

## Perceptions of Vaccine Efficacy, Illness, and Health Among Inner-City Parents

By: Virginia Keane, Bonita Stanton, Lisa Horton, Robert Aronson, Jennifer Galbraith and Nancy Hughart

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### **Abstract:**

Summary: A resurgence of measles in the past decade has focused attention on the limitations of current immunization programs, particularly for inner-city, low-income populations. As part of a larger study of immunization rates, we discussed perceptions of disease severity and vaccine efficacy, as well as the prioritization of the tasks of parenthood, with 40 parents of infants living in inner-city Baltimore to discover their beliefs about immunization. Vaccines were considered only partly successful; susceptibility to chickenpox after vaccination was repeatedly cited as evidence of vaccine failure. Fever was seen as a primary indicator of illness; thus, vaccines were believed to cause, rather than prevent, illness. Immunization was not considered a high-priority parental responsibility. These findings suggest future interventions be aimed at changing parental perceptions of vaccines as ineffective and of fever after immunization as an indicator of illness. Finally, immunizations should be made easily available, even during clinic visits for a child's illness.

### **Article:**

#### **Introduction:**

The United States experienced a steady decline in the annual incidence of measles during the two decades following the introduction of measles vaccine in 1963. However, the past decade has witnessed a resurgence of the disease. This resurgence has increased attention on the inadequacy of current immunization programs, particularly for inner-city, low-income populations, where high rates of delayed immunizations prevail.<sup>1-3</sup> Accordingly, the Centers for Disease Control is currently sponsoring several research efforts to examine the relationship of client, provider, and health-care delivery system factors to immunization rates in order to design interventions to improve these rates. A substantial body of literature exists addressing client- and provider-related factors contributing to immunization-seeking behavior.<sup>4-7</sup>

Client (parental) factors that have been identified as major determinants of immunization-seeking behavior include socioeconomic status, attitudes toward health care, and knowledge and perceptions of both the severity of the illness their children would experience from infection with the disease and the efficacy of the vaccine in preventing disease.<sup>4,5,8,9</sup> However, prior to developing interventions based on these findings, further exploration of parental conceptualization of disease severity and of vaccine efficacy will be necessary. How do parents determine if a disease is severe? What disease symptoms will a vaccine prevent (or cause)? For what duration? Exploration of these perceptions is particularly important as familiarity of the general population with the diseases for which immunization is available declines.<sup>10</sup> Further, beyond perceptions of diseases and vaccine efficacy, it is essential to explore the perceived relative importance of childhood immunization in the broader context of parenting. Among the numerous tasks involved in parenting, where do activities concerned with maintaining the health of children rank? Among these health maintenance activities, where does immunization-seeking rank? Answers to these questions may have a profound impact on the viability of interventions to improve immunization rates.

Focus-group discussions have gained acceptance as a way to begin exploring such issues.<sup>11</sup> A focus group (generally four to 12 people) is a form of group interview that relies on the interaction between group members (rather than between an interviewer and respondent). Topics are supplied by the researcher and the discussion is guided by a moderator. The data generated by the focus groups are transcripts of the discussion.<sup>12</sup>

In October 1990 we conducted a series of focus-group discussions among inner-city parents and guardians to generate hypotheses regarding immunization-seeking behavior and to develop the client related questions to be included in a community-based survey. In this paper, we discuss clients' perceptions of disease severity, vaccine efficacy, and the tasks of parenthood.

## **Methods**

### ***Subject Recruitment***

Focus-group discussions were conducted in Baltimore in the fall of 1990 among parents/guardians of infants aged 18 to 24 months. Subjects were recruited from three sites. The Pediatric Ambulatory Center (PAC), the community based health center of the Department of Pediatrics, University of Maryland School of Medicine, provides primary medical services to low-income, urban children from birth to 19 years of age. Seventy percent of the 8,700 enrolled patients receive medical assistance (MA), and 75% are African American. By 24 months of age, nearly 50% of toddlers in the catchment area are delayed in one or more immunizations.<sup>13</sup> The pediatric emergency room (PER) of the University of Maryland School of Medicine provides 24-hour emergency care to children up to age 21. Approximately 18,000 patient visits are made annually; 80% of these visits are made by African Americans and 75% by persons receiving MA.

