remedies (Geissler, et al. 2000).

It is notable that Kleinman's writings on the operationalization of the explanatory model are scanty, which Weiss (1997) suggests was intentional. Given his broad agenda for clinical, teaching, and research-based applications, perhaps he did not want to suffocate future users of his model with rigid theoretical tenets. While this model was intended for use by anthropologists, clinical practitioners, and cross-cultural psychiatric researchers, the theory is also applied today in nursing and clinical studies: topics include mental health disorders such as depression (e.g. Kokanovic, et al. 2008; Piven, et al. 2008) and schizophrenia (e.g. McCabe and Priebe 2004), somatic diseases such as diabetes (e.g. Skelly, et al. 2006) and stroke (e.g. Wilson 2010), and abnormal biological events such as preterm labor (e.g. Mackey and Boyle 2000). The framework has even been employed in studies outside healthcare, such as for research on youth violence (Biering 2007).

Although its influence is widely acknowledged, anthropologists have mostly dropped the explanatory model framework to move toward more organic, poststructuralist conceptions of culture. Some take a critical view of the explanatory model as a framework formulated by an anthropologist to holistically understand the structure of health care systems, but now used predominantly by clinicians to identify causal links between beliefs and risk behaviors. In this way, biomedicine "reduce[s] the complexity and richness of anthropological knowledge to a few reified and practical concepts" (Scheper-Hughes 1990:191) such as explanatory models, reconciling 'culture' with its positivist worldview. However, researchers in the clinical and public health sciences maintain that the explanatory model can be used to foster genuine collaborative research in fields such as cultural epidemiology.

1.2 THE USE OF EXPLANATORY MODELS IN CULTURAL EPIDEMIOLOGY

Broadly defined, cultural epidemiology is the interdisciplinary study of the relationships between human health and culture. This field is a counterpart to social epidemiology, which addresses the social determinants of disease and disorder and the impact of social forces on their distributions. While there is substantial overlap between these two epidemiologies, they can be distinguished as complementary domains of inquiry with respective emphases on social and cultural phenomena (Trostle 2004).

The term *cultural epidemiology* does not denote a field, but rather an array of opportunities for collaboration and exchange between anthropology and epidemiology upon which various cross-disciplinary researchers have capitalized (see Trostle and Sommerfeld 1996). The beginnings of this interdisciplinary relationship go as far back as the disciplines themselves, although the relationship between anthropologists and epidemiologists has at times been weak (Trostle 1986). The methodologies employed in these two disciplines have been characterized by the qualitative vs. quantitative and interpretive vs. explanatory dichotomies, although this portrayal ignores the complexity of each field's approaches and the opportunities for collaboration between them (Inhorn 1995; Trostle and Sommerfeld 1996).

To define the area within cultural epidemiology that is relevant to this critique, it is useful to refer to a distinction among three major paradigms described by James Waldram (2006). The first paradigm involves ethnographic studies by medical anthropologists about health issues that may interest epidemiologists, although epidemiologists are rarely involved in the research. The second involves traditional ethnographic research in which culture is incorporated as a variable in statistical analysis. Anthropologists may be consulted during measurement of this variable, but the results often fail to satisfy anthropology's complex and highly nuanced

conceptualizations of 'culture.' The final paradigm involves the use of ethnographic methods to provide a more anthropologically-informed characterization of culture. As Waldram explains:

> Ideally in this model, ethnography is seen as central to identifying 'local representations of illness' prior to the deployment of an instrument designed to gather individual-level data that may lend themselves to quantification and input into the broader, statistically oriented exercises of the epidemiologist (Weiss, 2001, p. 6). [2006:75]

This third paradigm is the one in which the explanatory model has played an important part, and it is the one upon which this thesis focuses. One of the oldest and most widely applied methodologies of this paradigm is the EMIC, which is a flexible semi-structured interview guide (SSIG) that researchers can adapt to different cultural contexts to elicit information about local categories of illness (Weiss, et al. 1992). The EMIC methodology involves preliminary ethnographic fieldwork, as well semi-structured interviews designed to collect both textual transcripts and categorically coded data (Weiss 1997). The McGill's Illness Narrative Interview (MINI) similarly emphasizes qualitative data, though it is less concerned with quantitative analysis (Groleau, et al. 2006).

Due to the length of time required for EMIC interviews, the Short Explanatory Model Interview (SEMI) was designed as a less time-consuming alternative to suit the needs of epidemiologists who need information quickly and from many respondents (Lloyd, et al. 1998). The SEMI involves more specific questions and probing than the EMIC, which relies on less targeted elicitation. The relatively recently developed Barts Explanatory Model Inventory (BEMI) attempts to abbreviate the interview process even further, bypassing the preliminary ethnographic step by compiling a comprehensive list of possible responses via a global literature review (Rüdell, et al. 2009). The BEMI includes both an interview guide and a checklist-format questionnaire, which can be employed on its own to elicit explanatory models in different cultural contexts (Bhui, et al. 2006).

Aside from the improving the measurement of "culture" for use in health-related studies – a defining concern for cultural epidemiology – the development of instruments such as the EMIC lies within a more general trend in anthropology toward "meaning-centered research." Using self-reporting, interviewing, and ethnography to assess phenomena that were traditionally viewed from an objective institutional perspective, anthropologists developed methods of measurement that are more sensitive to the diverse subjectivities of respondents. Methodologies were proposed to address the traditional concerns of social anthropologists, such as the nature of social support (Jacobson 1987), as well as patient satisfaction in the context of institutional healthcare. Specifically in the field of cross-cultural psychiatry, meaning-centered research was used to address Kleinman's (1977) categorical fallacy, by which institutionally-recognized concepts of disorder from one cultural milieu are assumed to be valid in another.

The instruments listed above, and meaning-centered research in general, demonstrate one way that anthropologists have established roles as applied researchers. The third paradigm of cultural epidemiology, in which anthropologists attempt to provide a more nuanced and contextualized way to measure culture for use in quantitative analysis, is one area where anthropologists have found a niche in the health sciences. I now turn to a more in-depth overview of the two methodologies that figured most prominently in the Karagwe study. I attempt to give an overview of the relevant information for each instrument, although more detailed descriptions are available in the corresponding methodological reviews.

1.3   THE EXPLANATORY MODEL INTERVIEW CATALOGUE

The Explanatory Model Interview Catalogue (EMIC) is a mixed methods research tool used to

elicit data about respondents' experiences, meanings, and behaviors in relation to a particular illness. The primary intentions of this SSIG are to establish "locally valid representations of illness and their distributions in cultural context" (Weiss 2001:5). Interviewers collect complimentary quantitative and qualitative data using an open-ended format with structured probes. The quantitative data are compiled to determine locally meaningful categories and to perform statistical analysis, often in cross-cultural comparison. The qualitative transcripts are used to clarify the meaning behind particular trends, or to confirm the coding strategy used to generate the quantitative results.

The five components of an explanatory model (etiology, symptoms, pathophysiology, course, and treatment) were reduced to three concepts: experience, meaning, and behavior (Weiss 2001). This reduction involved decades of conceptual restructuring by many intermediaries in anthropology and behavioral scientists, including scholars studying illness behaviors, illness narratives, and causal explanations. Weiss (2001) extensively reviews the conceptual frameworks that influenced his operationalization of the explanatory model, although he is somewhat vague about the direct linkages between his concepts and their predecessors. In his earlier work, he initially used the terms perceptions, beliefs, and practices, respectively (Weiss, et al. 1992), but experience, meaning, and behavior became the key concepts by 2001. These concepts are still in use in recent publications of EMIC research (e.g. Coreil, et al. 2010; Paralikar, et al. 2011; Schaetti, et al. 2010), and they are also referenced in other methodologies such as the MINI (e.g. Craig, et al. 2010).
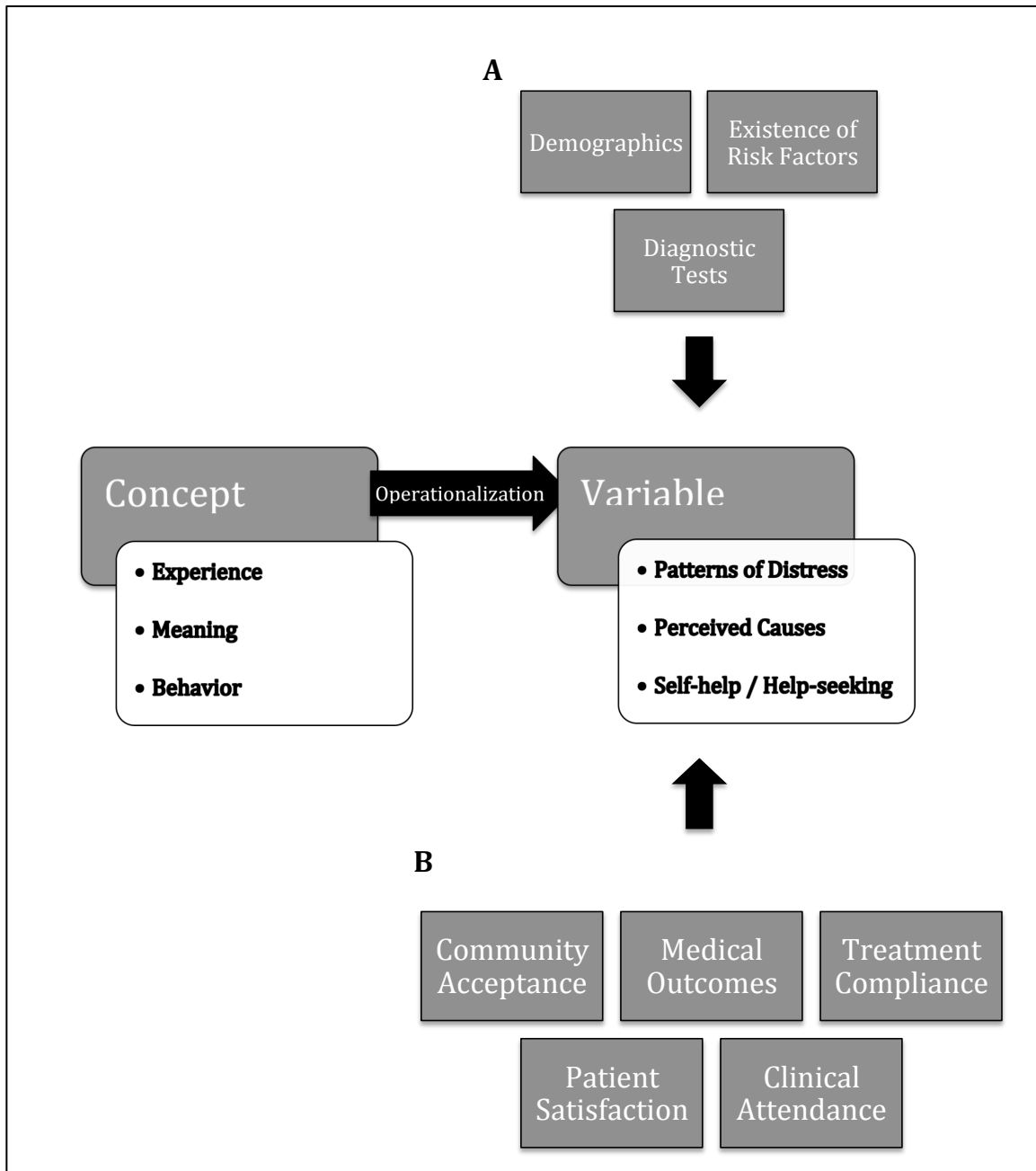
Figure 1. Operational Framework of the EMIC

The three concepts of experiences, beliefs, and behaviors were translated into the three operational components of the EMIC: patterns of distress, perceived causes, and help-seeking behavior (see **Error! Reference source not found.**). Each of these components consists of a set

f questions or variables on the interview guide. The section on Patterns of Distress (PD) asks about the physical signs and symptoms associated with disease, the section on Help-seeking Behavior (HS) asks which sources of support or treatment were or should be sought for the problem at hand, and the Perceived Causes (PC) section allows respondents to select the cause or causes of their illness.

During an interview using the EMIC framework, the interviewer asks questions in open-ended format and marks responses on a template. After allowing the respondent to complete his or her open-ended explanation, the interviewer probes for responses that they did not indicate. In this way, nothing that will be statistically measured is missed. Based on whether a response is provided spontaneously, after probing, or not at all, the interviewer can create an index of priority. After probing, they can also ask the respondent which response was most critical.

