Long-Term Impact of Worker Notification: Qualitative Assessment of a Community-Based Notification and Screening Program in Augusta, Georgia

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Background *Evaluation of high-risk worker notification programs often focuses on their immediate effectiveness in communicating information to individual workers. This approach leaves unexamined some important social processes that can influence worker notification's impact and public health consequences over time.*

Methods *To explore long-term effects, ethnographic methods were used for qualitative assessment of a community-based program carried out by the National Institute for Occupational Safety and Health (NIOSH) in Augusta, Georgia, during the early 1980s. More than a decade after the original NIOSH intervention, lengthy taped interviews were conducted with 70 members of the notified cohort (chemical workers exposed to beta-naphthylamine (BNA)) and 32 members of their families.*

Results *The notified workers expressed extremely positive feelings about having received the risk information. However, for non-obvious and unanticipated reasons, most had failed to implement the notification's primary health advice (annual screening for bladder cancer). Both the workers and their family members reported a number of ongoing concerns related to the program.*

Conclusions *The study findings suggest four strategies, all relatively low in cost, that are likely to increase the long-term public health benefits of worker notifications that rely on individually mailed written materials: (1) in designing worker notifications, take into account the information (accurate or not) that the workers already have, and determine what kind of information they most want and need; (2) define the notification audience broadly to include not only the study cohort but also family members and/or other similarly exposed workers; (3) when notifications recommend secondary disease prevention measures over long time periods, follow up the notification health advice with periodic reminders; (4) inform a wide range of community organizations and service providers (non-medical as well as medical) about the notification, and encourage them to provide appropriate support to the notified workers and their families.* Am. J. Ind. Med. 44:113–123, 2003. *Published 2003 Wiley-Liss, Inc.*†

KEY WORDS: risk communication; worker notification; occupational disease; right to know; beta-naphthylamine (BNA); bladder cancer; medical screening

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Accepted 14 April 2003
DOI 10.1002/ajim.10249. Published online in Wiley InterScience (www.interscience.wiley.com)

INTRODUCTION

During the 1970s, the National Institute for Occupational Safety and Health (NIOSH) became aware that a large number of chemical workers in Augusta, Georgia, had potentially suffered occupational exposures to the dye chemical beta-naphthylamine (BNA) through their employment at a local plant, Augusta Chemical Company (ACC). At the time, BNA was known to be a potent bladder carcinogen in humans [IARC, 1974]. A number of industrialized nations had already banned its production, and US producers were rapidly phasing out the chemical due to liability concerns. ACC was the last plant in the nation still actually manufacturing BNA. BNA production ceased at ACC in 1972, but by that time over 1,000 workers were thought to have been exposed. They were mostly African-American men with relatively low incomes and limited formal education who were not unionized and had never been warned of BNA's dangerous health effects. In the words of one analyst, the situation was ''highly polarized by racial discrimination, poverty, and substantial lack of understanding of toxic hazards [Tillett et al., 1986]. The site presented a compelling scientific and public health rationale for NIOSH research.

The BNA exposures among ACC workers came to light during a time of mounting sensitivity about government-sponsored health research, with both internal professional staff and outside public interest groups calling for government agencies to become more proactive in making research findings available to the study subjects when serious adverse health effects were discovered [Bayer, 1987; Needleman, 1990; Millar, 1989]. Responding to these concerns and pressures for more active risk communication, NIOSH decided to target Augusta as one of the sites for developing the agency's worker notification procedures. A similar NIOSH program was conducted during the same period for BNA-exposed workers in Lock Haven, Pennsylvania [Tillett et al., 1986; Marsh et al., 1990]. Both programs sought to inform the exposed workers about the link between BNA exposure and bladder cancer, and also to impress upon workers the importance of health-protecting measures such as annual testing to detect bladder disease in its early stages.

Much has been written about the Augusta notification, the converging political and ethical concerns that brought it into being, and its complex interconnections with other simultaneous efforts to help the exposed workers [Crapnell, 1981; Omang, 1981; National Institute for Occupational Safety and Health (NIOSH), 1983; Schulte, 1983; Schulte and Ringen, 1984; Hornsby et al., 1985; Schulte et al., 1985a,b; Stern et al., 1985; Ruttenberg and Powers, 1986; Schulte, 1986; Tillett et al., 1986; Baker et al., 1989; Needleman, 1993; Leviton, 1998]. As a pioneering effort, the program carried out in Augusta included a number of features not typical of NIOSH's current worker notifications, such as extensive outreach activity, medical screening for the notified workers, and direct engagement of agency personnel in community controversies. However, typical or not, the Augusta program offers lessons regarding worker notification's long-term impact that can be useful for professionals working in occupational health and risk communication.

