Cultural Interpretations of Asthma: Exploring Explanatory Models of Families, Key Informants, and Health Care Providers within the Cambodian Community

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The Merrimack Valley—as in many locales around the country (Trends, 5/01)—is facing a rapid rise in pediatric asthma (American Lung Association, 2001). In greater Lowell—again as in many other locales—an asthma coalition has been formed to combat this growing health problem. The coalition in the Merrimack Valley brings together many providers attempting to address the rapid rise in childhood asthma; participants include school nurses, respiratory therapists, home visitors, home inspectors, university researchers, leaders from the city health department, and workers representing the state’s Healthy Home Initiative.

The collective work of the coalition is taking place in an increasingly diverse Merrimack Valley. Lowell has the largest Cambodian community in the country, as well as large Brazilian, Dominican, and Puerto Rican populations; in addition, all countries in Africa are now represented among Lowell’s residents (Massachusetts Department of Community Development, 2002). In the school system over half of the children come from immigrant or ‘English as a Second Language’ backgrounds (Massachusetts Department of Education, 2001). Thus, parents from many different cultural perspectives are struggling with their children’s asthma. And while asthma rates are high in general, they are particularly high in poor communities and in communities of color (Grant, Lyttle, and Weiss, 2000; HHS Action Against Asthma, 2000; Miller, 2000). Moreover, many families arrive in the United States with pre-existing exposures to health problems (Carpenter, Chew, Damstra, Landrigan, Makalinao, Peralta, & Suk., 2000).
A major topic of informal discussions at the monthly meetings of the Asthma Coalition is that within diverse communities the typical approaches to providing information seem not to be working. Families are clearly not being reached; even after instruction by health providers, families are failing to adopt those practices that are needed to reduce the numerous asthma triggers in the home. The tendency is to assume that the problem somehow lies within these families and reflects their unwillingness or inability to follow medical advice. They are often not doing what providers say they should to safeguard the health of their children. At coalition meetings, we share story after story of home visits that end with limited progress and result in nagging worries that technical information about the management of pediatric asthma is not being understood (see also Clark, Feldman, Evans, Levison, Wasilewski, and Mellins, 1986; Eggleston, Malveaux, Butz, Huss, Thompson, Kolodner, and Rand, 1998; Warman, Silver, McCourt, and Stein, 1999).

Of course, this issue of reaching culturally diverse families is by no means limited to the health problem of asthma (Frye and D’Avanzo, 1994; HHS Healthy People 2010, 2000). A cultural divide is prominent for many health problems (National Leadership Summit on Eliminating Racial and Ethnic Disparities in Health, 2002), and it is a challenge that many communities are increasingly confronting as they become more diverse (Coppens, Silka, Khakeo, and Benfey, 2000; HHS, 2001). Nowhere is this point more forcefully made than in Fadiman’s award winning book “The Spirit Catches You and You Fall Down,” (Fadiman, 1997), a book that many see as offering the most telling description yet of the missteps that can take place when health care providers and the families they care for come from vastly different cultural backgrounds. This book—now
required reading in medical schools across the country—portrays cultural misunderstandings among well-intentioned people, misunderstandings that play themselves out within a medical context and that figure ultimately in the death of a child (Mark, 1998). In Fadiman’s book, Hmong parents who do not speak English repeatedly bring their infant daughter to the emergency room where her seizures perplex the physicians. The parents distrust the physicians who keep changing the medical regimen in an attempt to stop the seizures; the physicians distrust the parents and doubt their willingness to adhere to the guidelines set up by the physicians. And the parents show ambivalence about the disappearance of seizures, seizures that within their culture mark the child with special significance. Fadiman’s book raises urgent questions about how to keep cultural misunderstandings—with their potential for life-threatening consequences—from recurring as new immigrant and refugee groups make their homes in the United States (Menon, 2002).

So, what is to be done to reduce cultural misunderstandings? In this paper, and in the work we have begun, we argue that the problem has very little to do with good intentions, or the lack thereof, and thus cannot be solved by attention to intentions. The crux of the matter has to do with changing the information base available for interventions. And changes in the information base will result only by changing the approach by which information is gathered. In this paper we will argue for what we call the ‘research cycle approach’ and we will describe here how we have begun applying this approach to uncovering knowledge about the Cambodian perspectives on asthma.