For qualitative data collection, the interviewer is assisted by a recorder who makes comprehensive textual transcripts of the entire conversation. This can later be translated, coded for analysis, and referenced to explain other associations. Textual data is seen as complementary to statistical data, so the transcripts are critical to the methodology.

Specific variables, in the form of interview questions, are derived for each category based on prior ethnographic work and available literature from relevant studies. There is a great deal of flexibility in the types of questions that can be asked, allowing researchers with a wide variety of research targets to adapt the EMIC to their needs. For example, Coreil and colleagues (2010) tailored the patterns of distress section to address tuberculosis stigma, ultimately compiling the items to create a scale for comparison of stigma between Haitians living in Haiti and Haitian immigrants living in Florida. There are also a number of optional sections; for example, most interview guides include a section on general illness beliefs (Weiss 1997). This section asks

about a variety of illnesses to obtain more general information about the sorts of explanatory models through which a respondent makes sense of illness.

The acronym EMIC refers to one half of the emic-etic dichotomy. Whereas emic units derive their meaning from people's various semantic networks, etic units include items from clinical diagnostic instruments that measure the supposedly "objective" categories of scientists. While anthropologists reject the idea that etic units are more real or true than emic units, they recognize that they are more useful and easily understood by physicians and public health planners. The first study that Weiss carried out using the EMIC, which focused on the perceptions, beliefs, and practices related to leprosy in Mumbai, India, compared emic data gathered through EMIC interviews to etic data collected through clinical tests, such as the Combined Hamilton Depression and the Anxiety Rating Scale, among others (Weiss, et al. 1992).

Although etic information is not collected using the EMIC, it can be tested statistically against emic data to detect correlations of practical relevance to public health and clinical clients (see **Error! Reference source not found.**). Etic data can come in the form of sample characteristics (Group A in the figure) or clinically measured outcomes (Group B). Statistical tests can also be carried out to detect associations among EMIC variables or to compare data across different groups of respondents.

The EMIC is a method for both descriptive and analytical research about explanatory models. Complementary qualitative and quantitative data involved in both levels of analysis, such that the local validity of quantitative results are determined through qualitative textual analysis. A more detailed account of the EMIC can be obtained from one of the three articles

detailing the methodology (Weiss, et al. 1992; Weiss 1997; Weiss 2001), or a review of one of its applications.

1.4   THE BARTS EXPLANATORY MODEL INVENTORY

Whereas the EMIC offered an operationalization of the explanatory model that emphasized anthropological approaches such as ethnography and open-ended interviewing, it also requires a great deal of effort on the part of interviewers as well as respondents. Additionally, there were concerns about researcher bias due to variations in the methods of data analysis (Bhui and Bhugra 2002). These criticisms were leveled at the SEMI as well, indicating a need for an even shorter instrument with more rigid rules for data collection and analysis. As Rüdell and colleagues explain, "The lack of brief assessment instruments that are also able to pick up culturally variable beliefs makes it difficult for clinicians and researchers to understand and recognize the effects of cultural influences on perceptions" (2009:338).

The Barts Explanatory Model Inventory (BEMI) was compiled through thematic analysis of published studies about the ways that people explain their mental distress. The studies needed to include enough detail about a particular person's account of distress to qualify as "analogous to an actual account" (Rüdell, et al. 2009:338). In each of these cases, perceptions of distress were identified and connected in simple schematics. These schematic were used to categorize each perception of distress into one of five domains based on the explanatory model framework: "identity, cause, consequence, course, or control/treatment" (Rüdell, et al. 2009:339). Within each domain, the list of perception items was categorized into distinct

groupings. For example, the 'cause' category includes over forty possible items, and they have been grouped into the psycho-social, supernatural, behavioral, natural and physical themes (Rüdell, et al. 2009).

The inventory has been used in both an interview format (BEMI-I) and a questionnaire format (BEMI-C) in which respondents indicate the presence of different perception items in a checklist developed from the inventory. Although most studies apply both types of instruments (Rüdell, et al. 2009; Rüdell, et al. 2008), its has been shown that the questionnaire alone can distinguish among the explanatory models of distinct ethnic groups (Bhui, et al. 2006). Due to the ease with which the checklist can be employed, it has been posited as a useful tool for both research and routine clinical use (Bhui, et al. 2006).

It is notable that, while the EMIC and BEMI both rely on the explanatory model framework, they are quite different in their goals within cultural epidemiology. First, the BEMI has been used predominantly for research on mental distress (Rüdell, et al. 2009), whereas the EMIC has been used to study the emic aspects of mental disorders, tropical diseases, and other health problems in which individuals experience stigmatization (Weiss 2001). Additionally, the EMIC has been used for public health research on the affects of migration (Coreil, et al. 2010) and gender constructs (Atre, et al. 2004; Vlassoff, et al. 2000) on ideas about illness, whereas the BEMI has a much narrower purpose in clinical research (Rüdell, et al. 2008) and psychiatric diagnostic approaches (Bhui, et al. 2006).

These overviews of the EMIC and BEMI should be adequate for the purposes of this study. The key methodological summaries of the EMIC (Weiss, et al. 1992; Weiss 1997; Weiss 2001) and the BEMI (Bhui, et al. 2006; Rüdell, et al. 2009) were key in the development of the questionnaire used in the Karagwe study. Consequently, the critiques raised in Chapter 3 are

most relevant to these summaries, which represent the methodological foundations of the EMIC and BEMI. Before presenting these reflections and critiques, I will provide an overview of the Karagwe study in Chapter 2.

2.0   THE 2010 KARAGWE STUDY

During my junior year of college at the University of Pittsburgh, I developed an interest in the explanatory model framework proposed by Arthur Kleinman (1980).   While his landmark manuscript provided a comprehensive perspective on the concept of an explanatory model and the theoretical matrix in which it should be understood, I was overwhelmed by the many and varied ways that this framework has been operationalized in contemporary research.   While searching through research articles relating to the explanatory model, I often came upon studies involving the EMIC.   I was attracted by the prominence with which Kleinman's work figured into its development.   Weiss, et al. (1992:820) directly trace the three central variables of perceived cause, patterns of distress, and help-seeking behavior to an operational structure tentatively suggested (via a footnote) in *Patients and Healers* (Kleinman 1980).   The fact that Weiss had studied under Kleinman at Harvard University seemed to reinforce the EMIC 's legitimacy as the most direct operationalization of Kleinman's theoretical work.

In order to learn more about the EMIC, I set out to apply this framework in an independent research project.   The purpose of this chapter is to describe this research project, which I carried out in rural northwestern Tanzania in 2010.   The findings of this research are intended to meet the planning needs of a local cooperative, and I report the results of the research at the end of this chapter.   Since my critiques of explanatory model research in cultural epidemiology were derived from reflections on this study, I provide a more thorough overview of the research design process than is typical in the methods section of a research report.   I put a

great deal of emphasis on my relationship with local cooperative, which influenced my methodological choices during project design.

In most publications of applied clinical anthropology research, the authors provide little background on the relationships between clients and researchers. This information is excluded from journal articles in the name of brevity or because it should have little to no impact on the findings of well-performed research. If mentioned, the client may be identified in the acknowledgements section or, if the study took place at the client's healthcare facility, in the description of the study's setting and participants.

While a condition for an ideal research study is that the identity of the client has little import for research findings, a discussion of the researcher-client relationship is pertinent to a critical reflection on the research design process. The questions and methods that I chose for this study were all based on the needs and preferences of the NGO that became my client. Any applied research intentionally seeks to make his or her work relevant to the individual, group, or institution that he or she is assisting, and this pressure obviously impacts the ways that research is performed. I do not intend to portray the client as a corrupting force that intentionally manipulates research findings, but rather to emphasize the ways that researchers such as myself can be influenced by the search for relevance and concerns about application of their work.

I was particularly disturbed by the ways that this search for relevance or purpose affected my theoretical framework. The ways that I conceptualized cognitive processes, perceived the elicitation process, and categorized responses were drastically altered by my motivation to procure information that would be useful in the immediate circumstances of the NGO. While some of my mistakes can be written off to naiveté and inexperience as an undergraduate researcher, the influences of the search for relevance are unmistakable in my conceptualization

and theoretical outlook. Furthermore – and of importance to a critique of the EMIC and BEMI – my shift in perspective and approach was never countered by the methodological overviews summarized in the preceding chapter (Bhui, et al. 2006; Rüdell, et al. 2009; Weiss, et al. 1992; Weiss 1997; Weiss 2001). In fact, some of the language used in these publications sometimes seems to condone my poor methodological choices.

In this chapter, I will describe the epidemiological conditions of HIV in Karagwe, explain my relationship with Karagwe Development and Relief Services (KADERES), recall how I developed my research agenda, and review the selection and derivation of my methods. This chapter concludes with a report of the data and basic findings. Some of my analyses are not included here due to doubt about theoretical bases of my approach. These results are explained and presented in Chapter 3, where I consider them as part of my reflection and critique. In Chapter 4, I will comment on the influence of the search for relevance on my work.

2.1   DEMOGRAPHIC AND EPIDEMIOLOGICAL OVERVIEW OF KARAGWE

The study took place in Karagwe, a rural district located in the northeastern corner of the United Republic of Tanzania. Karagwe is the largest district in the Kagera Region, which occupies the section of the country west of Lake Victoria, south of Uganda, and east of Rwanda. The people of the Karagwe district have primarily been classified into several ethnic groups including Haya, Hangaza, and Subi, although the Nyambo group is most populous (Killewo 1994). Each group has a distinct language, but most people also speak the national language, Standardized Swahili. The most recent national census in 2002 reported a growth rate of 2.9 percent in Karagwe and a

population of about 424,287 people, almost a quarter of the more than 2 million people in the Kagera region (National Bureau of Statistics 2006).

The first case of HIV-1 detected in Tanzania occurred in Kagera in 1983, and by 1986 a cumulative total of 847 cases had been recorded in the region, constituting over 55 percent of the total cases reported in the entire country (Killewo 1994). Of course, this distribution of HIV cases must be considered in light of the poor capacities for HIV detection and surveillance at the beginning of the epidemic. Rural surveillance problems persisted well into the last decade in many low and middle-income countries, where the plausibility of epidemic curves based on inadequate data need to be judged by experts rather than by strict quantitative statistical analysis (Grassly, et al. 2004). Although Tanzania's HIV surveillance systems have long been judged positively by international criteria (Garcia Calleja, et al. 2010; Garcia-Calleja, et al. 2004; Lyerla, et al. 2008), surveillance data in Kagera through the early 1990's suffered from both infrastructure problems, such as a lack of testing facilities, as well as social deterrents, such as fear of being identified as an HIV-positive person at the clinic or hospital (Killewo 1994).

Tanzania's earliest institutional responses to the appearance of HIV were carried out by the Technical Advisory Committee on AIDS (TACAIDS), which formed in 1985 as the National AIDS Task Force and initiated the National AIDS Control Programme (NACP) in 1988 to deal with the epidemic. With the introduction of the NACP and the arrival of various NGOs on the scene, preventative interventions were initiated in Kagera along with services such as home-based care for infected people and general care for AIDS orphans. In 1986, experts came together to form the Kagera AIDS Research Group (KARP), a collaborative interdisciplinary effort that emerged from a partnership between the Tanzanian government and the Swedish Agency for Research Cooperation with Developing Countries (Killewo 1994).

In many parts of Tanzania, especially Iringa, Mbeya, and Dar es Salaam, HIV prevalence has continued to grow into the last decade (Frumence, et al. 2010). Highlighting the severity of the epidemic for some regions, surveillance studies of HIV in antenatal care facilities reported an 18.2 prevalence rate in Iringa during the period from 2005 to 2006 TACAIDS 2008. Conversely, in the 1990's the KARP reported a reversal of trends in Kagera, with prevalence decreasing steadily in all six districts of the region, including the densely populated Bukoba Urban district (Killewo, et al. 1990).[1]

Researchers divided Kagera into three sections based on levels of HIV infection: a high-prevalence area in the Bukoba Urban district, a medium-prevalence area in the surrounding districts of Bukoba Rural and Muleba, and a low-prevalence area in the rural districts of a Karagwe, Ngara, and Biharamulo (Killewo, et al. 1990). Throughout the 1990's all three sections experienced a significant decrease in prevalence, with Karagwe decreasing from 4.5 percent in 1987 to 2.6 percent in 1999. Incidence also fell in all districts during this time, and the trends for both prevalence and incidence were most pronounced among young women (Kwesigabo, et al. 2005). The 2007-08 Tanzanian HIV / AIDS and Malaria Indicator Survey (THMIS), which is currently the most up-to-date source of information on national HIV prevalence, estimates an average 3.4 percent of the population in Kagera is HIV-positive (TACAIDS 2008).