Persons from these two sites eligible for participation included guardians of all infants aged 18 to 24 months who utilized the services of the PAC or PER during July 1990. Eligible persons were initially contacted by letter (and subsequently by telephone and/or home visit) inviting them to participate in a two-hour group discussion of why parents do or do not use health-care services, including immunization services.

The YWCA Comer House is a shelter accommodating approximately 32 homeless families in inner-city Baltimore. Seventy-five percent of its occupants are African American. All parents (guardians) residing at the shelter in October 1990 were eligible to attend the focus-group discussion. The director of the homeless shelter described the group discussions to the guardians and invited them to participate.

### ***Format and Analysis of the Focus Groups***

Discussion guides were developed around the domains of the protection motivation theory (PMT), a model for behavior change which proposes that environmental and personal factors combine to pose a potential threat. A maladaptive response is mediated by a balance between rewards accompanying the behavior change and the perceived severity of the threat and perceived personal vulnerability to the threat. An adaptive response is mediated by balancing the response efficacy (perceived likelihood that the action will reduce the threat) and self-efficacy (belief that the individual can complete the adaptive response) with the response cost (adverse consequences arising from the adaptive response).<sup>14</sup>

A focus-group format was selected in order to generate a large number of hypotheses in a limited amount of time.<sup>12</sup> Discussions were directed by word associations and explicit questioning. Word associations were employed to aid in establishing an understanding of the boundaries of a domain (the conceptual arena under Study).<sup>15</sup> Words serving as prompts are listed in Table 1. Participants were also questioned directly regarding their conceptualization of illness, health, and vaccine efficacy, and, their perception of the broader issues and challenges faced in parenting. The focus-group format was supplemented by individual interviews with half the participants; selection was based on mutual convenience.

### ***Conduct of the Groups***

Participants were divided into three focus groups. Each two-hour focus-group session was led by a trained moderator and assisted by a facilitator. Sessions were audiotaped. At the end of each session, a pediatrician

answered medical questions. Refreshments were served, and each participant was reimbursed \$10 for travel expenses. Child care was provided.

The study was approved by the University of Maryland Institutional Review Board. Informed, written consent was obtained from all participants.

### ***Analysis***

Transcriptions of the audiotapes were read independently by three pediatricians and two anthropologists, who prepared summary sheets of key findings. These findings, reported below, were used in the development of a questionnaire currently being used in a community-based survey of immunization behaviors.

## **Results**

### ***General***

Forty parents participated in the focus-group discussions. Investigators were able to contact 54 guardians (53%) of the 101 toddlers aged 18 to 24 months who were seen in the PAC and 10 guardians (48%) of the 21 non-PAC patients who were seen in the PER in July 1990. Reasons for failure to contact families included a wrong telephone number (four [7%]); disconnected phone (11 [19%]); moved, no forwarding address (eight [14%]); no answer to five or more phone calls (24 [41%]); parents no longer had custody (two [3%]); and other (nine [16%]). Thirty-one (57%) of the PAC and three (30%) of the PER families agreed to participate; 25 (41%) and three (30%), respectively, actually participated. Of the approximately 32 guardians of children residing at the YWCA homeless shelter, 12 participated. Thirty-eight (95%) of the participants were African American.

Ages ranged from 19 to 32 years. A summary of the word associations from the three groups is displayed in Table 1. Selected associations are further explored in the text.

### ***Conceptualization of Illness***

To assess how mothers conceptualized disease severity, we asked three questions: 1) "What is a healthy child?" 2) "How do you keep your child healthy?" 3) "How could you tell if your child were sick?" Word associations to the prompts "illness" and "health" supplemented responses.