This research cycle approach directs attention to topics that often receive short shrift in the research process. These topics include the temporal cycle of collaborative
involvement, the distribution of power within collaborative relationships, and the ways in which planning for how information will be used should be a priority at the very outset of any research project. Although these ideas about the research cycle have found their fullest expression within the research context, they have great applicability to all parts of the cultural divide that emerge in health care situations. And they are particularly valuable when, as is the case of the work of the local asthma coalition, research is directed at enhancing practitioner success. The concept of the research cycle is described in more detail below, and we then illustrate these ideas through the work we have begun in a collaborative research project with Lowell’s Cambodian community.

This paper will begin by describing the research cycle approach. We then describe how we have applied this approach to investigate parental views of pediatric asthma. We end with a discussion of the benefits and costs of making this approach central to the way UML health researchers collaborate with diverse communities.

**Research Ethics and the Research Cycle**

The ideas of the research cycle began to emerge under a National Institute of Health grant in which UML researchers worked with colleagues from Syracuse University (Dianne Quigley), Tufts University (Doug Brugge), Brown University (Phil Brown), and the University of North Carolina (Steven Wing) to identify lapses in ethics in environmental health research with underserved groups (Research Ethics Resource Book, 2002). As the literature now stands, it suffers from three limitations. First, although the research ethics literature is extensive, much of this work emphasizes egregiously unethical behaviors on the part of researchers. As a result, the literature provides remarkably little guidance for how to handle ordinary, everyday ethical
dilemmas. Second, most ethical analyses focus on a single point in the research process: the step in which the “subject” is participating in the study. As a part of informed consent, each subject is told exactly what he or she will be doing during a study and what the benefits and costs for that subject might be. These analyses do not focus on the many steps leading up to the selection of the research nor do they consider those ethical steps involved in the aftermath of the study in which attention is given to such questions as who owns the data and how the data will be used. Third, Institutional Review Boards have focused on ensuring the safety of individual subjects but have inadequately considered the impacts of the research on the communities represented by the participants (e.g., a tribal group, an ethnic community living in a particular area). Scant attention has been given to the difficult issues of how to ensure community rights in research, including rights to data dissemination and ownership or control over how data will be used to bring about community change.

The Research Cycle approach emphasizes attending to the ethical dilemmas that have the potential to arise at each step in the research process, including the many steps that lead up to, take place during, and occur after the research study. These steps include how the research problem is selected and who is involved in making this decision, how the method of study is decided upon, who is chosen to participate in the study and how is this decision made, who interprets the results, to whom do the data belong, how the rights to publication of data are decided, and how the plan is made for using the data for ameliorating the problem under study? Each of the steps is important and careful attention to each contributes to strong research collaborations. Each makes it possible to
build collaborations that continue over time, involve multiple cycles of studies, and show clear eradication of problems in the community.

Within the NIH-funded partnership, we have discovered the usefulness of this research cycle framework (Silka, 2002). This framework acts as a constant reminder that rather than focusing on an isolated study, it is important that researchers and their community partners develop ways to work together before, during and after each study. From the beginning of a planning process to the sharing of research findings, it is important to chart out a cycle of responsibilities so as to increase the likelihood that ethical research will lead directly to effective, ethical interventions that address community problems such as those represented by high rate of pediatric asthma.

**Objections When an Integrative Approach is Not Used.** Academic researchers who take a narrow focus to the study of environmental health problems—who pursue research in the absence of a research cycle approach—are increasingly the targets of sharp criticism from leaders of underserved communities (O’Fallon, Tyson, & Derry, 2000). The criticisms are many (Murphy, Scammell, & Sclove, 1997; Sullivan, Kone, Senturia, Chrisman, Ciske, & Kriger, 2001; Whitehead, 1993). People from underserved communities increasingly criticize research that calls for active participation of the community in providing data but seems to bring little benefit to the community (Barnett, 1993; Israel, Schulz, Parker, and Becker, 1998). Although the rate of publication may have increased, the problems in the community remained little changed. Complex questions for research that might emerge from community understanding of their own lives are not uncovered (Quigley, 2001). Possible vectors influencing environmental health—known only by those with a deep understanding of life patterns in a particular
community or tribal group--remain unidentified because researchers are not working in partnership with community members and thus remain unfamiliar with questions that should be asked (Quigley, Sanchez, Goble, Handy, & George, 2000). Cynicism among community leaders is growing about whether the intent of researchers is indeed to gather information in ways that will aid underserved communities in addressing problems such as lead poisoning or pediatric asthma or whether the intent continues to be one of pursuing a line of research that is primarily of interest to academic researchers (cf. Murphy, Scammel, & Selove, 1997; Seattle Town Meeting, 2000). Community leaders encounter research that is constructed in ways that fail to map on to delivery systems operate so that change will be very hard to introduce. In short, in many ways the research and application agenda become disconnected without attention to the cycle of research and application.

**Beginning by Building the Local Understanding of the Research Cycle Approach.** How then can these ideas be put into action in a diverse community where research and action increasingly target underserved groups? In Spring, 2002, the first author developed UML’s first ever course ‘Research Ethics with Underserved Groups.’ The course, taken by graduate students in community psychology, work environment, and regional economic and social development, as well as by Cambodian community leaders and health providers, was designed to combine the study of the research ethics literature with an investigation of local research with underserved groups and how that research could more effectively be carried out by applying a research cycle approach. The course was organized entirely around the research cycle concept.
Students examined the research ethics literature, examining the problems that are emerging as more research is carried out in underserved communities as a result of NIH’s call for greater work on social disparities in health (HHS *Healthy People 2010*, 2001). Many of the readings focused on immigrant and refugee populations and the special challenges that result when research is carried out with groups and individuals who have little experience with the American system of research. The students read case studies written especially to prompt deeper reflection on the experiences of Cambodian refugees in the research enterprise (Silka, 2002). The intent of this course was not only to provide students with exposure to the ethical issues that arise in collaborating on research in underserved communities, but also to prepare the students to develop a series of resource materials and guides for local researchers and community leaders on the *Research Cycle* approach and how it can be implemented in all of the data collection processes that are carried out in the community. The class culminated in two workshops offered for researchers and community leaders on ways to apply the *research cycle* approach. Guides for community members and for researchers were also developed by the class on the *research cycle* approach and these resource materials have now been translated into Khmer and are available on the web. As we describe in the remainder of this paper, these guidelines have been instrumental in shaping the approach we are taking to learning about Cambodian views of pediatric asthma and applying those ideas to developing more effective, community-driven interventions that will address the concerns being raised throughout the discussions in the asthma coalition. As we shall see, all of the elements of the *research cycle* approach are being given consideration (i.e., building a relationship first, considering the problem from the community’s perspective, developing an approach
that is governed by community and researcher discussions, focusing on possible uses of
the data at the very outset of the program of activities, and following an iterative process
of gathering data and gathering feedback on the data so as to design robust interventions).
The result can be a process that addresses the ethical objections that underserved groups
raise and that results at the same time in stronger, more robust interventions.

**Exploring Cultural Interpretations of Asthma: The Listening Project**

As noted at the outset of the paper, the Greater Lowell Asthma Coalition
continues to struggle with the question of how to design educational interventions that
meet the needs of refugee and immigrant families living in Lowell whose children have
asthma. Simply following the generic recommendations of Healthy People 2010 or of
NHLBI in relation to asthma is insufficient (i.e., make sure that persons with asthma
receive formal education to assist in managing their illness; make sure they receive
written asthma plans and instruction on the administration of inhaled medications and
monitoring signs and symptoms in assessing and removing environmental triggers; make
certain that young children receive frequent monitoring of symptoms, and administration
of medications and that their families receive education on signs of exacerbations).
Important as these recommendations are, they focus on a single element in the process of
understanding an illness and so the solution that they point to—*more* education of the
same type—simply fails to view the situation in broad enough terms that other factors
contributing to the failure to reach diverse families can be readily entertained.

It may be the case that families do not need to have more information or to have
the same information repeated in various ways. Barriers to adherence to asthma regimens
may instead reflect a poor understanding on the part of the providers of how people from
different cultures view the disease. Parents and families may have a different view of the illness, its origins, and its treatment than that held by the current American medical culture. Health care providers have a tendency to define disease in relation to a pathophysiologic process whereas patients may view the illness and its treatment as having multiple meanings and as being connected to daily patterns of family life in multiple ways (Emilio, Green, & Betancourt, 1999). Such sociocultural differences may lead to poor provider-patient communication and create barriers to effective treatment where each side to the communication effort feels they he or she is not being understood.