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[1] Until the year 2000, the region was divided into six districts, with the district of Bukoba Urban containing the capital and most densely populated area. After 2000, Kagera consisted of 8 districts. Part of Bukoba Rural was sectioned off as the Misenyi district, and Biharamulo was divided into a smaller district of the same name and the new district of Chato.

2.2   MEETING THE CLIENT

In early 2010, while preparing for a language-focused cultural immersion program in rural northwestern Tanzania, I was put in contact with members of KADERES, a cooperative operating in Karagwe District of Kagera Region. I alerted them to my interest in conducting illness-related anthropological research, and they responded with a brief description of the organization's intentions to expand programming to people living with HIV and AIDS. We planned to meet upon my arrival in early July.

In July I met with the Executive Secretary of the organization at their office in the district center of Kayanga. He explained several of the organization's past and ongoing projects, including an agricultural warehousing program for the district's peasant farmers, as well as the building of district dispensaries and school water tanks in collaboration with the local Rotary club. The group was working to expand its services to AIDS affected families, especially those in which the family head was sick and the financial security of the others was at risk. The preliminary plan was to provide loans, business training, and health education to 1) facilitate hand-over of income generating responsibilities and 2) ensure proper care of HIV-infected family members. The group expressed an interest in research that would support their planning needs. However, they also explained that they understood I had come to conduct academic research, and I was reassured that they would support my work regardless of its relevance to their planning process.

After being informed about the organization, I briefly outlined the aims of the EMIC methodology and explained my intention to perform academic research using a modified version of this instrument. My focus was on people's representations of HIV and AIDS in local support groups, which are organized by the district HIV counseling network. These groups were

conveniently easy to access for surveys, and they were also the most likely recipients of educational and financial services from KADERES's new programming. With the understanding that academic and planning-oriented aims could both be met in a single survey study, I set out to design a project that could collect anthropological data about people's explanatory models of HIV and AIDS while also meeting the planning needs of KADERES's project expansion.

2.3   DEVELOPING A RESEARCH AGENDA

My research design was limited by a number of factors, and it is important to review these at the outset, as they required me to deviate substantially from the EMIC framework. First, I did not have sufficient comprehension of the Swahili language to conduct open-ended interviews. Although I considered the possibility of training a translator, I did not possess the funding required to hire someone. Additionally, my study was limited to the three weeks that our study abroad group was staying in Karagwe, so I would not have time to train a translator in interviewing and recording. I therefore decided to conduct survey-based research, following the EMIC framework as closely as possible.

The restraints of time and language skills also prevented me from conducting extensive preliminary ethnographic work, as the EMIC requires (Weiss 1997). I had already performed a basic literature review of the cultural context of HIV in East Africa, although there were few studies from the Karagwe region specifically. Therefore, I contacted informants, including the head physician of a nearby hospital, several teachers at a local secondary school, and members of KADERES, to provide background information on the ways that people in Karagwe might

understand and respond to HIV. Their input allowed me to narrow my research questions to those that might be of relevance to the circumstances of the area.

Aside from providing useful clinical information for health practitioners, information about explanatory models and health beliefs bring attention to the needs and perspectives of those receiving health services, and in this sense "they are also important in their own right" (Williams and Healy 2001:465). However, in order to target data collection to the needs of KADERES, I needed to tailor the EMIC's operational categories to questions that were relevant to the proposed program expansions for families affected by HIV and AIDS.

I reasoned that the perceived causes section could measure issues related to health education and knowledge. In past studies in Tanzania, lay etiologies have been used to measure the reach and effectiveness of HIV education. A survey-based study of beliefs about STIs and sexual practices in the Muleba and Biharamulo districts of Kagera found that most people believed that HIV is sexually transmitted (Temu, et al. 2008). Although the majority of people did not believe that HIV could be transmitted through clothing, several responded that it could. In general, beliefs about HIV were compatible with the biomedical perspective, which may be attributed to the fact that over 80 percent of people had been subjected to some form of HIV education. As the respondents in this study would all be members of the district counseling network, I expected them to have similar exposures.

Other studies addressed the role of non-medical beliefs in both a positive and negative light. According to Zou et al. (2009), beliefs that HIV is a punishment from God correspond to a fatalistic outlook; people who hold such beliefs often harbor a sense of shame and withdraw from social networks. However, they also recognize that religion is often an important basis for community organization, urging people to work together to deal with AIDS. Similarly, while

some medical practitioners perceive a natural tension between allopathic and traditional medicine, a participant observation study in Mwanza, Tanzania indicated that traditional and biomedical beliefs may not contradict one another in people's cosmologies (Plummer, et al. 2006).

In regard to the help-seeking section, I aimed to collect information about people's treatment seeking behaviors that would be useful to KADERES. Researchers describe Tanzania's health system as pluralistic, and they recognize a variety of treatment options including traditional healers, biomedical establishments, religious centers, or the loose collection of non-institutional sources often described as 'self-help,' 'home,' or 'family.' Treatment from biomedical facilities is a minimal necessity for management of HIV, and the government provides anti retro-viral drugs free of charge. Aside from the government, allopathic treatment services are available through international organizations' programs, the private sector, and civil society. In order to coordinate with everyone involved in the management of HIV, KADERES would need to know the domains from which HIV-positive people are seeking services, both currently and before diagnosis.

The patterns of distress section seemed less relevant to questions about knowledge level and behavior. Rather, the PD section of the survey was an opportunity to assess the self-reported needs of the community. Aside from physical symptoms, I would develop a question about the social problems associated with HIV infection. These data would help KADERES to target the largest problems reported by HIV-positive people.

2.4   DESIGNING THE QUESTIONNAIRE

Over the next week, I worked on a quantitative questionnaire that could elicit information on the most prevalent experiences, meanings, and behaviors in relation to HIV in Karagwe. However, due to my decision to construct a questionnaire instead of an interview, I looked more closely at the BEMI-C used in psychiatric research on explanatory models. Bhui and colleagues (Bhui, et al. 2006) have shown that the checklist-formatted questionnaire could be applied by itself to detect culturally distinct explanatory models. Additionally, it did not require prior ethnographic research as it was based on thematic analysis of previous research (Rüdell, et al. 2009). I therefore developed a questionnaire in which respondents could answer questions by ticking selections from a list of possible choices. These lists were derived from the results of previous studies in East Africa (Lugalla, et al. 2004; Plummer, et al. 2006; Temu, et al. 2008; Wringe, et al. 2009; Zou, et al. 2009), as well as informants in Karagwe and the BEMI inventory itself.

2.4.1   Item Development

While the EMIC and BEMI would include questions about the perceived identity of the person's illness, this question was unnecessary amongst a cohort of HIV support group members at a group meeting. Additionally, the questions about perceived course of the illness seemed irrelevant to the needs of KADERES. Instead, I focused on the three major categories laid out by the EMIC, formulating questions about PC, PD, and HS (see Table 1).

I included a demographics section to gather basic information about the cohort such as religion, educational level, occupation, and age. I also added a section about general illness beliefs (GIB) unrelated to HIV, following from instructions provided in Weiss 1997. Informants

explained that in rural Tanzania, headaches are less medicalized than in the US, and people do not often deal with them using drugs. A headache is also considered to be a less severe ailment than HIV, although it can at times be associated with malaria and therefore require treatment. I posited that questions about headaches would reveal the degree to which respondents might refer to non-biomedical treatments and etiologies, even if their explanatory models of HIV are in line with allopathic medicine.

Table 1. Survey Questions on Karagwe AIDS Questionnaire

Section	Question
GIB	*What are the causes of headaches?*
	If a person has a headache, where should they seek help?
PD	*What were the signs of your HIV prior to diagnosis?*
	What symptoms do you experience due to your HIV at present?
	How does life change when you have HIV?
HS	*Where did you seek help for this problem prior to diagnosis?*
	Where do you seek help now that you know about your HIV?
	Why did you agree to get tested?
	When you were tested, how did you feel?
PC	*How do people become infected with HIV?*
	What caused your infection?

Because this study did not include rigorous preliminary ethnographic research, I included an open-ended write-in option at the end of each item. I also included an open-ended comments section at the end of the survey. While many respondents added options that I had not included in the checklists, not all respondents were able to write their responses due to literacy level.

2.4.2   Problems with the Questionnaire

Certain aspects of the survey are not listed above, even though they are visible in the copy of the questionnaire that appears in the appendix. These aspects created confusion during the administration of the survey, and the data were therefore excluded from the study. For example, I attempted to add greater depth to questionnaire data by asking respondents to indicate their top priority response. They could do this by circling the response that seems most important. This is inline with the instructions of the EMIC, in which interviewers rate responses based on whether they were provided spontaneously during open-ended narratives or after probing. EMIC interviewers also wrap up each interview question by reviewing the respondent's answers and asking them to choose the most important or salient responses (Weiss 1997). Respondents had difficulty understanding my instructions, so prioritization is not reported here. I will discuss this aspect of the study in Chapter 3.

2.4.3   Translation and Piloting

The questionnaire was initially translated to Swahili with the help of students and teachers at Karagwe Secondary School. Additional suggestions for response items and the layout of questions were provided throughout the translation process. In an initial pilot stage, the questionnaire was administered to four respondents in Rwambaizi, all of whom had been diagnosed with HIV and who regularly visit the clinic. I was accompanied by a volunteer from KADERES, who translated during my interactions with respondents and clarified questions on the survey. He was also a pastor, so his presence may have affected responses at this stage. Two of the respondents completed the survey on their own, and two required the survey to be read to

them. I made note of confusing phrases, misleading words, and items for which instructions were not clear.

After the piloting stage, an English teacher at the school was consulted about items that had been confusing or which had not been interpreted as intended. Some responses that had been selected by all pilot respondents were broken into more specific responses to increase sensitivity. Instructions were adjusted for clarity, as there had been some confusion on certain items. A school administrator provided a back translation to English. This questionnaire was submitted to an IRB for final review.

2.5 METHODS

2.5.1 Survey Administration

The survey, which is included in the appendix, was administered at three gatherings. The first was in Kayanga at a meeting of support group leaders. The second and largest meeting was also at Kayanga during a full group meeting. I was not in attendance at the last gathering, which took place in Rwambaizi; the Head of District AIDS Counseling administered these surveys. For all respondents, self-administration was preferred, but if the respondent wanted assistance, the survey was read by volunteering assistants or myself. Respondents were encouraged to do the surveys without consulting others. Pieces of information not included on the questionnaire were recorded by assistants or myself. These included gender of the respondent, whether they required assistance, and any circumstances that may have influenced the respondents' selections, such as consultation with other respondents during the survey.

2.5.2 Data Analysis

Survey data were reviewed in Karagwe with teachers and students at the local secondary school and staff at KADERES. Open-ended written responses were clarified with local contacts and translated to English text. All quantitative data was coded and entered into SPSS (IBM). Frequencies of responses were tabulated, and cells with low numbers could be combined with other related cells to yield higher numbers for statistical tests, as in EMIC studies (Weiss 1997).

I also attempted to elicit data for comparison of illness representations before and after diagnosis. I developed before vs. after question pairs for the items about physical symptoms (PD) and treatment sought (HS) in . However, many respondents indicated confusion about the difference between the questions, as I had difficulty requesting them to recall pre-diagnosis thoughts about PD and HS in Swahili. Additionally, some of the response options from the HS section needed to be excluded because this survey was originally intended to be distributed in a hospital. Some of the responses about treatment were context-dependent and did not make sense at the new survey sites. For example, one possible response about treatment options was "this hospital only." This makes little sense if the survey is distributed in a support group meeting room. Variables that were rendered meaningless by the survey site were excluded from analysis. For the PD section only, McNemar's exact test was used to indicate significant changes in respondent's paired answers to before-and-after questions. These findings are reported below, although they are critically discussed in my reflections in Chapter 3.

Two types of analysis were carried but are not reported here due to skepticism about validity. First, Fisher's Exact tests were used to detect associations between binomial variables of the different categories (GIB, PC, PD, and HS). According to the theory guiding the explanatory model approach, certain symptoms, etiological beliefs, and treatment-seeking

preferences should be semantically related because they are used in the same narrative to explain an illness episode. Exact tests were preferred over estimates using chi-square distributions because many cells had values less than 5. Again, these results are problematic and are not reported here; they are instead discussed in Chapter 3.

Second, I intended to compare the degree of plurality in responses about HIV and headaches for the sections of the survey addressing PC and HS. However, the headaches question elicited associations with malaria that I had not anticipated. For instance, I had intended the response 'mosquitos' to be a physical cause of headaches that was not biomedically accepted. However, informants indicated that respondents probably inferred headaches to signify malaria, and 'mosquitos' was one of the most common responses. Consequently I lacked certain categories of responses for the questions about headaches, so help-seeking plurality could not be compared with HIV. I therefore excluded the results of the GIB section from this report.

2.5.3 Ethics

This study was carried out with Approval from the University of Pittsburgh Institutional Review Board (IRB# PRO10050001). Appropriate local authorities, including the Karagwe District Medical Officer, were contacted prior to survey administration. Requested documentation was provided, including IRB clearance and a research description. An introductory script was prepared and read to all potential questionnaire respondents via translator. Verbal consent was received prior to survey distribution. Strict confidentiality and anonymity were maintained for all respondents.

2.6   DATA AND FINDINGS

2.6.1   Sample Characteristics

Twenty-eight respondents gave consent to complete a survey. However, two surveys were excluded from the data because most of the answers were missing, yielding a sample size of N=26. The demographic information for these respondents are compiled in Table 2. Due to an unclear directive for survey assistants, gender information was only collected in 14 of the 26 cases. Also, the item inquiring about the respondents' distance to the nearest doctor was excluded because most respondents consulted the group for a collective estimate.

The age of respondents ranged from 25 to 70 years, with a mean age of 47. Most respondents were Christian, four were Muslim, and no other religious groups were represented. Many respondents were widowed. There were three possible response values for spouse: "live", "dead", or "none". "Divorced" was not distinguished from "single" in the third category due to advice about cultural sensitivity from contacts at the secondary school. However, this may be an important category for future research due to the problems faced by people, especially women, whose spouses leave them when their HIV tests come back positive.

The educational system is modeled after the British system, in which students undergo 7 years of primary schooling (*elimu ya msingi*) and 4 years of secondary schooling (*elimu ya sekondari*). If students want to apply to a university program, they also complete two additional years of secondary school, but such a demographic was not represented in this sample. Most of the respondents had completed primary school, but only 23 percent had completed Form 4 of secondary school.

Table 2. Sample Characteristics

	Mean	Median	SD	Min-Max	N (valid)
Age	47	46	11.27	25-70	26
Annual Income	312,625	280,000	234,770	20,000 to 10,000,000*	25
* TSh 10,000,000 value excluded as outlier for calculations of mean, median, and standard deviation [N (adjusted) =24].					

	Frequency	Proportion	Cumulative	
Gender				N (valid) = 15
female	11	.73		
male	4	.27		
Religion				N (valid) = 26
Christian	22	.85		
Muslim	4	.15		
Occupation				N (valid) = 26
Farmer	22	.85		
Shop Owner	2	.08		
Retired	1	.04		
Other	1	.04		
Marriage Status				N (valid) = 22
Single	2	.09		
Married	7	.32		
Widowed	13	.59		
Education				N (valid) = 26
None	5	.19		
Primary School Grade 2	1	.04	.81	
Primary School Grade 3	1	.04	.77	
Primary School Grade 4	3	.12	.73	
Primary School Grade 7	10	.38	.61	
Standard 4	6	.23	.23	

Farming was the most common occupation, with an average monetary income of about 313,000TSH per year, equivalent to about 215 USD in 2010 (exchange rate 1450 TS: 1 USD). The income of one retired individual was an outlier at 10 million Tanzanian Shillings, the 2010 equivalent of about 6,900 USD. During data analysis, local contacts noted that the majority of

farmers in the area are peasant farmers, growing food for their own consumption as opposed to commercial sales. As a result, incomes are probably rough estimates of income derived from sold crops. The family probably consumes most of total crop output. Local cooperatives such as Karagwe Development and Relief Services (KADERES) are working with local and international authorities and organizations to improve the market price for local produce.

2.6.2 Patterns of Distress

Clients were asked about the symptoms they experienced prior to being tested for HIV. They were also asked about current symptoms. As reported in Table 3, fever, headaches, loss of appetite, and tiredness were most commonly indicated as both signs of a problem prior to diagnosis and symptoms experienced after diagnosis of HIV. Some responses, including fever, headaches, malaria, weakness, sickness after eating, and nausea, were reported at higher frequencies as pre-diagnosis symptoms than current stressors. Other responses, such as bad sleep, sadness, nervousness, and overt anger, were more common after diagnosis. "No symptoms" was an option for both the pre-diagnosis and post-diagnosis experience, but it was only accepted as a valid response if no other symptoms were indicated. One respondent did not provide responses to these items (N = 25). McNemar's Exact tests were not performed for the "other symptoms" response variable because some respondents specified different symptoms for this variable before and after HIV diagnosis.

Table 3. Signs and Symptoms Experienced Prior to and After HIV Diagnosis

Response (Signs and Symptoms)	Signs prior to diagnosis		Current symptoms (post-diagnosis)		Statistical Association
	Frequency	Proportion	Frequency	Proportion	p-value (McNemar 's)
Fever	21	.84	15	.60	.070
Headaches	18	.72	15	.60	.453
Loss of appetite	16	.64	14	.56	.687
Tiredness	15	.60	14	.56	1.000
Nausea	15	.60	12	.48	.375
Malaria	14	.56	11	.42	.250
Weakness	14	.56	10	.40	.219
Bad dreams	11	.44	12	.48	1.000
Weight loss	11	.44	10	.40	1.000
Stomach aches	10	.40	11	.44	1.000
Bad sleep	9	.36	13	.52	.388
Sadness	9	.36	13	.52	.219
Nervousness	9	.36	12	.48	.375
Loss of libido	9	.36	10	.40	1.000
Suspicion of a problem	9	.36	6	.24	.250
Sickness after eating	9	.36	5	.20	.219
Overt anger	8	.32	12	.48	.125
Changes in bodily appearance	7	.28	7	.28	1.000
Excessive heat	6	.24	8	.32	.687
Other symptoms	5	.19	2	.08	N/A
Chest pains	4	.16	6	.24	.625
Diarrhea	3	.12	4	.16	1.000
Tuberculosis	3	.12	3	.12	1.000
Coldness	2	.08	2	.08	1.000
No symptoms	1	.04	0	0	

While the first two items focused on somatic and mental symptomatic experiences, the third item in the PD section inquired about sociocultural concerns and fears about AIDS. Responses were chosen from a list of social challenges that respondents have experienced or

might experience as a consequence of AIDS. These results are reported in Table 4. All but one respondent provided answers to this section (N = 25). Frequencies and percentages here are calculated based only on valid responses.   The respondent who indicated "other" wrote "wasiwasi", which can generally be translated as "anxiety" or "nervousness."

Table 4. Fears and Social Concerns about HIV

Response (Social concerns and fears)	Positive Response	
	Frequency	Proportion
Social Stigma	22	80%
Living without hope	20	80%
Loss of friends	17	68%
Financial Difficulties	17	68%
Being without support	17	68%
Inability to work	15	60%
Living in pain	14	56%
Difficulty obtaining treatment	7	28%
Rejection by family	5	20%
Breaking of marriage	5	20%
Other	1	4%

2.6.3   Help-seeking Behaviors

Respondents were asked how they seek treatment for their illness (N = 24). They were also asked how they sought help prior to their diagnosis. The most used sources of treatment for HIV (see Table 5) prior to diagnosis were religious centers, *duka la dawa* (medicine shops), and counselors, although the counselors were probably introduced to respondents during the process of AIDS testing. At the time of the survey, respondents depended on the nearby hospital, friends, and the AIDS support group (see Table 6). Home-based care was also indicated as a common strategy.

Table 5. Sources of Treatment Prior to HIV Diagnosis

Self-Help and Help-Seeking Strategies Before Diagnosis	Frequency	Proportion
Spoke with Counselor	14	58.3%
Prayer	14	58.3%
Duka la Dawa	14	58.3%
Church	12	50.0%
Rest	8	33.3%
Changed Diet	8	33.3%
Friends	7	29.2%
Family's Medicine	7	29.2%
Ate More	6	25.0%
Herbs	5	19.2%
Mosque	4	15.4%
Traditional Healer	4	16.7%
Other	0	0.0%

Table 6. Current Sources of Treatment of HIV

Current Treatment Strategies	Frequency	Proportion
Nyakahanga Hospital	19	79.2%
AIDS Support Group	17	70.8%
Friends	12	50.0%
At Home	9	37.5%
Clinic Nearby	8	33.3%
Place of Worship	8	30.8%
Distant Clinic	4	15.4%
Traditional Healer	1	4.2%
Herbal Shop	1	4.2%
Other	0	0.0%

2.6.4 Perceived Causes

Respondents were also asked about the causes of *ukimwi*, the Swahili acronym for AIDS. This question was asked in terms of the epidemic generally and the respondents' own illness specifically. All respondents indicated that sex without a condom could result in AIDS transmission, and most indicated that this was the cause of their own infection. Many also

recognized the risk of sex with multiple partners and form parents to children. Some people selected blood transfusions as possible causes. See Table 7.

Respondents were asked to provide a self-evaluation of their state of health at the time of the diagnosis. They were also asked to indicate whether their test was sought as a result of their own initiative, motivation by the family, or a recommendation by a doctor. Most respondents indicated that they were either ill or slightly ill at the time of their diagnosis. Only 5 had been tested while healthy. However, most people (11 respondents) reported that they had sought the test mostly under their own volition.

Table 7. Perceived Causes of HIV

Perceived Causes of "ukimwi"	Generalized Causes of "ukimwi"		Cause of Respondents' "ukimwi"	
	Frequency	Percentage	Frequency	Percentage
Sex without a Condom	23	100.0%	20	95.2%
Blood Transfusion	16	69.6%	6	28.6%
Sharing Needles	15	68.2%	4	19.0%
Sex with Many Partners	15	65.2%	7	33.3%
Parents have AIDS	11	47.8%	2	9.4%
Sharing Water	2	8.7%	2	9.5%
Physical Contact with AIDS patient	0	0.0%	0	0.0%
Witchcraft	0	0.0%	0	0.0%
Mungu	0	0.0%	0	0.0%
Heredity	0	0.0%	0	0.0%
Other	0	0.0%	0	0.0%

2.7 BASIC FINDINGS

Just as traditional epidemiological data can be used to extract information about the distributions, modes of transmission, and risk factors of disease, the questionnaire-derived data reported here about people's representations of HIV was compiled to describe the ways that HIV is experienced, conceptualized, and managed in Karagwe. The data indicate self-reported behaviors, as well as symptoms experienced and meanings attributed to HIV infection.

The findings indicate that malaria and related symptoms (headaches, fever) were common forms of distress experienced both prior to and after diagnosis. Recurring malaria is often an indicator of HIV as people with suppressed immunity are unable to completely rid their systems' of malarial plasmodia. Respondents also indicated nausea, tiredness, loss of appetite, weakness, weight loss, and stomach-aches as symptoms, though these can be associated with a host of opportunistic infections or other HIV-related problems. Although they was not included in the checklist, urinary tract infections, eczema, "muscle-stretching" in the legs, and vaginal irritation were also listed. Three individuals noted that the signs leading them to get tested were not physical symptoms, but the death of their spouses due to AIDS.

Bad dreams were also noted both before and after diagnosis. Bad dreams after diagnosis could be due to antiretroviral drugs such as Efavirenz, which have been shown to cause neuropsychological effects such as dreams (Clifford, et al. 2009). The prevalent occurrence of bad dreams prior to diagnosis deserves further research. Although all of these physical symptoms could be a clinical significance, they are also relevant for educational outreach by the counseling network.

Individuals also indicated that their medicines are very potent and can cause problems if nutrition is inadequate. Because nutritional security depends on financial security, there is

clearly a need for economic and financial support from KADERES, including microfinance loans and training for income generation projects. Additionally, the prevalence of symptoms such as weakness, tiredness, nausea, and recurring malaria indicate the need to hand-off physical labor and business practices to healthy family members. KADERES could facilitate this transition through its programming.