The Augusta notification and screening program was officially launched in 1980, heralded by a great deal of coverage in local TV and newspapers. It continued until 1984, when the funding period (and all official contacts between the workers and NIOSH) came to an end. Intervention occurred at three different levels. First, individual letters were sent to the entire cohort of current or retired workers who were known or suspected to have had BNA exposure, whether living outside the Augusta area or residing locally. The letters informed the workers in lay language that NIOSH research and other scientific evidence showed a strong link between BNA exposure and bladder cancer. Secondly, the notified workers were invited and strongly encouraged through related outreach efforts to participate in a medical screening program free of charge. For those living in the Augusta area, about 80% of the group, screening was made available at local medical institutions through contracts with NIOSH. Workers living outside the area were to be screened through their personal physicians. The screening served the double function of detecting treatable disease while also providing NIOSH with additional epidemiological data for research purposes. Of the 1,094 workers who were sent notification letters, 655 ultimately participated in the screening (472 living in the Augusta area and 183 living elsewhere). As a third level of intervention, the program also attempted to build the medical community's capacity for dealing with this occupational disease problem by sending 900 individual letters to local physicians and negotiating actively with key medical administrators and associations in the Augusta area.

The notification unfolded within a very heated political and legal context. Prior to and during NIOSH's program, BNA-related civil lawsuits were brought against the company by 167 former ACC employees, totaling about $330 million in claims. One hundred twenty cases were settled out of court but, much to the disappointment of the claimants, the awards totaled less than 1% of the amount initially sought [Pinkham, 1988]. Subsequently, about halfway through the notification period, the Georgia Supreme Court ruled that any remaining BNA claims belonged in the state's workers' compensation system, even though they would be automatically denied there because Georgia's statute of limitations on occupational chemical exposures had long since expired for the ACC workers. Both the workers and the company's management (at this point, a large chemical conglomerate that had acquired ACC in 1967) reacted to the legal disputes with anger and bitterness. The litigation was covered in great detail by local media, further inflaming public opinion throughout Augusta and heightening both negative and positive feelings about the notification.

Adding further complexity, a community-based support program funded by the National Cancer Institute was being carried out simultaneously in the workers' neighborhood by an organization called the Workers' Institute for Safety and Health (WISH). Because WISH was locally perceived as union-oriented and supportive of the workers' BNA-related litigation, this organization's involvement was a sore point for many of Augusta's business and political leaders, as well as for the medical institutions that played central roles in the NIOSH screening. The lawyer representing ACC's parent corporation took particular aim at an African-American community activist affiliated with WISH, branding him publicly (although inaccurately) as an "admitted communist and convicted felon" who had burned the American flag [Leviton et al., 1998]. As reported in local news media, some members of Augusta's local elite viewed NIOSH and WISH as close allies and condemned professional staff from both organizations equally as outsiders, labor sympathizers, and unwelcome examples of federal intrusion into local affairs.

The evaluation presented here revisits Augusta more than a decade after the NIOSH program ended, exploring this program's long-term consequences for the notified workers and their families. While specific effects of the notification itself cannot be isolated from effects of related events such as the flood of public discussion, litigation, and simultaneous advocacy efforts, the setting is ideal for examining overall program impact in a broad sense [Fetterman et al., 1996; Patton, 1997].

MATERIALS AND METHODS

A combination of qualitative and quantitative methods was used in this descriptive case study, a "multi-method" approach increasingly favored by program evaluators [Brewer and Hunter, 1989; Needleman and Needleman, 1996]. The main body of data, collected over a 3-year period from 1994 through 1997, came from 102 lengthy taped personal interviews with a random sample of notified workers living in the Augusta area and all recruitable family members who had been living in these workers' households at the time of the original notification.

Sampling and Data Collection

This study's purpose did not require seeking generalizable statistics, which would have been ill-advised in any case because of survivor bias from attrition due to deaths in the cohort over the years. Instead, in order to gain qualitative insight into what the notification had meant to those most affected, we needed a purposive sample of workers who had been fully involved in the program within the Augusta community setting, particularly those at greatest risk. Statistical power issues are irrelevant for this kind of non-probability sampling, just as they would be for a focus group. We set the worker sample size at 70, a level we felt would give us good data saturation among those with the appropriate characteristics while still being feasible within our research resources. Starting with the original NIOSH notification list, we first identified all surviving cohort members who had participated in the medical screening and were still living in the Atlanta area, numbering approximately 400. We stratified this list by risk status ("high" or "not high") based on exposure histories and other information recorded during the original screening. We randomly sampled from each of the two risk categories, over-representing the high-risk workers so that the final sample was half "high-risk" and half "not high-risk." Where interviews were declined (mostly due to workers' illness), substitutes were drawn randomly from the remaining names on the appropriate list. Random selection did not, of course, alter the sample's non-probability nature, but it did minimize possible bias from non-random selection by the researchers.

The family respondents also made up a purposive non-probability sample, in this case built in "snowball" fashion. As the workers were interviewed, they were asked to suggest names of appropriate relatives. If the suggested individuals fit the pre-set criteria (i.e., they were regarded as family by the worker, still lived in the Augusta area, and had been living in the household or close by at the time of the notification), they were contacted and asked if they would grant an interview. In addition to workers' wives or long-term companions, the family sample also included some adult children, cousins, siblings, and a few non-related household members who were "close like kin." We were able to identify only 35 individuals who fit the criteria, all but three of whom granted interviews.

We supplemented the interviews with over 400 hours of field observation in the workers' community and also held informal discussions with a variety of local medical professionals, worker advocates, attorneys, business leaders, and journalists who had publicly supported or opposed the NIOSH notification and screening program during its active years. While not included in the present report, these additional data sources provided useful context for interpreting the interview data.

The taped interviews with workers and family members took place for the most part in the workers' homes. We used a detailed interview guide with 175 questions, some open-ended and some with 5-point Likert scale response formats, developed and extensively field-tested during the project's first-year reconnaissance phase. After pre-testing, most of the worker/family interviewing was done by a team of five salaried research assistants recruited from the community and specially trained for the task.

Data Analysis

After transcription from the audiotapes, the interview data were analyzed qualitatively using procedures standard in social science research [Patton, 1990; Denzin and Lincoln, 1994; Miles and Huberman, 1994]. In qualitative analysis, narrative texts (in this case, interview transcripts) are coded for meaning, usually line by line or paragraph by paragraph. The coded units are then regrouped to reveal underlying themes that otherwise would not be easily apparent. The codes themselves are developed through a process of ‘‘constant comparison’’ [Strauss and Corbin, 1998] in which the analyst develops a preliminary coding system based on initial ideas and close reading of about a dozen transcripts; then applies the tentative coding system to additional transcripts, adding and modifying as needed; finalizes the coding system when it no longer seems to need changes in order to capture data content; and then goes back and applies the finalized coding scheme systematically to all transcripts, including those used to develop the preliminary codes. Various computer software packages now available for qualitative analysis can greatly facilitate the task of data coding and sorting; this study made use of QSR NUD.IST 4.

Gaining Research Access

Obtaining in-depth interviews with the workers and their families was no easy matter. Many workers had mixed feelings about the research aspects of the original NIOSH notification, and did not wish to participate in further research unless they could see some point in it. Gaining their cooperation involved many months of preliminary trust building. A community-based research advisory board was established early in the project, and proved invaluable in avoiding potentially alienating mistakes. To give one example, we had initially planned to offer incentive payments to the study respondents, as is often done in interview-based community research. The board advised strongly against this, particularly one member who was an influential opinion leader within the workers' community. He was himself a member of the notified cohort, had signs of bladder disease, had lost a close relative to bladder cancer that he attributed to BNA exposure, and his son had been killed in an accident at the chemical plant. At one of our planning meetings, he spoke movingly of the anguish the workers had suffered and explained that ‘‘paying us would demean our story.’’ On this advice, we dropped the idea of payment. The interviewed workers and family members later confirmed the wisdom of this decision, saying that if they had been paid, providing us with data would have seemed like a ‘‘hustle’’ and they may have given false or perfunctory information.

Ultimately, the notified workers and their family members agreed to cooperate with the study only because they hoped to have their side of the story reported as the reactions of taxpayers and service consumers, rather than as research subjects. The workers in particular wanted to let risk communication professionals know what went right and what went wrong from their point of view, so as to ‘‘help other workers like us in the future.’’

RESULTS

Profile of the Study Sample

Roughly paralleling the original notification cohort, the worker interview sample was all male with most (76%) being African-Americans born and raised in the Augusta area during the 1920s and 1930s. The sample's median age at the time of our interviews was 64, meaning that most were in their forties or early fifties at the time of the NIOSH screening and notification program. About half were high school graduates, but a third had ended their formal education in grade school at about the third grade level. Twenty-one percent reported that they had never earned over $15,000 a year at any time in their lives. However, the overall picture was not one of poverty or social marginality. At the peak of their earning power (not necessarily while working at ACC), the majority were paid between $25,000 and $30,000 a year. Seventy percent of the sample were home owners, typically in the Bethlehem Area of Augusta. Many (40%) of those interviewed had served in the military during World War II, the Korean conflict or in Vietnam.

The interviewed workers had regarded their jobs at ACC favorably even though the work itself was sometimes unpleasant, and they had encouraged friends and relatives to seek employment at the plant. Therefore, many in the sample were related as cousins, brothers, brothers-in-law, or fathers and sons. Almost all (90%) of the interviewed workers had been married at the time of the original notification and the majority are still married, for a median period of 36 years. Relatively few (16%) report currently living alone. Religious faith played an important part in their lives and a number of them were serving as deacons in local churches. Their well-established social networks, reinforced by numerous kinship ties, made word-of-mouth communication natural and easy within the community.

The sample also contained a sub-population (24%) of white workers living on modest incomes but generally more affluent than the minority workers. They lived outside the Bethlehem Area, often outside Augusta's city limits, and were generally unconnected with any social networks related to employment at ACC.

What the Workers Remember About the Notification

Almost without exception, the interviewed workers said they were glad they were notified; 96% of the entire sample gave this response, including all of those in the high-risk category. The news that BNA could cause cancer reportedly came as a complete surprise. Even after more than a decade, the workers recalled vividly how the information about their health risk hit them, as one put it, ‘‘like a bombshell.’’ Ninety-one percent said they had not known this information prior to the NIOSH notification program in 1980. Many in the sample (33%) had thought of BNA as a harmful irritant, but did not think it posed any long-term danger of fatal disease. Over half (53%) of those interviewed reported worrying ''not at all'' or ''very little'' about long-term health effects from BNA exposure, prior to notification.

Two-thirds of the sample group had a clear recollection of getting the NIOSH notification letter, and about half of these said that reading the notification letter was the very first time they learned about the danger. However, the other third could not recall getting the NIOSH notification letter as a distinct event. It seems to have merged in their memories with information from other sources. This is not surprising, considering that the NIOSH program generated over 50 local newspaper articles and extensive television coverage. The workers explained that as the screening got underway, local media coverage overshadowed NIOSH's direct communication efforts in terms of providing them with ongoing information. This fact was recognized by the NIOSH notification officer at the time, who observed in a subsequent publication that ''in actuality, the news media perform the real notification'' [Schulte, 1986]. Word-of-mouth also became an increasingly important source of information, both accurate and inaccurate, especially among a sub-group of high-risk workers who habitually gathered at a local club to discuss litigation against the company.

The workers' view of the notification was heavily affected by the fact that it was accompanied by a medical screening program, which is not typically a feature of NIOSH notifications. The agency undertakes screening primarily to determine the extent of disease in an exposed worker cohort, and considers medical evaluation to be the responsibility of employers, insurers, and/or local health departments. However, this fine point of policy was never clearly understood by the Augusta workers and their families. They tended to interpret the NIOSH screening as a support program aimed at redressing a gross social injustice and helping the victims on an ongoing basis. This perception, still strongly held by those interviewed, has led to continuing bewilderment as to why the screening program was eventually discontinued (or as one worker put it, ''just dropped'') by its sponsors.

After Notification

Overall, the interviewed workers still felt strongly positive about the NIOSH program. While most of them no longer talked about it much with friends and family, almost half of them said they still think about BNA and bladder cancer "often." About a third said the thought is almost always with them.

Although the notified workers considered the NIOSH intervention an extremely important event, they moved on with their lives. Most of them eventually left their jobs at ACC, in part because the company drastically reduced its workforce; it closed down completely in 2000 [Pavey, 2000]. After leaving ACC, the notified workers typically took up other employment. Ironically, in some cases they moved into jobs that involved a high risk of additional toxic exposures. For example, one of the workers most concerned about BNA's health effects left the chemical company to set up his own business spraying houses for pest control. Additional exposures subsequent to working with BNA potentially further compromise the health of these workers, and also make it more complicated to interpret morbidity and mortality patterns in the cohort over time [Needleman, 1997].

Were There Unintended Consequences?

Somewhat over half (54%) of the interviewed workers said their lives were affected in major ways by getting the news about BNA (whether from NIOSH or from other sources), and they were very concerned. The remaining 46% say the impact of the news was ''very little'' or ''none at all.'' Reality-based concern is not necessarily an undesirable consequence of notification, given that the program was intended to motivate these exposed workers to obtain annual medical tests. However, it is important to note that their level of concern did not necessarily match their objective health risk. That is, high concern was expressed by some but not all of those with the highest actual exposures as rated by NIOSH. Those with high levels of concern tended to be members of the close social network that made up the legal settlement group, who also had relatively greater involvement with the WISH advocacy efforts occurring simultaneously with the NIOSH notification.

Among those who said they were greatly affected, few (less than 10%) reported feeling socially disadvantaged by the notification in terms of employment discrimination, credit discrimination, or insurance denial based on their risk status. The major negative consequence mentioned was psychological stress—anger, worry, thinking about the risk. However, the way the workers raised this issue suggests that they did not blame the messenger for these painful feelings. In responses to open-ended questions, they described feeling upset about being exposed in the first place, upset about being kept in the dark for so long by their employer, upset about the possibility of needing medical treatment—but not upset that someone finally gave them the risk information. In fact, getting accurate information and an opportunity for testing seemed to be regarded as a major stress reliever.

Very few mentioned strain on family relationships as a consequence of notification. However, the notified workers reported being reluctant to talk with their families about the BNA exposures, so they may not have a full understanding of how other family members felt about the situation. As discussed below, our interviews with family members suggest a number of unanticipated strains and burdens on intimate relationships that in principle seem avoidable, if taken into account in the process of notification.

Participation in the NIOSH Screening

NIOSH began sponsoring medical testing in 1980 through contractual agreements with the Medical College of Georgia (MCG) and the Richmond County Department of Health (RCDH). The interviewed workers remember being tested at MCG one or more times through the NIOSH program, with about two-thirds having completely negative test results.

Most (74%) said they initially placed ‘‘a lot’’ of importance on this screening program, and felt ‘‘very’’ or ‘‘somewhat’’ positive about it. In retrospect, the majority of those interviewed reported still feeling ‘‘very’’ or ‘‘somewhat’’ positive about the original NIOSH-sponsored screening. Based on these responses, it is tempting to conclude that the original screening program served the notified workers well. However, the situation was in fact more complex. Participating in the screening appears to have been a very difficult step for many of the workers to take. Some said they felt extremely intimidated by the thought of even entering the grounds of MCG, an imposing state-funded medical complex occupying many square blocks in the center of town. They thought of MCG as a space-age medical facility dominated by and oriented toward Augusta’s white residents, off limits and unreceptive to minorities. Shortly after the beginning of the screening, rumors began to circulate in the workers’ community about mistreatment at the hands of medical staff, particularly in the process of cystoscopy (visual inspection of the bladder wall by means of optical instruments inserted by catheter through the penis). Whether these stories were accurate or not is debatable. Most (80%) of the sample report that they were treated ‘‘well’’ or ‘‘very well’’ in the original screening; 15% say they were treated ‘‘badly’’ or ‘‘very badly.’’ As one family member related:

> *In the original tests at the Medical College, a lot of crude things were done. Some real terrible things happened. They did a biopsy on my father; but you know, they didn’t give him anything for the pain. He came home in agony. The pain was so bad I had to get in touch with the doctor. He got smart with me. I couldn’t believe he would be so insensitive. I finally had to say, ‘Look here, my father was your patient, and he’s screaming in pain; we have to do something for him.’ He finally did prescribe something. My father has never forgotten that experience; neither can I.*

Workers also reported fearing that painful medical procedures would be used to punish them for engaging in litigation against ACC. One of the workers identified as an activist in the litigation claimed that his cystoscopy at MCG was deliberately carried out without anesthetic, causing him excruciating pain. His account spread like wildfire at the time. Even 15 years later, many of those we interviewed recounted this reported incident in great detail.

True or not, these gruesome stories still form the central image that many in the Bethlehem community associate with the original medical screening. They play into community residents’ more general apprehensions about racial minorities being used as ‘‘human guinea pigs’’ in experiments such as the Tuskegee syphilis studies, a reference that came up in a number of the interviews. The fact that free screening was made available by the government for a short period, and then was discontinued, left the workers even more confused about whether the original screening was truly meant to help them or was just a way of gathering research data.

NIOSH could not fully anticipate or fully control the dark undertones that the medical screening program acquired. But knowing about these perceptions helps in understanding why some of the notified workers still harbor suspicions about why they were tested in the first place, and wonder whether they should fully trust the information and recommendations given them. Because of past apprehensions, their present decisions about getting annual medical testing are not simply routine preventive health care choices that any rational informed person would make. For at least some of these workers, annual testing continues to be an act requiring great personal courage, unlikely to be undertaken without considerable reinforcement and encouragement.

Long-Term Understanding and Retention of Health Information

One major focus of our evaluation was to investigate the workers’ present knowledge about BNA and its health effects, as a primary goal of the notification had been to improve the BNA-exposed workers’ understanding of their health risk. Table I summarizes the workers’ present knowledge level, consolidating a large number of interview response items into ‘‘accurate’’ or ‘‘inaccurate’’ knowledge

TABLE I. Workers’ Knowledge About BNA and its Health Effects, 15 Years After the NIOSH Intervention

Concerning this issue, the workers’ current knowledge is:	Accurate	Inaccurate
Name of the chemical involved (N = 68)	62 (91%)	6 (9%)
BNA can cause (bladder) cancer (N = 69)	51 (74%)	18 (26%)
The disease has a latency period (N = 70)	51 (73%)	19 (27%)
Early detection is important (N = 62)	57 (82%)	13 (18%)
Effective treatment is possible (N = 69)	18 (26%)	51 (74%)
Warning signs of bladder cancer (N = 70)	37 (53%)	33 (47%)
Is bladder cancer contagious? (N = 70)	48 (69%)	22 (31%)
Are the worker’s children at risk? (N = 70)	22 (31%)	48 (69%)

BNA, beta-naphthylamine; NIOSH, National Institute for Occupational Safety and Health.

for the major facts contained in the notification. ‘‘Don't know’’ responses were counted as inaccurate.

The notification's central message—that BNA exposure is hazardous to human health—seems to have been well retained. Most (91%) of the notified workers reported that they did remember BNA as the chemical which was the focus of the message, with 50% offering specific facts about the chemical's identity such as its full chemical name and industrial use. Knowledge about BNA's specific human health effects was somewhat weaker. About three-fourths of the sample associated BNA with cancer in general, but only a little over half identified ‘‘bladder cancer’’ as the specific risk. A small proportion of the workers remembered the health effects inaccurately, naming diseases not known to be related to BNA. Almost one in four said they simply did not remember the chemical's health effects.

A key part of the notification message was that bladder cancer develops slowly and can become manifest long after the time of exposure, an essential piece of information that the exposed workers needed to understand in order to appreciate the importance of lifelong testing. Once reminded that BNA can cause bladder cancer, 73% accurately remembered the idea of a long latency period and only one worker held the inaccurate opinion that later development of disease was impossible. Still, about one in four was ‘‘unsure’’ about whether bladder cancer could develop years after the exposure. As for the role of early detection in treating bladder cancer successfully, the workers' present understanding was again reasonably accurate. About 82% of the interviewed workers felt that early detection makes a difference. A small number (7%) inaccurately reported that early detection did not matter, and some workers (11%) said they did not know.

Workers' views on the efficacy of treatment were not optimistic. While about a quarter of the sample thought that doctors could cure bladder cancer, more than a third said the disease could not be cured, and more than a third said they did not know. These opinions may in part reflect gaps in the information the workers were given. The NIOSH materials had emphasized the importance of screening and early detection, but did not include a discussion of probable treatment outcomes. The important point to note is the continuing high level of uncertainty among the workers over whether medical treatment can deliver a definitive cure.

Bladder cancer's physical symptoms had been mentioned in the NIOSH notification materials and heavily emphasized in the NIOSH medical screening. In retrospect, more than a decade later, about half the interviewed workers could still recall symptoms of bladder cancer with a fairly high level of accuracy (that is, they mentioned two or three major warning signs). However, the other half (47%) were unable to list even one symptom of bladder cancer.

In addition to examining what was retained from the NIOSH information itself, the present study included more open-ended exploration of what the interviewed workers said they knew, did not know, or would like to know about BNA and its health effects. We found that they held some very inaccurate interpretations of BNA's health effects in areas that the NIOSH materials had touched on briefly or not at all. These areas of uncertainty deeply trouble the workers and their families to this day. For example, about a third of the interviewed workers were unsure whether bladder cancer can be transmitted from one person to another through close contact, especially sexual contact; a small number (5%) were convinced absolutely that this sort of transmission is possible. On another issue of high concern, a full 40% of the worker sample felt that men exposed to BNA can pass a health risk on to their children, and an additional 27% thought this might possibly be true.

The workers also raised a number of unanswered health questions. They had expected the NIOSH program to give them general information about a range of health issues related to BNA, rather than information limited exclusively to occupational BNA exposure and exclusively to bladder cancer. In open-ended parts of the interviews, the concerns that cropped up most frequently were:

- Could BNA have been brought home on work clothes, putting family members at risk?
- Should family members be tested?
- What other diseases might be related to BNA exposure, besides bladder cancer?
- Could BNA pose a risk to the health of community residents who lived near the plant but never worked there?
- If you are not insured and cannot afford to pay for medical tests yourself, what are your best options for protecting your health?

The workers' distress and continuing uncertainty about such issues points up some of the difficulties inherent in combining notification's broad goal of promoting public health with its narrow goal of disclosing specific study results from epidemiological research.

Long-Term Understanding and Use of Health Advice

The NIOSH materials had stressed two major preventive measures: not to smoke, and to get annual urine tests to check for early signs of bladder cancer. The notified workers were given these messages at every opportunity, in written NIOSH materials, in community meetings, and verbally from program staff and medical professionals as part of the screening program. In the interviews, we explored whether this health advice was understood and also how the workers had used it.

Without exception, the interviewed workers knew that smoking is bad for your health, and a positive change in their smoking behavior has certainly occurred over time. At the time of the NIOSH notification, 70% of those in the present study sample had been recorded as smokers. At the time of our interviews, this rate had fallen to 41%. Even more striking, only 10% of the respondents reported smoking ''heavily'' (a pack or more per day) at the time of this evaluation. However, the notification's advice on smoking cessation has been so massively reinforced by national health education and publicity in recent years that it is not reasonable to attribute these behavior changes to the NIOSH program alone.

On the need for annual medical testing, it appears that the relevant factual information did get across and was well remembered. When asked if workers exposed to BNA ''need to keep on getting tested even after they've been tested once with negative results,'' almost all respondents (93%) replied ''yes,'' with most (63%) citing long latency as the reason. Three-quarters of them had in fact been tested after their original NIOSH screening, suggesting that the notification achieved its central purpose. However, a deeper look shows a less hopeful picture. For most, the additional screening had been essentially initiated by researchers, either as follow-ups during the 4-year NIOSH program or as part of a state-funded epidemiological study carried out some years later by a local physician. In the absence of these research programs' incentives and outreach efforts, not much testing took place. Based on the detailed screening histories provided to us by the interviewees, only about a third of the sample shows evidence of seeking tests on their own, and 43% of the sample report not being tested at all during the 5 years prior to our interviews.

This pattern contrasts sharply with the workers' expressed intentions. Over 90% of them say they would like regular medical monitoring and 44% say they hope to get tested once a year in the future. But based on their actual testing experience over the 5 years prior to this evaluation, these health-protecting intentions may not materialize. A large proportion of the sample (42%) report not knowing if they will be able to get tested in the future, even though they consider it important to their health.

What keeps them from implementing their plans? We had expected cost and medical access to loom large as barriers. However, except for some with manifest disease (who did find treatment costs extremely difficult to manage), these potential barriers were described as hardly important at all. Most of the interviewed workers (73%) have insurance coverage through the Veterans' Administration, Medicare, or private policies.

When asked directly why they have not gone for testing more regularly, the workers' most common explanation was that they had not been notified to do so (see Table II). That is, they had received no reminders or notices advising them to be tested again. This attitude—that if testing were needed, someone would tell them to do it—appeared again and again in the interviews. As one worker put it, ''I just go with the program. Tell me where to go and I'll be there.'' Despite their solid understanding of the latency period for bladder cancer, they still felt that someone in a professional position would urge them to go for testing, if it were really important. Apparently, even though the message itself was well understood, one-shot notification without periodic reinforcement has not been effective with these workers in terms of achieving long-term compliance with health advice. They have not forgotten the advice, but it is not by itself moving them to action. Those most likely to get tested are the workers in the legal settlement group, who receive annual invitations to participate in a screening program that the company was court-ordered to provide for them as part of the settlement. Some of the workers who receive these invitations have chosen to use personal physicians or the VA hospital in preference to the company's medical office; however, there is benefit in the annual reminders.

TABLE II. Workers' Reasons for Not Getting Tests on Their Own During the Last 5 Years (N = 34)

Reason	N	Percentage (%)
I have not been notified to do it	17	50.0
I saw no need	10	29.4
I saw a need, but just have not taken action	2	5.9
I saw a need, but had no access to medical care	1	2.9

Table III summarizes the workers' interpretation of what hinders testing within the cohort as a whole, not just for themselves personally.

Family Voices

Very little is known about how risk notification affects the families of notified workers. We asked both the workers and their family members about this, interviewing them separately. Full discussion of effects on the family is beyond the scope of this report, but in many cases, the Augusta notification appears to have had strong negative effects on family life that were not always recognized or discussed even between husbands and wives. The workers themselves claimed that the notification's impact on family life was minimal. However, the family members we interviewed expressed over and over again that they had been very worried

TABLE III. Obstacles to Regular Testing Mentioned by Workers Without Prompting (N = 66)

Problem	N	Percentage (%)
Lack of regular reminders and information	29	43.9
People just put it off	22	33.3
Fear and denial	10	15.2
People do not understand the need	2	3.0
People have medical access problems	2	3.0

by the situation. They felt they needed more information but could not get it from the workers, who were trying to shield their families from the bad news. Family members told us:

> *He was concerned—really, more like scared. He went to have the tests. He didn't let me know, but I knew it anyway, because I know him. But I couldn't say I knew.*

> *I needed to know more, like what the danger signs are to look for, to know whether someone you love is ill.*

> *It was the husband who got contaminated, but the wife had to bear the stress and stuff; it's really hard to go through that.*

> *I think it would have helped me if I could have gone somewhere and talked with someone . . . because of the unknown, not knowing what to expect.*

> *We need moral support. I mean, we really need to be supported more than we was. I mean, it was hard to be alone in this.*

We heard stories of married couples' sex lives being clouded by fear that bladder cancer might be transmitted through intercourse; wives' concern that children conceived after the father's BNA exposure might grow up unhealthy; years of worry about possible BNA exposure to family members from dust brought home on clothes and shoes. For some family members in the study, our interviews were the first time they had ever spoken their fears out loud. The wall of silence within families not only caused psychological burdens, but also prevented family members from encouraging the notified workers to keep up with annual testing. Some of the workers' wives struggled with tears as they explained their dilemma:

> *The only reason some of the notified workers went [for screening] was because some family member talked them into it. But sometimes a man don't like that, and you hate to interfere. I never knew how to tell him to go.*

> *I did think the [NIOSH] screening was very important, but he didn't want me to go with him, and I never knew how it was or what happened. I didn't want him to feel bad, so I didn't mention it no more.*

A number of social services in the local area could have been mobilized to help with family emotional problems and to support the program's health advice. We were told that a local community organization in the Bethlehem Area would have been happy to organize volunteers to visit affected families; the local United Way could have provided service referrals through its ''First Call for Help'' hotline; ministers in local churches said they would have been willing to help form support groups; the Medical College of Georgia's Social Work Department could possibly have provided outreach and services. However, the program's other challenges demanded more attention. The value of social support resources was not fully recognized, and they went untapped.

DISCUSSION

Judging from the Augusta workers' own reports, the NIOSH notification (along with related activities) succeeded extremely well in some respects. More than a decade later, those notified were still fairly well informed about the health effects of BNA and about ways to reduce their risk of bladder cancer. Despite their often-expressed feeling of being ''left in the lurch'' when the program ended, they felt generally very positive about the NIOSH intervention.

The bad news is that even though the interviewed workers understood and remembered the notification's health advice, a large proportion of them have not been acting on it. They consider lifelong annual medical testing to be a high priority and are quite worried about their health, but they are not actually getting any regular follow up screening. Lack of insurance coverage, a likely candidate as a barrier to service, did not show up as a major factor; most of these workers are insured (although coverage restrictions and high co-payments did seem problematic in some insurance plans).

Perceived susceptibility and perceived efficacy, two psychological factors that many researchers have found to influence health behavior, did not appear critically important for these workers' long-term compliance with health advice. Perceived susceptibility showed no connection with whether the workers got regular screening. A sense of efficacy in being able to avoid illness did seem related to regular screening, but the temporal sequence of the relationship appeared to be the reverse of what is usually assumed. Workers commonly reported that they first decided to get screened on other grounds, such as persuasion by relatives and friends or ''just going with the program,'' and only later became convinced that regular screening could effectively protect their health.

The workers' own interpretation is that even when they have access to medical services, they avoid being tested because of apprehension about what the tests might show. They say they intend to get tested, but dislike thinking about it and keep putting it off. Apparently this inertia is easier to overcome when the need for testing is supported by family members or a relevant social network, or reinforced by regular reminders (as was the case among the legal settlement group, who were by far the most likely to get ongoing testing).

Almost without exception (99%), the workers and family members say they would like to receive screening reminders and updated information on BNA and health through a newsletter, mailed annually or even more frequently. A newsletter would have functions beyond providing information. It could create a surrogate support network for the cohort and transform individual personal problems into a less fearsome collective one. The family members we interviewed were especially interested in informational outreach that did not depend on the notified worker transmitting the information to others. They felt that brochures or newsletters sent to the entire household would make internal family discussion easier.

CONCLUSIONS

Four strategies, all relatively low in cost, seem likely to increase the long-term public health impact of worker notifications that involve individually mailed written materials. These strategies are especially relevant where the intervention goals include compliance with health advice for the purpose of secondary disease prevention.

First, in designing worker notifications, consideration should be given to what kind of information the workers already have and what kind of information they most want and need, so as not to leave burning questions unaddressed. This would require a modest preliminary reconnaissance effort very early in the planning stage before materials are drafted, perhaps through a focus group or telephone interviews with a few key informants knowledgeable about the population.

Second, particularly for hazards that are serious and ongoing, the audience for whom the notification is intended could be defined more broadly so that information is given not only to the at-risk study cohort but also to others personally affected. For example, the notification might include dissemination of risk information to similarly exposed workers not in the study cohort, and/or informational materials specifically addressed to the notified workers' families. Such materials would need to be designed in a way that respects the workers' individual privacy.

Third, in the case of notifications that recommend secondary disease prevention measures over a long time period, the health advice may have greater success if followed up with periodic reminder notices. If annual diagnostic testing is being advised, individual reminders or a general newsletter reminder mailed out each year could serve as a cue to action.

Fourth, when a specific geographic community is involved and there are long-term secondary disease prevention possibilities, the notification effort could include contact not only with local medical providers but also with selected local human service resources such as churches, United Way, civic clubs, social service agencies, and neighborhood improvement associations. Both medical and non-medical service providers could be encouraged to support the notification effort by addressing the notified workers' unanswered questions and helping them and their families with service concerns on an ongoing basis even after the notification itself is concluded. This kind of intervention, known as "community capacity building," is based on well-established traditions in the field of community development [McKnight and Kretzmann, 1990; Leviton et al., 1998; Chaskin et al., 2001].

As we have seen in the case of Augusta, these four steps have the potential to make a critical difference in how notification information is perceived and used over time by the notified workers and their families, enhancing notification's long-term benefits for public health.

ACKNOWLEDGMENTS

The authors thank Paul Schulte, Sandra Tillett, Knut Ringen, William Johnson, Marlene Johnson, Ernest Alterkruse, James Sturgis, Addie Powell, Wilbert Allen, George Gudger, and other major actors in the original NIOSH notification for their insights and advice during the course of the evaluation study. We also thank the managers of Synalloy (Blackman-Uhler) Corporation; Frank Rumph, Richmond County's Health Commissioner; Leonard and Margaret Brubaker, who generously shared their own research findings and current contact information on the notified cohort; the local interviewers and graduate social work students who helped collect and analyze the interview and field data; and the study respondents who contributed their time, help, and frank opinions.

REFERENCES

Baker EL, Schulte PA, French JG. 1989. Worker notification activities at the National Institute for Occupational Safety and Health: Past and present. In: Landrigan PJ, Selikoff IJ, editors. Occupational Health in the 1990s: developing a platform for disease prevention. Vol 572. New York: New York Academy of Sciences, Annals. pp 144–150.

Bayer R. 1987. Notifying workers at risk: The politics of the right-to-know. Am J Public Health 76:1352–1356.

Brewer J, Hunter A. 1989. Multimethod research: A synthesis of styles. Newbury Park: Sage.

Chaskin RJ, Brown P, Venkatesh S, Vidal A. 2001. Building community capacity. New York: Aldine de Gruyter.

Crapnell SG. 1981. Worker notification: The new right to know battleground. Occup Hazard 43:52–56.

Denzin NK, Lincoln YS. 1994. Handbook of qualitative research. Thousand Oaks: Sage.

Fetterman DM, Kaftarian SJ, Wandersman A, editors. 1996. Empowerment evaluation. Thousand Oaks: Sage.

Hornsby JL, Sappington JT, Mongan P, Gullen WH, Bono SF, Altekruse E. 1985. Risk for bladder cancer: Psychological impact of notification. JAMA 253:1899–1902.

IARC. 1974. IARC Monogr 4:97–111.

Leviton LC. 1998. Worker health in black and white. In: Leviton LC, Needleman C, Shapiro M, editors. Confronting public health risks: A decision maker's guide. Thousand Oaks, CA: Sage. pp 89–124.

Leviton LC, Needleman C, Shapiro M. 1998. Confronting public health risks: A decision maker's guide. Thousand Oaks, CA: Sage.

Marsh GM, