The Essential Role of Research in Community Pediatrics

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ABSTRACT. Several recommendations in the American Academy of Pediatrics policy statement “The Pediatrician’s Role in Community Pediatrics” underscore the essential role of research as an agent of change to promote the health and well-being of children. This article provides (1) a framework for thinking about research in community pediatrics, (2) special considerations important in conducting community-level research, (3) an example of community-level research that has significantly decreased mortality in children (prevention of sudden infant death syndrome), (4) an example of a current issue illustrating the importance of community pediatrics research (promotion of school readiness), and (5) a discussion of future directions for research. Many of the leading health problems facing the United States as outlined in Healthy People 2010 are problems that affect children or have their roots in childhood and are likely to be addressed by community-level research and interventions. It seems clear that pediatricians should be learning to participate in, advocate for, and conduct more community pediatrics research. Pediatrics 2005;115:1195–1201; research, community pediatrics, primary care.

ABBREVIATIONS. AAP, American Academy of Pediatrics; SIDS, sudden infant death syndrome.

The American Academy of Pediatrics (AAP) policy statement “The Pediatrician’s Role in Community Pediatrics”1 calls for pediatricians to reaffirm their responsibility to promote the health and well-being of all children in the community. Several of its recommendations underscore the essential role of research as an agent of change in fulfilling this responsibility:

• Use community data to increase understanding of the health and social risks of children and the opportunities for collaboration.
• Work collaboratively with others to identify and mitigate hindrances to the health and well-being of children in the community.
• Seek to improve the effectiveness and efficiency of health care for all children and ensure a medical home for all children.

To fulfill its role, community pediatrics must be based on a broad range of evidence. Longitudinal, epidemiologic research is needed to trace the determinants and consequences of health status across the life span. Observational and experimental clinical research is needed to assess the attributes of health care and test the effectiveness of interventions to improve and ensure its quality. Health services research is needed to guide the development of systems of care that ensure service accessibility, integration, equity, and efficiency. Quantitative and qualitative approaches to research are needed for an in-depth understanding of how and why things work (or do not work) to ensure children’s well-being. This article provides (1) a framework for thinking about research in community pediatrics, (2) special considerations important in conducting community-level research, (3) an example of community-level research that has significantly decreased mortality in children (prevention of sudden infant death syndrome [SIDS]), (4) an example of a current issue illustrating the importance of community pediatrics research (promotion of school readiness), and (5) a discussion of future directions for research.

A CONCEPTUAL FRAMEWORK FOR PLANNING AND EVALUATING COMMUNITY PEDIATRICS EFFORTS

Broadly speaking, community pediatrics aims to prevent or ameliorate problems of child health and well-being for all children. A conceptual framework is an essential tool for expressing the system of variables that gives rise to a problem of child health and well-being and laying out a plan to address the problem. Twenty-five years ago, Green and Kreuter2 began development of such a framework to guide the process of planning interventions to improve the quality of life by improving health-related behaviors. They argued that preceding intervention, one must carry out research to inform the intervention design (“precede”); after intervention implementation, one must proceed with additional research to ascertain and understand its effects (“proceed”). Figure 1 illustrates an adaptation of their precede-proceed framework for application in community pediatrics. The framework’s first 5 steps precede development of interventions. The research conducted in these 5 steps informs the development of interven-
tions aimed at achieving the ultimate goal of child welfare. Steps 6 through 9 involve implementation of the intervention and research to measure and explain results.

In the context of community pediatrics, the process begins with determining the quality of children’s lives and their welfare. In a given community, this can be accomplished through research activities such as population surveys and interviews with opinion leaders. Health (including developmental status) contributes to quality of life; thus, the second step is to determine what aspects of health or development are associated most strongly with quality of life in a given community. At this stage, research using existing data sources can provide community-level data on health and demographic attributes.

In the third step, one identifies factors at the individual and environmental levels that influence the health problem of interest. Research and theory can be used to identify these factors. Research is important in estimating the prevalence of candidate factors and the strength of their associations with the health or developmental problem of interest. Prevalence and strength of association are useful in setting priorities, ie, targeting the specific individual, family, and/or environmental factors to address as the mechanism for improving child outcomes.

The targeted individual and environmental factors themselves are influenced by malleable antecedents. These antecedents can be broadly classified as “predisposing,” “reinforcing,” and “enabling” variables. Predisposing variables are attributes of the individual, such as knowledge and beliefs. Reinforcing variables are aspects of interpersonal relationships, such as the approval or encouragement of important others, that influence an individual's behavior. Enabling factors are environmental attributes that facilitate (or impede) an individual's behavior. In the fourth step, one draws on theory and empirical research to provide a rationale for focusing on specific variables in ≥1 of these 3 broad categories. The range of predisposing, reinforcing, and enabling variables is enormous and includes not only attributes of individuals and the availability of resources but also political and legal factors.