The most common forms of social distress associated with HIV included fear of stigma, loss of friends, financial difficulties, loss of support, and inability to work. Respondents also noted a fear of losing hope and living with pain. One person wrote that they experience general *wasiwasi* (nervousness or anxiety) about their situation. The prevalence of concerns about stigma and losing support indicate the need for a strong support group.

Financial difficulties were listed by seventeen people as a source of anxiety in relation to HIV. Many people used the open-ended comments section at the end of the survey to indicate a need for small loans and economic support in order to start small business initiatives, buy more nutritious foods, and pay for children's school fees:

> *Those of us suffering from HIV beg for help such as small loans, so that we afford to buy the nutritious foods we want. (Female Respondent)*

> *We AIDS patients have many problems, so we ask for the government to try to help us to pay for our children's school fees and to give us funds for subsistence farming and to buy foods that are good for our health. (Female Respondent)*

Only five people indicated that they fear rejection by their families or breaking of their marriage, indicating that the family is a fairly stable source of support for most people. Nonetheless, KADERES should assess the family situation of each client to ascertain the situation in the family, as some individuals indicated a fear of future family problems.

Because the respondents were part of an HIV support group, it was expected that they would attend the hospital and their support group regularly. It is clear that the members of this

support group see their network as an important source of support; aside from the hospital, *friends* and the *AIDS support group* were the most commonly selected sources of help. Churches and mosques were listed a major source of help prior to diagnosis. Although there were fewer people seeking religious help after their diagnosis, 8 percent still consider their place of worship to be a major place of help in regard to HIV. Several people still seek help from distant hospitals. Although this may be for other reasons, some of them may be doing so to avoid being seen by neighbors while seeking HIV-related services, a scenario raised by the head doctor of Nyakahanga Hospital. As mentioned above, fear of stigma was a major source of distress among the cohort.

The fact that support groups have access to many educational materials from the Ministry of Health may be one reason that respondents overwhelmingly indicated biomedical causes of HIV, including sex without a condom, sex with many partners, sharing needles, and blood transfusions. No one mentioned God's punishment as a cause of or reason for infection; support groups tend to challenge ideas that promote shame or stigma. Only two people chose an answer that was not compatible with the biomedical etiology of HIV infection: sharing water with an infected person. Based on this finding, I suggest that it is not necessary for KADERES to designate a high proportion of resources to basic health education about HIV, as the support group seems to be effective in educating group members. However, further research would be required to assess other areas of HIV education, as well as the state of knowledge among nonmembers of the support group.

The findings of the study indicate the need for KADERES to provide business and entrepreneurial training, as well as financial support such as low-interest micro-finance loans. If

any HIV education is to be provided, it should be directed at the general community in regards to stigmatization, which is a major concern among support group members.

In this chapter, I have attempted to provide a general overview of the study that I carried out in Karagwe, Tanzania. While relevant findings were reported, there were many problems with the methods of data collection and analysis that were employed. In the next chapter, I reflect on some of these problems and consider their broader implications for the EMIC and BEMI research methodologies.

3.0   REFLECTIONS

In this chapter, I critically review the research process in Karagwe to expose the problematic assumptions inherent in my methods. The critiques below are derived from difficulties encountered in my own research, but they have implications for the EMIC framework from which my survey questions were developed. My critiques are not generally aimed at more analytical or predictive investigations because my study aimed to elicit descriptive data about explanatory models. Nonetheless, because I used the inventory and questionnaire-format of described by Rüdell and colleagues (2009), some of my comments are relevant to the BEMI. Additionally, most clinical analytical studies carried out under the explanatory model framework are at least somewhat descriptive insofar as they render information about respondents' experiences, beliefs, and behaviors.

This chapter is divided into two sections. The first addresses methodological issues regarding preliminary ethnographic research, which is largely excluded from some studies, especially those employing the BEMI. I question the claims about the comprehensive or universal nature of explanatory model methodologies. In the second section, I address more theoretical issues, such as the cognitive basis of explanatory model research and the ways that culture is conceptualized in EMIC studies. To explain each critique, I will move through four stages: 1) reflection on my research in Karagwe, 2) consideration of relevant criticisms from medical anthropologists and cultural epidemiologists, 3) description of implications for EMIC

and BEMI methodological overviews, and 4) review of contemporary research applications of the EMIC and BEMI frameworks. This last stage is touched upon again in the final chapter of this paper, when I suggest ways to address the problems raised in this reflection.

This reflection owes a great deal to existing criticisms of trends in cultural epidemiology, especially an article by James Waldram (2006). His article, one of the few critical methodological reviews focusing specifically on the EMIC, helped me to make sense of many of the problems that I encountered during data analysis and to bring structure to my arguments. While Waldram focuses on several early studies that were formative in the interview guide's development, I turn my attention to several more recent applications of the EMIC. Nonetheless, Waldram's comments on formative landmark cases are important for understanding the trajectory of EMIC research over the past ten years and how it has come to be understood by researchers today. I aim to add to his comments using my own research experience in Karagwe.

3.1   METHODOLOGICAL REFLECTION: PRELIMINARY ETHNOGRAPHY

The primary and most elementary error in my study in Karagwe was my decision to collect descriptive data using an instrument that is primarily analytical. My decision to employ a checklist-style questionnaire to study explanatory models in Karagwe was based on the claim that the BEMI checklist could collect valid information about explanatory models when employed on its own (Bhui, et al. 2006). A questionnaire seemed like a good alternative to an interview, overcoming the language, time, and financial limitations I faced. My assumption was that this questionnaire could be used to construct a general overview of prevalent explanatory models – a snapshot of local representations about illness. However, a questionnaire is not an

appropriate way to collect this kind of data. And in defense of the BEMI checklist, Bhui and colleagues (2006) never make the claim that it can be used to create useful schematics or maps of explanatory models. Rather, it assesses the components of explanatory models to search for statistical correlations with other types of data. BEMI studies test for predictive associations between beliefs and behaviors, as well as diagnostic associations among beliefs, ethnicity, and mental disorder.

However, I raise issue with the idea that an adaptable inventory – such as the Barts Explanatory Model Inventory – can replace an ethnographic research phase. During the design phase of my research questionnaire, I depended upon three sources for background information: 1) published AIDS research from Tanzania, 2) local informants in Karagwe, and 3) the BEMI. From the anthropological perspective, there are obvious weaknesses in these forms of preliminary data collection. None are focused specifically on the target group of this study: HIV-positive support group members in Karagwe. Although the local informants can provide at least some information specific to the geographical location of the study, they do not necessarily share the same representations about HIV as infected people. In fact, their perspectives can diverge significantly: People at the school may hold preconceptions about HIV and even stigmatize the illness. The head doctor of the contact certainly knows a lot about the biomedical health status of the people in local support groups, but most of his conversations with them are restricted to the clinical setting.

My confidence that the questionnaire could be adequately adapted to the local context in Karagwe was challenged by my observations before and after data collection. While administering questionnaires, I noticed a number of respondents laughing or chuckling at the inclusion of *mganga wa kienyeji* (traditional healers) and *duka la mitishamba* (herbal shops) in

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the help-seeking section, as well as the inclusion of *uchawi* (witchcraft) and *Mungu* (God) in the causes section. At the time, I assumed this to mean that they found these response options silly, and they were wondering why I had even included them in the survey.

Conversations with students in both Karagwe and Dar es Salaam revealed the oversimplification of many of the response options provided in the survey. For example, witchcraft is only one type of so-called supernatural phenomena. A separate phenomenon with more positive valuations is *mizimu* (magic). Additionally, traditional healers are differentiated in their places of origin, the types of ailments with which they deal, the kinds of powers upon which they draw. None of these finer distinctions appear in the survey.

What these examples indicate is that open-ended discussions, long-term study, and participant observation are required to determine what items would be most appropriate for a research instrument adapted to local contexts. In an instrument such as the EMIC, which must be fine-tuned to the local cultural context, researchers must use ethnography "to identify valid representations with reference to the framework of locally valid categories of experience, meaning, and behavior" (Weiss 2001:16). This notion is seconded by Waldram, who emphasizes the "need to undertake baseline ethnography… as an important first step in any attempt to develop or employ instruments designed to measure culture or its components, such as values or 'beliefs' about illness" (2006:74).

3.1.1   The Assumption of a Comprehensive Inventory

Substituting an analytical instrument for a descriptive one was a mistake, but it was in part based on the idea that the BEMI contained a comprehensive inventory of the possible components of

explanatory models. If the domain of possible responses was already defined, there seemed no reason for preliminary ethnographic research. The questionnaire could be used to determine which responses from the whole domain of possibilities are valid and prevalent in Karagwe. Because the BEMI is specifically targeted at mental distress, I expanded the domain of possible responses to include those relevant to HIV in East Africa. But the notion of identifying a comprehensive list of possible causes via literature review was the same.

However, one must be skeptical about the comprehensiveness of such an inventory. For example, Weiss and colleagues (1986) used a predecessor to the EMIC framework, stresses the importance of ethnographic research, to study narratives of mental disorder in India. Ethnographic fieldwork elaborated on the different kinds of traditional healers operating in the area, including "*ojhas, fakirs, maulanas, pujāris, pandits, etc*" (1986:383). The researchers also recorded the specific healing temples that were attended by people seeking spiritual services. This attention to detail provides the context for later studies that involve quantitative analysis, which can then pick up on intracultural variation in treatment-seeking preferences, rather than lumping everyone under the broad categories of traditional and spiritual healers.

Some of the treatment options in Weiss, et al. 1986 are related to Ayurveda, a widespread and well-studied system of medicine involving the balance of bodily substances, or humors. While a great deal of information about this medical system can be found in a literature review, it is still necessary to conduct ethnographic research to understand how Ayurvedic medicine manifests in the local context of the study. Illustrating the process of 'glocalisation,' Elizabeth Hsu (2002) describes how Traditional Chinese Medicine (TCM) has taken on new forms and meanings in the context of Dar es Salaam, where Chinese doctors trained in TCM are serving Tanzanian patients

and responding to their preferences as consumers. In a globalizing and glocalising world, basic ethnographic work is a necessary step to adapt a research instrument to a new set of respondents.

3.1.2 The Assumption of Universal Meaning

One must also question the universal character or meaning of inventory items in the BEMI. For example, Bangladeshi patients in a BEMI study indicated that the cause of mental distress "was 'in their bones'" (Rüdell, et al. 2009:344). This study employed both a checklist and an interview guide to collect data. Whereas the response "in their bones" would be categorized among physical or bodily causes in the inventory, interviews revealed that the idiom indicated a social influence arising due to family dynamics. As explained in the study, "Here the interview data were useful to understand a very different use of language specifically a lack of a bio-medical meaning associated with the term 'bone'" (Rüdell, et al. 2009:344). To presuppose that a particular response has "bio-medical meaning," or any other type of meaning for that matter, is to presuppose that respondents share a similar framework with the researcher. Such conclusions cannot be drawn without baseline qualitative research.

Furthermore, when possible responses are grouped into categories such as *physical*, *social*, and *spiritual*, the categories say more about the researchers' assumptions than survey responses say about respondents' explanatory models. My decision to place 'traditional healers' into one lump category – alongside a more diverse range of biomedically-oriented selections such as hospitals, clinics, medicine shops, and home-based treatments – indicates my particular interest in biomedical treatment options.

Similarly, Rüdell and colleagues (2008) used the BEMI to measure the frequencies by which a sample of Black-Caribbeans, White Britons, and Bangladeshis use 'traditional healers'

to deal with distress. Rather than determining how well or how similarly this response applies to each ethnic group, they applied an institutionally approved description of traditional healers provided by the WHO. It is questionable whether "traditional healer" refers to the same category of treatment-seeking responses amongst respondents. Notably, White Britons were less likely to see traditional healers than Bangladeshis, but they were also more likely to seek herbal remedies, relaxation and massage, and yoga activities to deal with distress. It is plausible that these services function as analogs of traditional healing in "Western" societies, but without ethnographic groundwork this is an unconfirmed assumption.

Recent EMIC studies have also stressed the importance of baseline ethnographic research. While studying tuberculosis stigma amongst Haitians, Coreil, et al. (2010) began with an extensive research phase that included participant observation, media monitoring, and 182 open-ended, in-depth interviews. Teuton, et al. (2007) preceded semi-structured EMIC interviews of Ugandan religious and traditional healers with unstructured interviews, focusing on open-ended responses to a vignette about bipolar disorder and schizophrenia. In both studies, information gathered from the initial exploratory phase is used to formulate the EMIC instrument in the next phase.