A healthy child was described as a happy child, one who eats well. Factors contributing to keeping a child healthy included proper diet, bathing, semiannual dental checkups, sunshine, adequate sleep, proper dress, and "keeping their shots up to date." Nearly every mother reiterated the importance of a "good diet"; the importance of "letting the sun shine on his face" was mentioned by several mothers. By contrast, immunizations were mentioned only once. In the word associations with "health" as the prompt, immunizations were never mentioned, although other health-promoting factors were expressed.

In response to the question, "How could you tell if they were ill?" much of the conversation focused on fever. Mothers varied in their response to detection of a fever. Most comments reflected a sense of urgency: "If I just noticed a fever, I just jump up and take him"; "After the first day if her temperature didn't go down, then I'd rush her straight to the emergency." In the word associations, "illness" evoked descriptions of the impact of illness on the parents "worry," "long nights," "running back and forth to the hospital"), the effect on the child "sad," "pain," "crying"), and a single reference to a clinical indicator of illness, "fever." Specific illnesses were not listed.

### ***Conceptualization of Vaccine Efficacy***

We explored this issue through one direct question ("Do you think that baby shots work?") and through word associations with "shots," "immunizations," "needles," "clinics," "doctors," and "nurses." There was a wide range of perceived efficacy of vaccines, with some guardians believing they were protective but others citing examples of children who had been vaccinated and still became ill with the disease. The majority of the comments expressed qualified belief in their efficacy: "I believe that they work, but they don't last long"; "The shots are supposed to last until the next shot, but in between that, the child might get measles"; and "But you

know what I don't understand about the shots, after they givin' [sic] them the measles and rubella shot ... why [do] they still get the measles?" One mother noted that vaccines work unless the mother contracted the disease, in which case the child would as well. In the group discussions, several parents expressed skepticism about the efficacy of immunizations, based on the fact that children get chickenpox, a disease they thought immunizations should prevent. In the individual interviews, seven out of 20 parents spontaneously stated that vaccine immunizes children against chickenpox. Colds and the flu were also mentioned as vaccine-preventable diseases by several participants.

In the word associations, "shots" evoked substantially more discussion of the immediate sequelae than of the long-term outcomes. Six immediate (all negative) outcomes were noted ("pain," "fear," "crying," "screaming," "up all night," "fever"). "Fever" was noted by five respondents. Only two long-range outcomes (both positive) were noted ("helpful," "no worry"). However, even the woman who noted that they were "helpful" further observed: "Well, they are helpful, but sometimes they [give] your child a nice, long fever." The woman who responded "no worry" added by way of explanation "because they might not get the chickenpox." "Immunizations" evoked little discussion in any group. Additional insight into the ambivalence some mothers feel about vaccines was provided by one woman who, while speculating on why some parents did not seek immunizations for their children, suggested: "Maybe they don't want their children to go through pain ... even though I brought him here to get his shots."

"Clinics" evoked discussion regarding long waits and frustration, although some positive attributes were mentioned. "Doctors" prompted a discussion indicating their importance ("can't live without them," "help," "he'll ease the mind") but concern regarding their competence ("It's good to have a doctor's opinion, but you want to be very choosy ... who you get for your baby. It's complicated."). The criteria for judging competence appeared to include correspondence of the doctor's assessment of the gravity of the situation with that of the mother: "Well, when your child gets sick ... [doctors will] say 'OK, call ... first' ... but I'm ready to hail a cab and say, 'Take me there.' And then, when I get there, they say it's not what I think it is." "Nurses" evoked descriptions both of their role ("someone who helps the doctor," "utility infielder") and of their attributes ("patient," "considerate," etc.). There was no mention of doctors or nurses as health educators or of their role in preventive medicine.

### ***Broader Concerns Regarding Child-Rearing***

Despite the fact the participants had been informed that the topic for discussion was immunizations, there was little mention of diseases for which immunizations are available and/or immunizations in a general discussion of parenting. As one parent summarized: "I think [illegal] drugs has [sic] really taken over. I know you're here for immunizations, but drugs has [sic] taken over."