The fifth and sixth steps are to design the intervention model and specify its implementation system. The model defines the intervention. It should explicitly link each component of the model to desired expected changes in the targeted predisposing, reinforcing, and enabling variables. The implementation system identifies the policies and resources that will be put into play to bring the model to life, which can include administrative procedures and protocols, training, supervision, and monitoring and feedback of service access, delivery, appropriateness, and quality.

Step 7, process evaluation, focuses on how well actual services adhere to the model and reasons for departure. Step 8 focuses on how well the intervention actually succeeds in achieving desired changes in proximal outcomes. Step 9 assesses change in the ultimate outcomes: child health and well-being.

SPECIAL CONSIDERATIONS IN CONDUCTING COMMUNITY-BASED RESEARCH

Because of emphasis on the biomedical model in conducting research, many young pediatricians and child health investigators may be unfamiliar with the special nuances of conducting community-based research. These considerations are especially important when engaging in research with communities that are socially isolated and/or disadvantaged. The success of the research enterprise and the interventions that are expected to flow from the research require a detailed understanding of the ethical and social dynamics of the communities in which and with whom the research is conducted.

The most important factor for researchers to understand in dealing with many socially identifiable communities is that risk-benefit analyses perceived as highly favorable by researchers and even by academically based institutional review boards may be regarded entirely differently by the community. This disconjugate view stems, in part, from the following 2 sources: the community’s previous cultural experiences and interactions with the biomedical establishment and perceptions of potential harms that are community specific and might not be recognized by the investigators themselves.

Although the model as proposed by Green and Kreuter (Fig 1) is intentionally intervention focused, carrying out steps 1 through 3 of the precede-proceed model may be problematic in certain commu-
nities. For example, broad-based attempts to establish levels of child health may be perceived as threatening in communities in which removal of children (eg, to boarding schools) is a recent, painful, and community-wide psychological trauma (eg, many Native American communities). The fear that the discovery of suboptimal conditions for children will lead to another round of community dislocations and removals could be a major barrier in gathering even minimal preliminary data in such communities. Furthermore, experiences such as the notorious Tuskegee experiments have left many communities with an inherent distrust of research entirely.

It is critical, therefore, that community-based research begin with community consultation, which is not always easy. Identifying who should be consulted, who the community has authorized to speak for them, and the limits of that authorization can be a difficult and time-consuming task. However, because the integrity of the data in steps 1 through 3 requires broad-based community support in its gathering, community consultation in the planning of any community-based research project is essential.

Cultural competence by the investigators is also essential to complete step 4 of the precede-proceed model. Clearly, beliefs about health and disease are deeply rooted in cultural values. Furthermore, understanding reinforcing or enabling factors that contribute to a specific health problem requires a deep understanding of the cultural roots of those factors. No program designed at altering tobacco use in Native American adolescents, for example, will be successful unless grounded in a thorough understanding of the traditional role that tobacco has played in this community since long before the arrival of Europeans.

From what we have noted, it should be obvious that community participation also is critical in the fifth and sixth steps of the precede-proceed model. The development of an intervention model and identification of the policies and resources to implement that model necessarily must be highly community specific and, therefore, guided and led by the community.

In summary, many of the communities most in need of broad-based efforts directed at improving child health and well-being are communities that present challenges to traditional approaches to biomedical and public health research. Thus, the promise of engaging in intervention-focused research in many communities will require the development of a cadre of culturally competent investigators who are willing and able to invest the time that it takes to engage such communities in the research enterprise. Failure to engage communities in steps 1 through 5 of the precede-proceed model will result, in many cases, in failure of the entire project.

COMMUNITY-LEVEL RESEARCH SAVING CHILDREN’S LIVES: THE BACK TO SLEEP STORY

When laypeople think of medical research, they imagine white-coated laboratory scientists doing something with rats, test tubes, and high-tech gad-gets or clinical trials in which patients receive experimental drugs. This is a narrow view of the origin of life-saving research. Although there have been many “medical miracles” arising from laboratory research, there also have been numerous instances in which the medical community took action against an illness without fully understanding its biological mechanism, let alone having a cure based on such an understanding. Epidemiology (step 2 in the framework presented in Fig 1) often has been far ahead of the biological sciences in discovering ways to fight disease and save people’s lives. John Snow, Florence Nightingale, and Ignaz Semmelweis were preventing deaths from bacterial infectious diseases before germ theory was developed and almost a century before the discovery of penicillin. Similarly, the British Navy was preventing deaths from scurvy a century before the Nobel Prize–winning work that described vitamin C. The link between smoking and lung cancer was discovered in the 1950s and led to spectacularly successful public health campaigns, although molecular biology has still not produced a cure. These are a few examples illustrating how community-based epidemiologic research has saved millions of lives.4