It is much easier to identify studies that do undertake preliminary ethnography than to identify those that do not. Many EMIC research teams include academics or healthcare professionals from the region of study who are familiar with people's ideas of illness. It was through such partnerships that Mitchell Weiss and various colleagues originally developed the EMIC (Weiss, et al. 1992). Other EMIC researchers refer to previous ethnographic experiences to develop the EMIC methodology, even if the study at hand does not include an ethnographic phase. In their study of the experiences of South African psychiatric patients, Ensink and

Robertson (1999) tailored their EMIC instrument to measure local illness representations using their experiences from a previous ethnographic study (Ensink and Robertson 1996). It must be assumed that researchers have some knowledge of the cultural context in which their study takes place, although not all publications make explicit where or how this knowledge was acquired.

It is important to note that there *are* quantitative approaches for determining if a set of responses represent a cultural domain: an example is cultural consensus analysis (Romney, et al. 1986). Basically, if particular interview responses account for enough of the variability in the range of all responses, then those responses qualify as cultural – or culturally correct – knowledge. Cultural consensus can be applied in studies of explanatory models, as demonstrated in Linda Garro's (2000) study of diabetes among the Anishinaabe. Nonetheless, quantitative consensus analysis requires the researcher to gather binomial data using a set of relevant questions, which must be composed based on prior ethnographic research.

3.1.3   The Assumption of an Unbiased Interview Structure

Aside from the necessity of an ethnographic phase in cultural epidemiology, it is also prudent to question the universal applicability of SSIG frameworks. Waldram (2006) points out that most researchers develop schemas to understand their data. In this light, the supposedly 'emic' nature of the operational groupings of the EMIC framework (PC, PD, and HS) come under scrutiny. While these categories aim to collect emic information about illness representations, they are actually etic in nature, emerging from the concerns of biomedicine and public health with clinical attendance and treatment adherence. As such, the EMIC categories may be biased by Western conceptions of mind and mental function, and researchers must question its universal

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applicability.

Any SSIG is essentially a schema, a framework that leaves most of the interviewer-respondent interaction open to improvisation, while constraining the interviewer to a basic set of rules or guidelines. These guidelines ensure that the interviewer 1) maintains reliability in the data collected across multiple informants and 2) touches on the complete set of predetermined questions to elicit a comprehensive data array from each respondent. The EMIC, as well as some of its close relatives, go a step further by encouraging adaptation of these rules and guidelines to new cultural contexts. Such flexibility is necessary because the dynamics of the interviewer-respondent interaction, the range of appropriate questions, and the expected categories of responses can change substantially for different groups of respondents.

However, some fundamental structure must be maintained across all applications to justify classification under a single catalogue of interview guides. For the EMIC, this basic structure is the three categories through which Weiss operationalized Kleinman's explanatory model framework: perceived causes, patterns of distress, and help-seeking behaviors. While this structure may be very basic, it can still harbor questionable assumptions about universal aspects of explanatory models.

Sienna Craig and colleagues (Craig, et al. 2010) made this observation while adapting the McGill Illness Narrative Interview (MINI) to a new cultural context in Nepal. While the MINI may be one of the most open-ended illness narrative tools available, it still advises interviewers to reign in respondents when their responses deviate from topics of interest. Additionally, although the MINI allows respondents to describe their illness experiences without applying specific illness labels, it still asks about causes or etiologies. It also refers to prototypical cases of illness, which correspond with individual illness experiences. These assumptions about the

individual character of illness and the nature of cause-effect relationships sometimes interrupted the narrative flows of respondents:

> The ways Mustangi respondents complicated assumptions about cause and effect as well as the relationship between individual and collective experience challenge one to carefully consider what is accomplished by labelling one narrative a 'prototype', another a 'chain complex', and others still a 'traditional' EM in terms of how it narrates the circumstances of, and conditions giving rise to, illness. [Craig, et al. 2010:14]

The EMIC framework can also constrain the interview process in undesirable ways. Craig, et al. (2010) recall an EMIC study in which "sometimes the flow of [the interviewees'] narrative broke from the structure of the interview, and insofar as the EMIC has an agenda, some balance and guidance is required to ensure that items are covered systematically" (Lee, et al. 2001:105, changes mine). In my own study, I came to question whether the HS category was too consumerist. Through discussions in Karagwe and Dar es Salaam, I have heard descriptions of healers who seek patients at their homes, akin to door-to-door healers. In other cases, the family arranges for a healer to visit, without any active "help-seeking" on the part of the affected person. In light of these considerations, the HS category probably reflects clinical and public health concerns with attendance and treatment adherence more than it captures a lay category.

In summary, my research suffered due to a lack of preliminary ethnographic research and ongoing collection of complementary qualitative data. The BEMI assumes that the preliminary ethnographic step can be bypassed through exhaustive thematic analysis of an extensive literature review. However, the idea that a single list can capture all of the possible illness perceptions ignores the ways that each perception can very in different contexts. Just as priests may have different roles in different cultural contexts, the role of witchcraft in the explanatory model of one person may not be analogous to witchcraft in the explanatory models of people in other contexts.

In light of this reflection, I conclude that the BEMI interview and checklist – both of which are based on a supposedly universal inventory – do not comprise an effective method to elicit descriptive data on explanatory models; rather it is a way to analyze explanatory model components in clinical studies. The applicability of the inventory to new cultural contexts should be considered with skepticism. A comprehensive inventory of perception items cannot be formulated through a literature review. Additionally, reductive response items are unlikely to have similar meaning universally, at least not in a way that facilitates cross-cultural comparison. And as discussed in the next chapter, these meanings cannot be understood as static, unchanging cultural beliefs. As such, researchers who use the BEMI to create interview questions to elicit descriptive data must tailor their instrument to the local context via ethnographic fieldwork. The EMIC is a better tool due for this kind of research due to its emphasis on ethnographic research to ground the interview guide, but researchers cannot adhere too rigidly to the SSIG because its structure may favor certain modes of thinking or responding about illness.

3.2   THEORETICAL REFLECTION: EXPLANATORY MODELS AND CULTURE

As indicated earlier, the necessity of ethnography in explanatory model research is one of Waldram's (2006) central points. However, he proceeds to explain that ethnography is not only for *methodological* development, i.e. adapting the interview to a new cultural group. Another critical role of ethnographic research is to answer the *theoretical* question of how the various interview responses constitute 'cultural knowledge,' or how people in the sample constitute a 'cultural group.' The EMIC must draw on ethnographic data to explain how individuals are "empirically linked to a specific group of people who, it should be argued, share fundamental

elements of knowledge, beliefs, values, heritage, and so on" (2006:81). Unlike the BEMI methodology, which lacks an ethnographic phase altogether and instead relies on a thematic inventory, the EMIC methodology does emphasize the importance of ethnographic research in the process of adapting the interview guide to new cultural contexts. The problem raised is that "the EMIC approach, as with the explanatory model approach more broadly, assumes culture rather than viewing culture as an empirical question" (Waldram 2006:81).

In this section, I turn away from methodological questions about the best ways to collect data about explanatory models, and I instead question exactly what explanatory model studies claim to know about illness representations or local cultural knowledge. I begin by considering an analytical strategy that I had hoped to carry out using data from the Karagwe study. Because I came to reject the theoretical basis of this form of analysis, I did not include the results in the report in Chapter 2. Based on reflections about this analytical strategy, I reconsider the explanatory model framework in light of schema theory, as well as the differences between static models and dynamic processes.

3.2.1   The Assumption of a Cultural Knowledge Pool

Previous studies using the EMIC have focused on the predictive correlations between beliefs and behaviors (e.g. Ahorlu, et al. 2005; Hetzel 2007). Similarly, Jadhav, et al. (2001) noted statistical relationships between other components of explanatory models, such as between perceived causes and patterns of distress. Among White Britons in London, beliefs in supernatural causes of depression were statistically associated with reports of sadness. In these examples, quantitative analyses are used to draw connection amongst the components of an

explanatory model. I hoped to do the same using tests of association, which would indicate the ways that the components of an explanatory model fit together.

I chose to carry out Fisher's Exact Tests between various responses to search for associations. In this way, I could quantitatively detect connections among responses, which could be compiled to create basic schematics of explanatory models. Tests of association were carried out for the responses to the Patterns of Distress section. All possible combinations of items were tested for Fisher's Associations using IBM's SPSS program, and the 47 statistically significant results ($p<0.05$) are reported in Table 8.

Some of the associations immediately stood out as interesting. For example, tuberculosis and chest pain were associated (Fisher's Test p-value = 0.002), the latter of which is a defining symptom of the former. Similarly, I detected triads of responses that were all connected to one another with p-values of less than 0.05. Some, such as malaria-headaches-fever and nausea-weightloss-stomachaches, make practical sense as co-occurring disease or symptoms. In these examples, it seemed likely that the survey detected associated aspects of people's explanatory models. I was at first encouraged to look into other associations for possibly meaningful links. For example, why does the data indicate an association among the experiences of overt anger, changes in bodily appearance, and weakness? This triad of symptoms and experiences seemed like an option for further study using qualitative inquiry.

However, returning to the questionnaire, I noticed that 'malaria' appears in the checklist prior to headaches, stomachaches, and nausea, all of which were associated with malaria. While there is an ostensible rationale for these associations, I wondered if the triad could actually represent a separate malaria explanatory model, which was engaged when respondents ticked

malaria as a response.   In this scenario, the malaria-headaches-fever association would not represent part of the HIV explanatory model, and respondents would not necessarily be expected to bring up headaches and fever when talking about HIV.

Table 8. Associations Among Patterns of Distress

Responses (A, B)	p-value (Fisher Exact)	Responses (A, B)	p-value (Fisher Exact)
Overt anger, Changes in bodily appearance	.001	Fever, Malaria	.014
Malaria, Loss of libido	.001	Loss of appetite, Malaria	.017
Malaria, Sadness	.001	Bad dreams, Sadness	.017
Weakness, Nervousness	.001	Loss of libido, Weight loss	.017
Tuberculosis, Chest pains	.002	Nervousness, Weight loss	.017
Nervousness, Sadness	.002	Sadness, Weight loss	.017
Nervousness, Suspicion of problem	.002	Stomach aches, Nausea	.018
Fever, Headaches	.003	Changes in bodily appearance, Nausea	.020
Weakness, Suspicion of a problem	.003	Malaria, Headaches	.021
Malaria, Weight loss	.004	Changes in bodily appearance, Weightloss	.021
Weakness, Weight loss	.004	Bad sleep, Headaches	.027
Malaria, Nausea	.005	Loss of appetite, Changes in bodily appearance	.027
Stomach aches, Weight loss	.005	Headaches, Sadness	.027
Headaches, Nausea	.007	Sadness, Suspicion of problem	.031
Loss of appetite, Loss of libido	.008	Malaria, Nervousness	.033
Bad dreams, Headaches	.008	Weakness, Sadness	.033
Changes in bodily appearance, Weakness	.008	Loss of appetite, Stomach aches	.040
Loss of appetite, Nausea	.009	Nausea, Loss of libido	.040
Stomach aches, Sadness	.009	Nausea, Nervousness	.040
Bad sleep, Overt anger	.010	Nausea, Sadness	.040
Malaria, Stomach aches	.012	Tiredness, Nervousness	.040
Bad dreams, Tiredness	.012	Overt anger, Weakness	.042
Stomach aches, Weakness	.012	Nausea, Weakness	.049
Nausea, Weight loss	.012		

To answer this question, I needed to reevaluate the theoretical conception of an explanatory model used in my research. When I designed the study, I assumed that explanatory models could be conceived as either semantic networks or narrative-based explanations. In the first sense, explanatory models are semantic networks connecting sickness experiences with knowledge, beliefs, and concepts about illness. In the second formulation, an explanatory model denotes the explanation itself, which people use to make sense of their illness and navigate the sickness experience. This distinction was characterized by Weiss, who explained that 'explanatory models' have been understood in different ways:

> First, as Kleinman initially suggested, they specify a comprehensive account of the semantic networks linking experience and concepts of patients, healers, and all other concerned parties, and as such, they refer to perceived causes, onset, mechanisms, course, and the treatment of illness… Second, the term is used in a narrower sense to refer more exclusively to the explanations, that is, the perceived causes of illness. [2001:14]

The original, cognitive understanding of explanatory models as culturally-structured semantic networks has been supplanted by a less objectivist, narrative-based understanding that focuses more on the explanations of illness than the semantic networks through which it is conceptualized. In my study, Fisher's Tests were intended to detect connections within the semantic network, without making any claims about the active, cognitive process by which explanations are produced. I assumed that I could focus only on the knowledge constituting explanatory models, avoiding the process through which respondents take part in the process of explaining.