The discussion regarding parenting generally addressed the parent as 1) protector/provider and 2) teacher. As protector, a "good" mother was described as one that takes care of her child, buys for it, insures that the child has all the shots, takes the child to all doctors' appointments, registers him in school on time, makes sure he attends school, keeps him away from the bad crowd, attends church, gives him chores. The importance of assuring the physical safety of young children was stressed (i.e., stopping the child from chewing on a telephone wire or climbing stairs). "Bad" mothers were described as mothers who "play favorites" and "don't clothe the child, but they'll clothe their man. And they'll feed their man steaks, when their child gotta eat hot dogs." Discussion of disease prevention or treatment as a major concern was limited to one parent who expressed concern about recurrent otitis media in his child.

The parents in all three groups spontaneously discussed their role as teacher/role model. Parents discussed the importance of protecting their young children from "bad influences" at an early age. Several parents expressed a concern that providing daily necessities and protection was so time-consuming and energy-depleting (particularly for single parents) that there was little time for the more compelling role of parent-as-teacher. Medical concerns were raised in this part of the discussion but were confined to substance abuse and AIDS.

## ***Discussion***

The composite parental perception of immunization that can be drawn from these statements does not bode well for maximizing immunization rates. Recent publicity about measles outbreaks may have impacted more on perceptions of vaccine efficacy (or lack thereof) than on perceptions of vulnerability and severity. Perceptions of vaccine efficacy were variable, but, in general, vaccines appeared to be viewed as offering only partial protection. Several parents spontaneously cited chickenpox as an example of a disease for which immunization is available and the prevalence of chickenpox as proof that vaccines do not work. Doctors, nurses, and clinics were largely described in terms of their curative functions rather than their preventive and/or health education functions. Fever was overwhelmingly discussed as the cardinal feature of illness, and vaccines were discussed more as agents causing fever and other hallmarks of illness than as agents preventing these symptoms. Finally, in spite of participant awareness of the overall purpose of the group discussions, there was little indication that immunizations were viewed as important in either health promotion or illness prevention. While there was a general perception of vulnerability to vaccine-preventable diseases, other threats to children's health, such as drugs, street violence, and "the wrong crowd," appeared to be perceived as a larger and more severe threat than diphtheria, whooping cough, polio, and measles. Consequently, among concerns relevant to child-rearing, immunizations did not emerge as a central issue.

We anticipated that the group discussion format would result in the elucidation of numerous issues related to immunization-seeking behaviors, many of which the investigators could not have predicted. While achieving this goal, the group-discussion format does not permit establishment of community norms, nor does it always provide expression of the full range of norms.<sup>12</sup> Therefore, it will be important to examine the hypotheses generated from this study through other methodologies, such as large community surveys using individually administered questionnaires. Accordingly, these findings were used to generate questions that have been incorporated into a broader questionnaire that is currently being used in a community based survey.

If validated by the survey, these findings have several implications for intervention strategies aimed at improving immunization-seeking behavior, thus increasing the number of immunizations. Educational strategies building upon local perception are more likely to be effective than strategies based on external perceptions.<sup>16</sup> As such, information on vaccine efficacy might best capitalize on the low perception of vulnerability and severity by reminding people that vaccine preventable diseases have left the collective memory because vaccines work. Likewise, campaigns may build on the accurate recognition that vaccines may fail, emphasizing the importance of maintenance of the immunization schedules as a way to decrease this risk. The misperception that chickenpox is a vaccine-preventable disease must be corrected in order to increase perception of vaccine efficacy. Strategies underscoring the "parent-as-protector" role may be effective in motivating inner-city parents to ensure maintenance of the immunization schedule. Perceived "costs" of immunization might be decreased by emphasizing for parents that the side effects they see following immunization (i.e., fever, crankiness) do not indicate illness but rather that the immunization is working.

Finally, as health-care providers, we must recognize the competing priorities and concerns in the lives of young, often single, inner-city parents.<sup>17, 18</sup> They may not, quite understandably, view strict adherence to an immunization schedule as a high priority. Therefore, it will be essential for the health-care system to ensure that immunizations are easily accessible and frequently offered, even at sick visits.<sup>10,19</sup>

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