One example that is immediately relevant to pediatrics involves SIDS and the Back to Sleep campaign. Back to Sleep has led to a dramatic decrease in SIDS, the leading cause of death between 1 month and 1 year of age. Back to Sleep is not based on laboratory research, because basic scientists have not yet discovered a biological mechanism for the cause of SIDS. However, a number of modifiable risk factors have been identified by community-based research (steps 3 and 4). As 1 reviewer put it: “Of the diverse methodologies, disciplines, and approaches to SIDS research, epidemiology has provided the most important and conclusive contributions to an understanding of the disorder.”5

In the years before Back to Sleep, prone infant sleeping had become very prevalent, partially as a result of recommendations from pediatricians who believed that it would help prevent gastroesophageal reflux.6 From the perspective of biological mechanisms, this made sense to physicians, but there was no epidemiologic evidence to support such a recommendation. As prone sleeping increased, SIDS increased. This was seen dramatically and tragically in the Netherlands, in which prone sleeping was actively advocated in the early 1970s (Fig 2).7

The rise in SIDS was very puzzling, and many potential causes were hypothesized. Table 1 illustrates the basic 2 × 2 table framework of epidemiologic investigation using real numbers from 1 of the early SIDS studies.8 Eventually, evidence accumulated from epidemiologic studies showed a significant independent association between prone sleeping and the risk of SIDS. In response to the discovery of this important new information, the public health community developed national prevention programs (eg, in 1991 in New Zealand). In 1992, the AAP officially recommended supine positioning.6 In 1994, Back to Sleep was launched (steps 5 and 6). As a result of this campaign, health care professionals,
including nurses in newborn nurseries, changed their infant-positioning practices, and the public changed as well, leading to a 66% decrease from 1992 to 1999 in the proportion of infants sleeping prone in the United States (steps 7 and 8).9,10 Since then, SIDS has decreased almost 50% in the United States (step 9) (Fig 3).11 Subsequent research indicates that passive smoking is now the number 1 risk factor for SIDS (return to steps 3 and 4).7 Perhaps a national public health campaign similar to Back to Sleep will be launched someday to address this important killer of infants (steps 5 and 6).

COMMUNITY PEDIATRICS RESEARCH: PROMOTION OF SCHOOL READINESS

School readiness is a timely issue for illustrating the importance of research to inform community pediatrics efforts to promote child welfare. Most research in the area of school readiness has focused on steps 1 through 4 of the precede-proceed framework, ie, research informing development of an intervention. Considerable research has traced the pathway from adverse consequences in adolescence and adulthood, including mental health problems, school dropout, and teen pregnancy, to antecedents at the time of school entry and back into early childhood.12–14

A broad range of studies has elucidated the links from early childhood experiences to successful school transition. The first years of life are a time of rapid brain development.15 Negative experiences (eg, maltreatment, impoverished learning environment) can have long-lasting effects (eg, academic failure, social and emotional problems, mental illness, substance abuse).16–19 Protective factors (eg, social support, positive parenting, healthy family functioning) can buffer these adverse consequences.20–22 Unfortunately, states’ reports show that 20% to 49% of children are not prepared to enter school ready to succeed.23 These research findings underscore the need for preventive strategies in early childhood.24,25 Furthermore, research demonstrates the need to ad-
dress risk and protective factors at several levels (macrosystem [culture], exosystem [community], microsystem [family], and ontogenic [individual]), because they have independent and interactive influences on child development.26,27

Research shows that pediatricians can play an essential role in promoting early childhood development and school readiness.28,29 However, it also has shown that pediatric health professionals often fail to identify children with developmental delays or risk factors for delays in a timely manner.30 A number of studies offer strategies to correct these shortcomings,30 including the use of validated instruments to elicit parent concerns31,32 and psychosocial risks33; restructuring the schedule of well-child visits and developmental screenings34; redefining the threshold for referral of children with suspected developmental delay35; and improved integration of pediatric care with other services to promote early child development.