However, Linda Garro points out that an explanatory model framework void of cognitive theory reduces the notion of cultural knowledge to a "cultural knowledge pool" (2000:283). Some anthropological methods, such as cultural consensus analysis, disregard cognition in the

study of knowledge. These methods presumably evaluate knowledge *per se*, without considering the way it is handled in the mind. Thus, this approach to studying knowledge assumes that "cultural content itself can be discussed and represented independently of cognitive processes" (Garro 2000:284). Contemporary applications of cultural consensus, such as research on 'cultural consonance,' reintroduce cognition by studying the ways that dissonance between a person's expectations and reality can cause mental distress (see Balieiro, et al. 2011; Dressler and Bindon 2000).

In my own study, I made an assumption similar to cultural consensus theory, which depends upon the premise that the emic data collected via the questionnaire constitutes a knowledge pool about HIV. In light of my reading of the emic-etic dichotomy of Kenneth Pike (1990), the cultural knowledge pool about HIV among support group members could be assessed via questionnaire data. Responses to survey questions represent emic units, and they can be evaluated collectively to expose patterns. And as Pike explains, "a patterned whole is itself a high-level emic unit" (1990:29), which I presumed to be knowledge.

However, Garro (2000) reconsiders aspects of her own study in light of schema theory, which conceptualizes knowledge as inseparable from cognitive process. A schema is a "simplified or prototypical conceptual framework integral to perceiving, organizing, interpreting, remembering, representing, making inferences about, and acting in the world" (Garro 2000:285). In the case of my study, the 'malaria' option on the checklist may have engaged a schema about malaria, which may have developed through interpersonal communication, health education media, or via a prototypical case of illness earlier in individuals' lives (Young 1982). This cognitive process, one of "remembering" something about malaria, may not have been engaged if 'malaria' had not been an option in the checklist. In that scenario, fever, headaches, nausea,

and other malaria-like symptoms may not have been associated with HIV-induced patterns of distress. This is of course speculation, as I did not collect qualitative texts to reveal the narrative process through which people recalled HIV-related distress.

Similarly, after compiling the results to find that everyone in the support group identifies with one of the two major religions in Tanzania, and furthermore that about 30 percent of respondents seek help from places of worship, I became suspicious that not a single person had selected God as a factor in their etiology of HIV infection. This could be partially attributed to a negative connotation that accompanies the verb *sababisha*, which was used to indicate 'cause' in the survey question. Perhaps respondents would consider God to have a contributing role in the course of their lives, but they would not believe that God cruelly forced this affliction upon them. The phrase *Mungu akipenda* (if God wishes) is commonly quoted in everyday life around Tanzania, indicating that – come what will – the future is ultimately in the hands of a higher power. It expresses the role of God in every person's future, but it does not assume malevolence in God's choices.

Unlike narratives, single questions do not allow respondents to express the many layers in their etiologies, which can include biological, spiritual, psychological, social, and other kinds of forces. By conducting open-ended interviews, I would be able to bring cognitive processes back into the picture, throwing the unlayered and untextured "cultural knowledge pool" into sharper relief. However, as I explain in the next section, one must also be skeptical about the ontological significance of the "knowledge pool," which should be viewed more as a useful concept than a description of cognitive reality.

3.2.2 The Assumption of Static Cultural Structures

An explanatory model framework that ignores cognitive processes can lead researchers to reify operational categories from the instrument as actual cognitive or semantic structures. As such, the notion of an explanatory model takes on more meaning than was originally intended: rather than a tool to conceptualize peoples' complex illness narratives, it becomes a reductive framework within which to fit people's explanations. Similarly, the EMIC methodology runs the risk of reifying people's quantitatively coded comments as concrete beliefs, in spite of the uncertainty with which they are expressed, (Williams and Healy 2001). DiGiacomo notes this problem in a list of epidemiological assumptions about culture, noting that many epidemiologists believe that:

> It is possible to reify culture as "values," "attitudes," or "beliefs" that attach to a particular social group, identified in ethnic, class, or behavioral terms, which is also reified and essentialized, represented as internally homogeneous, and marked as problematic. [1999:445]

This assumption of static cultural beliefs also underlies many cross-cultural studies in cultural epidemiology, which compare the explanatory models of people from different cultural groups. Waldram (2006) challenged the definition of "cultural groups" along the lines of ethnicity, nationality, or other demographic characteristics (e.g. Lee, et al. 2001; Weiss, et al. 2001). He urged EMIC researchers to make the presence of culture one of their research questions, rather than assuming that it is captured in the sampling procedure. Implicit in the notion that there are distinct cultural groups is the assumption that each has its own cultural knowledge structures – or explanatory models in the case of the EMIC – which can be elicited and compared.

This emphasis on structures, as opposed to process and change, is out of line with today's anthropological treatment of culture. An EMIC study that emphasizes change, fluidity, and uncertainty rather than a static schematic of beliefs would be more in line with contemporary culture theory. To do so, EMIC research need not give up on cross-cultural research altogether. However, cultural epidemiologists must reconsider the basis of comparison in their studies.

An example of cross-cultural research that does not break from contemporary culture theory is presented by Mölsä, et al. (2010), although they do not apply the EMIC framework. By conducting focus group and individual interviews with Somali refugees living in Finland, as well as Somali Islamic healers, the research team investigated how concepts of mental distress are changing among Somali refugees. Although no mention was made of explanatory models, the study does explain basic principles of Somali healing that are embedded in the collective memories of the respondents and recalled through stories from home. The intention is not to build a schematic from these principles, but to uncover how changes in lifestyle, environment, and society have affected Somali refugees' understandings of mental illness.

Recent EMIC studies are also turning away from basic cross-cultural research – and its notion of static cultural frameworks – to address transnational migration and its impact on people's understandings of illness. Coreil, et al. (2010) used the EMIC to elicit the experiences and meaning of tuberculosis stigma for Haitians, comparing trends between those who have moved to Florida and those who still live in Haiti. Rather than connecting beliefs into a model, they evaluate the ways that perceptions and fears of stigma have changed due to different social and political influences.

In my own study, I attempted to evaluate changes in the forms of distress that were most

prevalent before and after diagnosis with HIV. To accomplish this, I carried out McNemar's test, a paired test of association, to assess whether there was a significant change in the prevalence of each PD response from the pre-diagnosis to post-diagnosis survey item. Although the absence of statistically significant p-values may be due in part to the small sample size (N=25), it may also be due to my attempt to compare survey response directly. Rather than looking for differences in beliefs themselves, I should have collected complementary qualitative data to understand how particular themes and explanatory strategies emerged from the attempt to make sense of physical disorder.

My attempt to quantitatively associate and compare beliefs is similar to the EMIC's differential coding of spontaneous and probed responses, which some studies use to aid in data reduction (e.g. Atre, et al. 2004; Teuton, et al. 2007). This coding is integral to the EMIC's aims to create locally validated scales for quantitative analysis:

> Analysis variables for specified categories take into consideration whether a response (e.g. food as a perceived cause of the problem) was discussed in response to an open-ended query, whether it was reported only after probing, and whether it or something else was considered most important and/or first perceived cause… This approach makes it possible to attach numeric weight corresponding to the degree of emphasis a respondent places on the category. [Weiss 1997:248]

The numeric weights added to different responses are interpreted as measurements of the "emphasis" that respondents place on those statements. However, the ways that a respondent communicates an idea also have much to do with context. In my own interviews, respondents were probably influenced by the presence of the pastor from KADERES, to whom they would be less likely to discuss matters relating to sex. Additionally, people must have recognized his affiliation with KADERES because the open-ended comments section included many appeals for small loans and income generating opportunities, which were largely unrelated to my questions.

In EMIC interviews, whether or not a respondent mentions something without probing may be influenced immensely by gender, clinical setting, ethnicity, and a host of other factors. The numerical weights to measure "emphasis" risk reifying verbal communication forms as "priorities" in people's explanatory models.

As Williams and Healy explain, "theoretical knowledge, which forms an individual's particular cognitive structure, may remain 'embedded' within forms of action or beliefs" (2001:470). Although even the existence of embedded 'theoretical knowledge' is questionable, the point is that the beliefs should be meaningful to cultural epidemiologists only insofar as they reveal something about underlying attempts to remember, understand, explain, and deal with illness experiences.

In conclusion, a conception of schema theory demands attention to the effects of cognition on the process of explaining illness. My questionnaire attempted to connect the components of an explanatory model into a schematic, a task that inaccurately portrays culture as a web of knowledge and beliefs. This naïve undertaking mischaracterizes both the nature of knowledge, which cannot be understood apart form cognitive processes such as remembering (Garro 2000), and reifies beliefs as the primary units of cultural knowledge rather than the statements through which it is communicated and explained. In the next chapter, I consider how engaging in applied research can make assumptions such as these more palatable. I also suggest ways to deal with the issues raised in this chapter when conducting cultural epidemiological research.

4.0   CONCLUSIONS

In this chapter, I aim to provide some practical suggestions based on my research experience. Before I do so, I will consider some of the underlying forces that cause a rift between medical anthropologists and cultural epidemiologists – or, more broadly, applied clinical anthropologists – in regard to methodology and culture theory. Many of the problems in my study stem from my inexperience, but published criticisms (Craig, et al. 2010; Garro 2000; Waldram 2006; Williams and Healy 2001) raise similar problems and point out similarly problematic assumptions in professional research. I consider this rift, sometimes called the clinical-critical debate, in light of two possible influences: ideological differences and client-based market pressure (Morgan 1990). In light of my study, I argue that both forces are likely at play.

4.1   IDEOLOGICAL DIFFERENCES

Most medical anthropologists recognize the mind-body separation as a cultural foundation of biomedical theory, which long viewed itself as objective or "culture-free." However, even though biomedical objectivism has been challenged by relativism, the relativistic perspective seems to have penetrated more deeply among critical anthropologists than among clinical anthropologists.   The clinical anthropologist aims to improve the interaction between

practitioners of biomedicine and patients with diverse illness understandings and health epistemologies. For them, the mind-body distinction is an assumption influencing the practitioners' explanatory model of disease, which may contrast with patients' explanatory models of illness. By alerting physicians to such incongruences and providing tools to improve the doctor-patient transaction, medical anthropologists can improve patients' compliance and adherence to the treatment regimen (Kleinman 1980). Clinical anthropologists sometimes see themselves as the bridge-men and women in the clinical setting, facilitating patient-doctor interactions.

However, critical anthropologists argue that clinical anthropologists betray their relativistic outlook when they align themselves with the medical establishment. Scheper-Hughes has referred to clinical anthropologists as "the loyal opposition" (1990:191), challenging doctors to listen more carefully to patients' needs or to improve their cultural competency, but ultimately remaining faithful to the expanding healthcare institution:

> The oft-expressed professional concerns of clinically applied anthropologists with respect to 'establishing credibility' and 'legitimacy' within the powerful world of biomedicine and the fears of 'marginalization' or, even worse, 'irrelevancy' lead only to compromise and contradiction. [Scheper-Hughes 1990:191]

Many critical anthropologists continue to question the ability of biomedicine to deal with the problems it has labeled 'diseases' and 'disorders,' as well as the acceptability of biomedicine in all contexts. However, others feel that the time has come to move forward. The themes that arose during a meeting of medical anthropologists at the University of Kentucky in 1982 provide something of a prelude to this debate. A summary of the meeting by DeWalt and van Willigen stressed the need for a shift in medical anthropology's focus:

> Anthropologists have persisted in investing research effort in questions which have been largely answered. In the Third World context we need to change our research focus from questions of the acceptability of Western medicine to traditional consumers to questions of accessibility and allocation. [1984:845]

At some level, the clinical-critical debate seems to be grounded in disparate understandings of the current goals of medical anthropology in regard to the provision of healthcare services. Such disagreement may stem from different valuations of the 'goodness' of biomedicine's reach. Whereas clinical anthropologists view biomedicine as a tool to reduce suffering, critical anthropologists accuse biomedicine of changing the nature of suffering; "This funnelling of diffuse but real complaints into the idiom of sickness has led to the problem of "medicalization" and to the overproduction of illness in contemporary advanced industrial societies" (Scheper-Hughes and Lock 1987:27).

4.2   CLIENT-BASED MARKET PRESSURE

Some authors have also considered the pressure of the job market on the aims, methods, and even theoretical choices of medical anthropologists. Stephen Turner provides a useful, though cynical, definition of a disciplines as "cartels that organize markets for the production and employment of students by excluding those job-seekers who are not products of the cartel" (2000:51). In other words, Turner is describing disciplines as both consumers and producers in a market for university graduates. Disciplines want students to seek their degrees, so they need those degrees to be valuable. Therefore, they maintain strict rules on the employability of degree-holding graduates. What follows is the evolution of a burdensome essentialism: degree-granting institutions declare that they will only hire graduates with expertise and training in certain "essential" fields of knowledge. Under Turner's model, biomedical research institutions tend to have weaker disciplinary market forces because there is an alternative source of income than degree-seeking students; these institutions can instead sustain themselves on a constant

supply of service-seeking patients and public funding (Turner 2000). As such, rigid disciplinary constraints are loosened and researchers are free to innovate and move in directions that they see fit.

However, many academics are less convinced that applied health work allows medical anthropologists to free themselves from academic constraints. Rather, medical anthropologists are forced to court medical practitioners in order to obtain a position in the healthcare institution:

> One has the image of the timid anthropologist – certainly out of his milieu – tip-toeing through the minefields of the modern clinic trying to mediate or to prevent the most potentially pathogenic inter- actions and miscommunications from hurting vulnerable patients. [Scheper-Hughes 1990:191]

In this view, held by many critical anthropologists, it is the physician or public health professional who benefits from biomedicine's non-disciplinary structure. The constant flow of income from patients and public funding benefits those in power, who in turn can determine criteria for the kinds of researchers that the institution hires. To be hired, the clinical anthropologist is forced to acknowledge the biomedical model of disease as an exceptional case, betraying the relativist framework that is central to anthropology. The clinical anthropologist must train him or herself to aid, rather than challenge, the biomedical institution:

> As jobs become more scarce, medical anthropologists must be concerned with solidifying professional legitimacy, carving out a secure job niche, and determining the types of skills that will be saleable, necessary, and ethically defensible. [Morgan 1990:948]

4.3   THE SEARCH FOR RELEVANCE

In the case of the Karagwe study presented in Chapter 3, my methodological framework was influenced by the needs and preferences of the KADERES organization, which became my client

for this research project. Granted, the pressure was not economic; undergraduate research such as mine is not conducted for financial gain. However, I depended on KADERES for access to respondents and informational support throughout the study. Therefore, there were incentives for me to adapt my research framework to their needs.

The notion that clinical anthropologists pursue an applied career path either due to ideology or due to money over-reduces the motivations by which researchers make their decisions. It would be more apt to characterize the undertaking of applied research as a search for relevance. This search may be mediated by both market-forces and a genuine desire to render research findings useful. In the context of project planning in Karagwe, I attempted to develop my explanatory model research around the framework of knowledge, attitudes, and practices studies. While this motivation may have increased the usefulness of findings for KADERES, it also pulled me away from post-modernist interpretations of the explanatory model framework and more nuanced conceptualizations of culture.

For example, the three operational categories of the survey – perceived cause (PC), patterns of distress (PD), and help-seeking behavior (HS) – correspond to some degree with the Knowledge, Attitudes, and Practices (KAP) framework used in public health assessments by the WHO, USAID, and other international agencies. However, the KAP framework typically places normative values on different survey responses, distinguishing between "correct" and "incorrect" answers in relation to a "true" body of knowledge. For example, KAP studies often speak of disparities or inequalities in knowledge and education (e.g. Mushtaq, et al. 2011). The EMIC should maintain a perspective that is more relativistic and in-line with anthropology. Although characterizing answers as "right" or "wrong" does not fit within the framework of the explanatory models, my findings were most helpful or relevant where they commented on health

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education and clinical attendance. Granted, I maintained a somewhat relativistic perspective by considering all treatment options on equal footing and considering the PD section as an assessment of support group members' greatest challenges and needs.

Ideology and prior theoretical commitments can also influence a researcher's methodological choices. My undergraduate training was primarily in biology. Hailing from the "hard sciences," I was probably more susceptible to the reification of explanatory models as beliefs and perceptions. This mode of thinking parallels the ways that scientists often think of atoms, lightwaves, and other unobservable entities that take on a "real" character in scientific theories. In the context of cultural epidemiological research, anthropologists may find themselves working closely with academics from the more positivist traditions of the medical sciences, so they must be wary of how they communicate their methods and findings.

4.4   FUTURE EMIC RESEARCH

The results of this study demonstrate that useful information can be generated for non-clinical, community-based programs using the EMIC framework, although I would recommend against reducing the instrument to a questionnaire-format. Weiss also instructed researchers to consider the value of the EMIC for program planning, although he limited his recommendation to research on mental health:

> In addition to cultural research to support clinical assessment and the information that larger surveys provide, community-based research is needed to support the specific agendas of local mental health programmes… Local programmes require guidance from cultural epidemiological research to ensure planning takes into account relevant features of the community, and the composition and mental health-related activities of the extended health system already in place. [2001:25]

While my study suffered for reasons already mentioned, it enlightened me to certain assumptions that can mislead cultural epidemiological researchers applying the explanatory model. An experienced cultural anthropologist is unlikely to make these mistakes or assumptions, but cultural epidemiologists work within research teams including biomedical practitioners, psychiatrists, psychologists, and epidemiologists. What may be clear about culture to an anthropologist can become distorted in the context of cross-disciplinary collaboration. Although my inexperience with anthropology resulted in poor research design decisions, it may have influenced my framework to more closely match more positivist members of the cultural epidemiology research team.

The EMIC methodology requires researchers to undertake preliminary ethnography in order to tailor the SSIG to the local cultural context. While no EMIC study could completely eliminate this step, as has been done through use of the inventory in BEMI research, cultural epidemiologists must nonetheless be thorough in their ethnographic grounding. To ensure credibility, they should either describe the preliminary ethnographic phase in the study or make reference to a previous publication. Researchers who make claims of cultural competency reduce culture to a performance of rules and norms. Furthermore, published studies that do not explicitly describe the local meanings of certain responses can be misunderstood by readers, who may make assumptions based on their own interpretation of these responses. In a world characterized by 'glocalization,' meaning cannot be taken for granted (Hsu 2002).

While an SSIG fosters more standardized data analysis, it can also constrain respondents whose comments are not recognized as relevant in the researchers' agenda. EMIC researchers should remain skeptical of the three categories of the interview guide (PC, PD, HS) throughout data collection, as these categories may reflect a Western conception of causal relationships as

well as an individualistic view of the illness experience. These categories may be useful for analysis, but they are more likely to result in biased responses if they determine the course of interviews.

Finally, EMIC interview data must be collected with attention to the narratives from which this data is derived. Qualitative data are insightful in their own right, as evidenced by the comments provided in the open-ended sections on my questionnaire. Additionally, textual data is also critical for understanding quantitative results. Weiss explains how textual analysis of narratives can be used to "clarify the categories and to explain their role and significance" (2001:16).

I would add that qualitative data is important in order to avoid reification of quantitative categories as beliefs or knowledge. Rather than characterizing the EMIC as a tool to elicit explanatory models, it would be more in line with contemporary culture theory to regard quantitative EMIC data as an etic measure of underlying knowledge that is embedded in the cognitive processes of remembering and explaining. This in no way hinders researchers from using the EMIC to carry out comparative statistical analysis or to create locally-validated scales for assessing stigma, suffering, and other variables of interest.

The points laid out in this paper are relevant to most research applications of the EMIC. There are additional critiques for the volumes of EMIC research dealing specifically with clinical psychiatric diagnosis, as well as BEMI research, but I am not in a position to make comments on these issues. In Karagwe, I attempted to collect useful anthropological data for KADERES's program planning needs, and I was somewhat successful insofar as my findings reveal local knowledge about HIV, preferences for services, and challenges of dealing with AIDS. However, the strength of the EMIC is in its ability to stay true to a tradition of ethnography while also

allowing variables to be quantified or reduced to suit institutional needs. The questionnaire-based study that I employed ignored the dynamic context of narrative explanation through which illness representations are expressed, as well as the broader ethnographic context in which responses must be interpreted and understood. By committing to a thorough mixed-methods approach and paying careful attention to the meaning of 'culture' in the context of research, cultural epidemiologists can employ the EMIC to inform local agencies about the health-related knowledge, preferences, and values of diverse, mobile, changing communities.

APPENDIX A

Part A - Demographics

1. Age	years _____

2. Religion	0 Christian	1 Muslim
	2 Religion of Africa	3 None
	4 Other _____	

3. Husband or Wife?	Living	Dead
	Never Married	

4. Personal Occupation	farmer	shopkeeper
	none	other_____

5. Yearly household income	_____ Tsh

6. Education Completed	None	Primary level _____
	Secondary level _____	College
	Other _____	

Distance between house and your doctor?	km_____

Part B - General Illness Beliefs

1. I want to know about your thoughts of headaches. Many people suffer from headaches. First, this problem is caused by what? Please write X beside the cause or causes of this pain. You can write another cause in the square with "other".

mosquitos		lack of sleep		stress	
witchcraft		angry spirits		poor nutrition	
harsh sun		God		heredity	
anger		cold		intense heat	
sadness		other _____			

2. When a person suffers from a headache, he should seek help where? Write an X beside the answer or answers. You can write another answer in the square marked "other".

family at home		church or mosque		medicine shop	
doctors at the hospital		herbalist		community elders	
friends		traditional healers		nurses in the clinics	
other _____					

Part C - Patterns of Distress

1. What signs urged you to go get tested for AIDS? Please draw an X beside as your answer or answers. Draw a circle around the single most important sign.

no signs		body looked different		weakness	
fever		bad dreams		loss of libido	
bad sleep		too cold		tired or exhausted	
lack of appetite		overheated		nervousness	
discomfort after eating		pain in head		diarrhea	
malaria		pain in stomach		depression	
tuberculosis		fever		suspicion of problem	
much anger		nausea		weightloss	
other _____					

2. What problems have you experienced after your HIV screening? Please draw an X beside as your answer or answers. Draw a circle around the single most important sign.

no signs		body looked different		weakness	
bodily aches		bad dreams		loss of libido	
difficulty sleeping		too cold		tired or exhausted	
lack of hunger		overheated		nervousness	
discomfort after eating		pain in head		diarrhea	
malaria		pain in stomach		depression	
tuberculosis		fever		suspicion of problem	
much anger		nausea		weightloss	
other _____					

3. How does life change when a person has AIDS? Please mark as many responses as you like.

loss of friends		difficulty receiving treatment		uncertainty of future	
difficulty doing work		financial difficulties		breaking of marriage	
separation from family		fear of pain			
other _____					

Part D - Help Seeking and Treatment

1. Did you try anything to fix your problem before your AIDS screening? Please write an "X" beside your answer or answers.					
no other place		another hospital/clinic		herbs	
speak with a counselor		speak with family or friends		traditional healer	
rest		prayer		eat different foods	
go to church		medicine shop		eat less	
go to a mosque		medicine of family/friends			
other _____					

2. Where did you seek help after you discovered that you were HIV positive? Please write an "X" beside your answer or answers. Draw a circle around the place that helped most.					
this hospital only		a clinic nearby		herb shop	
a distant hospital		a clinic far away		church or mosque	
Nyakahanga		traditional healer		friends	
home		support group			
other _____					

3. Why did you decide to go get tested?					
I wanted to know my status		My family wanted to know		Doctor's advise	

4. How did you feel at the time of your test?					
I felt fine		I felt a bit sick		I was very sick	

Part E - General HIV / AIDS EM + Perceived Cause

1. Have you known other people with HIV or AIDS?			
Yes, about _____ people		No	

2. How can people become infected with HIV and AIDS? Check as many responses as you like. Circle the most common causes.					
blood transfusion		witchcraft		sex with many people	
sharing needles		God			
touching people with AIDS		sharing water		sex without condom	
parents have AIDS		heredity			
other _____					

3. How can people become infected with HIV and AIDS? Check as many responses as you like. Circle the most common causes.

blood transfusion		witchcraft		sex with many people	
sharing needles		God			
touching people with AIDS		sharing water		sex without condom	
parents have AIDS		heredity			
other _____					

4. Thank you for your time. I appreciate the information that you have provided, and I wish you good health. Do you have any closing comments that you would like to add to my report?

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