Rather than forcing immigrant families to be responsive to some preconceived notion of what the provision of asthma education should be like (which has low compliance rates even in the absence of cultural differences; Skoner, 2001), we have begun to ask whether there might be better ways to learn from families about their views of and concerns about asthma. By adopting the research cycle approach-- thereby giving careful attention to tying together the research question, the collection of data, and the use of the results to improve community programs and interventions--we hope both to gather useful information about diverse families’ views on asthma and to demonstrate the value of this research cycle approach for building sustainable collaborations between providers, communities, and researchers.

Starting in the fall of 2002, the four authors came together to begin to plan a research-action project that would begin with the concerns of providers but link these concerns with attempts to better understand asthma from family’s perspectives. The four authors are members of the Greater Lowell Asthma Coalition. Khan Chao, is from a refugee family, and works with refugee and immigrant youth who are primarily Southeast
Asian to enable these students to develop leadership skills in addressing urban environmental problems such as asthma. Phuong Phan is from a refugee family, and works with refugee and immigrant families through Lowell Community Health Center’s outreach partnership with UML’s Center for Family, Work, and Community. Dr. Susan Reece, is from a nonrefugee family, and is a Professor in the Department of Nursing, a member of the Asthma Coalition, and an educator who teaches doctoral students about research. Dr. Linda Silka is nonrefugee family and co-directs UML’s Center for Family, Work, and Community, facilitates the Greater Lowell Asthma Coalition, and leads the New Ventures Environmental Justice Project that brings together leaders in refugee and immigrant communities to address urban environmental problems such as asthma. Together the four authors have come together over the past year to build their working relationship by reviewing the literature on pediatric asthma and on cultural approaches to pediatric asthma and by developing a plan together for gathering information about how families from diverse background view asthma. The Listening Project is the result. This project begins with Cambodian families and will eventually include other refugee and immigrant families (e.g., African and South American) in Lowell.

**Setting the Stage with the Research Cycle Approach:** As has been seen, this approach emphasizes the importance to research of developing long term relationships between researchers and community leaders. Research should be designed in ways that contribute to ongoing relationships and those relationships should be used to design whatever research is undertaken. A major way to do this is at the very outset to consider how any information that is gathered will be used. In other words, what specific problems is the information intended to address? Will the research provide clear
information about how interventions should be designed? Will the information be as useful to ameliorating the problem as it is to elaborating on the nature of the problem?

It is apparent in the work we describe here that past attempts to understand asthma simply by considering the problem from the educator’s or researcher’s perspectives have not been fully successful. What is needed is an approach that brings together the community, educators, and researchers to develop a plan for understanding Cambodian perspectives on asthma.

What is it about asthma that makes it especially like to prompt complex and differing interpretations of the illness, its causes, and its treatment? Asthma as a chronic illness is dynamic in nature and is characterized by periods of exacerbation and remission (Rolland, 1994). Patients with asthma have symptoms that come and go, and families must be flexible, consistently managing the day-to-day regimens meanwhile being prepared to deal with acute crises or flare-ups (Rolland, 1994; Warman et. al, 1999). Transitions between exacerbations and remission may be frequent, and there may be uncertainty about what may trigger an attack. The unpredictability of an illness such as asthma is challenging for both patients and their families (Rolland, 1994). Further, there may be a variety of interpretations of what has caused the attack and what might be the best intervention. These interpretations have a base in one’s explanatory model of what one believes asthma to be.

An important component of pediatric asthma management is that the family or caretaker work in partnership with the health care provider (Warman, et. al, 1999). For such partnerships to develop there has to be a mutual understanding of the illness, its
Deciding on a Theoretical Approach. In order to better understand and to improve partnerships with patients and their families around asthma and asthma care, providers need to be aware of different meanings associated with the illness. However, no studies were retrievable about particular cultural views of asthma held by Cambodian families. Generally speaking, Cambodian (Khmer) health beliefs around illness center on imbalance or disequilibrium in relation to being in a “hot” or “cold” stat or from “turbulent” emotions (Frye & D’Avanzo, 1994). Home treatments relative to asthma have not been described in the literature, although avoidance behaviors such as avoidance of the winter wind to prevent further illness or coin rubbing to release bad wind have been described in relation to respiratory infections (Frye, 1991).

How then might we begin to understand the explanatory models held by parents (and providers, and community members) relative to asthma and asthma care for Cambodian children living in the Lowell community. The Explanatory Model (EM) as proposed by Arthur Kleinman (1980) forms a useful starting point. Kleinman (1988) has proposed three levels of meaning that are relevant to physical conditions. These are disease, or the biomedical approach to the person’s underlying condition; illness, or the patient or family experience of living with the condition; and sickness, or the larger societal or institutional interpretations. Explanatory models exist both for providers and for patients. Kleinman views health care as the interaction between the explanatory models of the providers and the patient. Within the explanatory model framework there are five major areas that explain illness episodes according to Kleinman. These are
etiology, time and mode of onset of symptoms, pathophysiology, course of sickness, and treatment (Kleinman, 1980). Patients and families are often hesitant to volunteer their own explanatory models to their providers out of fear of ridicule or intimidation. Thus, in the case of asthma, providers may know little about the explanatory model that a family uses to understand a child’s asthma, asthma symptoms, and asthma treatments.

According to Kleinman (1980), explanatory models can be explored by asking a sequence of carefully structured open-ended questions specific to the particular disease such as asthma. Through the use of such questions, understanding can be gained of the beliefs, fears, and perceived severity surrounding the illness. Once these are better understood, there is an opportunity to negotiate around family management and treatment. The Kleinman theoretical framework points to the value of having providers as well as families respond to questions that will expose their explanatory models. The areas of congruence and noncongruence can then be considered for evidence of where misunderstandings might arise.

In our work we have adapted the Kleinman approach to study the explanatory models of the asthma held by three groups: Cambodian families, health care providers, and Cambodian community leaders who often act as intermediaries in relationships between systems and families. We begin by asking families about their views of asthma, its causes, and its treatment. We then ask providers and community leaders the same questions in respond to a composite case study like that of the families. The end result will be information on views that will be used to redesign the ways in which asthma discussions and educational interventions happen between community leaders, providers, and families in our community.
We begin by interviewing Cambodian families who have children with asthma and who receive their health care from Lowell Community Health Center. In Appendix One we provide the questions we have constructed for the interview with parents as adapted from work by Kleinman (1988; 1980; Kleinman, Eisenberg, & Good, 1978). As the family views are being gathered, these are being used to develop case study materials for providers. Providers and key informants from the local community will receive a hypothetical case exemplar to read of a Cambodian child newly diagnosed with asthma. This case exemplar will be created by the four person research team based on the families included in the original sample. Once the key informants and providers have read the case study, they will be asked the same questions as the families. Then their responses will be compared with those of the parents to see how the explanatory models compare. The providers and the families will then be given the information about each others’ responses and they will be asked not only what they learn from this information about also how they would modify their approach or their communication based on this new information. The suggestions will then be used to design educational materials for the providers such as those who participate in Greater Lowell Asthma Coalition.

The Listening Project approach places families at the center of attempts to develop effective educational interventions. Rather than beginning with what providers typically do and looking at how families can adapt to this approach, we begin by first collecting information on the family’s views and this information is then used to develop case studies that providers will be asked to use to modify their educational approaches. This way of going about the research process is an especially important step when families come from very different cultural backgrounds than do the providers, as is the
case with Lowell’s Cambodian families. As noted previously, although little research has been completed that looks specifically at how Cambodians view asthma, much research has been completed on Southeast Asian views of breath and its centrality to views of health. The quality of one’s breathing holds a central place in Cambodian views; many foods and activities are seen as affecting breathing and various remedies are regularly taken that are intended to have their primary impact on breathing. Thus, a Cambodian child who has the condition of asthma and thereby experiences breathing difficulties may well be viewed as having a disease with important psychological and cultural ramifications. Educational and treatment options must be understood within these cultural experiences. The Listening Project is intended to bring these views to providers so that they can build tailored intervention partnerships with Cambodian families. The result within the research cycle approach is that interventions should be better adapted to family views; at yet another level, this approach should also be helpful by allowing new sets of issues and problems to emerge. Because partnerships are at the heart of this approach, it will be possible to begin a new cycle of research and intervention without the many startup problems that would exist in the absence of partnerships.

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The Listening Project is merely one of several projects now unfolding in Lowell in which partnerships are increasingly the basis on which research decisions are made. The Cambodian Health 2010 project is another such partnership. This multi-year initiative, one of a small number funded by the Centers for Disease Control, brings together the Lowell Community Health Center, the Cambodian Mutual Assistance Association, SABAI, and UML to identify impediments to effective delivery of health
care and prevention activities for Cambodian adults who are diabetic or suffer from cardiovascular disease. The researchers and health care providers working on this project receive their guidance from an elders’ council, a community advisory board, and a medical advisory group.

Within the Cambodian Health 2010, the selection of interventions is being guided by a variety of partnership initiatives. Within the Cambodian Health 2010, the research cycle approach has the potential to strengthen the connection between research and interventions. Toward that end, the first author of this paper has begun consulting with outside researchers on the Cambodian Health 2010 project to assist them in seeing how the research cycle approach can be helpful in tying together all of the elements of the project. That consultation has included working with the researchers to look at how community leaders can become more involved in selecting the issues to be studied, how decisions are made about research questions, how data are collected, and how data are used to improve programs in Lowell for Cambodian elders. By emphasizing a full cycle from research to intervention, this approach has the potential to deepen partnerships by tying together otherwise disparate themes of best practices, research ethics, and cultural competence.

Conclusion

Communities throughout the country are struggling with the very same issues we confront in Lowell: how do we make health care systems more responsive to the needs of diverse families without assuming that the problems will be solved by all families becoming the same. We have a long ways to go as a nation in meeting the health care needs of diverse families. Just how far we have to go was suggested by a recent national
health care summit. In the summer of 2002, The National Institute of Health’s Office of Minority Health sponsored a national summit addressing this widespread concern (National Leadership Summit on Eliminating Racial and Ethnic Disparities, 2002). Several thousand leaders from throughout the United States converged on Washington for a multi-day conference designed to uncover unmet health needs in diverse communities and identify ways that those needs might be met. A major theme of the conference focused on the growing immigrant population in the United States and the fact that their health needs not only are not being met; in many cases the health care community remains unsure just what the health needs are of these newcomer groups. Summit participates were reminded of the fact that at present one in every five children living in the US has at least one parent who is an immigrant. And summit leaders noted that the number of immigrants continues to grow. The summit leaders called for recognition of the fact that cultural understanding is no longer an option; if our health care system is to meet the needs of the full community, that system must bring cultural understanding into its core.

Not only do the changing demographics of the country have important ramifications for the health care industry, they also have implications for the research and training engaged in by universities. Sustained research collaborations as opposed to single studies call for new ways of entering into partnership so that underserved communities not only contribute to the development of the research agenda but these leaders also see clear and immediate benefits to community members in participating with researchers in partnerships on improving health care.
References


Silka, L. (2002). *Rituals and research ethics: Using one community’s experience to reconsider the ways that communities and research build sustainable partnerships*. Case Study prepared under National Institute of Health, National Institute of Allergies and Infectious Disease Grant Program for Research Ethics, D. Quigley, Principal Investigator.


Appendix One

Structured Interview: Cultural Interpretation of Asthma

Please tell me about how ________ (your child)’s breathing problem began. What was happening at that time? What did you notice that was different in your child? What happened next?

What do you call the problem?_______________ (words from the parent/guardian describing the breathing problem or asthma) (note to interviewer: the above word used for “the problem” should be used in all blanks below).

What does this ____________ mean to you? What does it mean to your child?

What do you think has caused ____________?

Why do you think it started when it did?

What do you think ____________ does?

How severe is ____________? (what do you believe will happen with this sickness)?

What kind of treatment do you think your child should receive? What are the most important results you hope he/she receives from this treatment?

What are the chief problems __________ has caused?

What do you worry most about __________?

How important or urgent is __________ to you?

What stands in the way of helping your child to get better?

What do you feel would help you (and your family) in caring for your child with this sickness?