Integration of pediatric primary care with other services for families with young children deserves special comment. Although pediatricians have a unique and valued role, they are far from the only influence on children’s early developmental course. Parents are influenced by family members, neighbors, and friends, as well as numerous health professionals in medicine and the public health, family support, and early childhood education and care arenas. These health professionals must work together, reinforcing one another’s efforts through consistent messages. Several strategies to service integration have been developed and are in the early stages of formal testing through research. Strategies include the Healthy Steps model36 and the Healthy Start program.37,38

In summary, research has shown the importance of promoting school readiness, shortcomings of our current system of services for families, and potential benefits of strategies to promote service quality, accessibility, and integration. We have some idea of what we need to do next to ensure that all children enter school ready to succeed: develop and test theory-based, integrated models to demonstrate efficacy; develop and test implementation systems to take these models to scale with fidelity; and continue to develop, test, and scale up enhancements to our system of services.

FUTURE DIRECTIONS FOR COMMUNITY-LEVEL PEDIATRICS RESEARCH

As the field of pediatrics has matured, so has the sophistication of community pediatrics research. Articles in this area are published in the most prestigious peer-reviewed journals and adhere to rigorous scientific standards. As the Back to Sleep example indicates, however, much of this research is done outside the United States. With respect to SIDS, this was not for a lack of federal funding for SIDS research, but US research focused extensively on basic science experiments, which have yet to yield any SIDS-stopping discoveries. A more balanced approach to researching this problem would have incorporated community-level epidemiologic research and potentially led to the discovery of the connection between prone sleeping and SIDS sooner, thereby saving lives. It seems clear that we should be doing more community pediatrics research.

We need to expand educational efforts to develop the next generations of community pediatrics researchers, which in turn requires the development of faculty skilled and experienced in community pediatrics research methods: from the basic research of epidemiology and biostatistics to applied methods such as quality of care assessment. One option for developing such faculty is through fellowship training in general academic pediatrics, community pediatrics, primary care research, preventive medicine, and related fields. An essential attribute of such programs is interprofessional training, with faculty and trainees from the range of fields pertinent to community pediatrics, including medicine, epidemiology, biostatistics, behavioral sciences, economics, education, community psychology, and health policy and management. Such training models are key for building community pediatrics research capacity by using
teams with the combined expertise to negotiate the planning, implementation, and evaluative research steps described herein to improve health for all children.

Residency program directors should make sure that physicians in training are aware of the availability of these opportunities for fellowships and advanced training. In addition, pediatric residency programs can introduce trainees to community pediatrics research. Residents may develop their own community-level projects through programs such as the Anne E. Dyson Community Pediatrics Training Initiative and Community Access to Child Health, participate in larger projects undertaken by faculty members, and learn from institutional and visiting faculty who share their community pediatrics research with residents.

Another option for developing faculty researchers is the Public Health Service K Award program. This program is aimed at academic faculty who wish to devote at least 70% of their time over 3 to 5 years to advanced research training in their area of interest. Some K Awards are specifically targeted at faculty early in their academic careers to engage in a well-integrated and individualized course of mentored learning activities and research. Other K Awards are geared to investigators at later points in their careers. Information on the K Award program is available through the Web sites of the National Institutes of Health (www.nih.gov) and Agency for Healthcare Research and Quality (wwwahrq.gov).

Those who do not aspire to the role of investigator can promote children's health at the community level through participation in research networks. Research networks are collaborations of clinical practice settings that carry out research that requires a large sample size or a number of practice settings. Pediatric and family medicine research networks are essential, for example, for research on diffusion of innovation, determinants of clinical practice, and the effectiveness of interventions across a range of populations. The AAP Pediatric Research in Office Settings network and the Continuity Research Network endorsed by the Ambulatory Pediatric Association are national networks that substantially increase the range of community pediatrics questions that can be addressed. Beyond this, they provide a template for creating provider networks in smaller geographic areas. Such networks must extend beyond pediatric health care sites. For example, to address issues of school readiness, networks should include other stakeholder groups such as family support, early childhood education and care, and early-intervention providers. They also need to incorporate community representatives to ensure that the questions asked are relevant and the answers derived make sense to the community. Academic and community pediatricians can contribute by joining existing networks and taking the lead or contributing to efforts to create local or statewide networks.

Overall, federal and private funding for health research has emphasized basic science and pharmaceutical development despite the enormous cost-effectiveness of population-level prevention research and the growing recognition of the effect of social and environmental health determinants. Indeed, if one looks at the federal government’s 10 leading health indicators from Healthy People 2010, one sees problems such as physical inactivity, obesity, tobacco use, substance abuse, irresponsible sexual behavior, low receipt of immunizations, violence and injuries, pollution, and lack of access to health care. These are problems that affect children or have their roots in childhood. They seem much more likely to be addressed by the development of community pediatrics interventions than new medical treatments for adults. Ultimately, a significant increase in community pediatrics research will require a paradigm shift in how the nation prioritizes an ounce of prevention research versus a pound of cure research. Pediatricians can help advocate for this needed change.

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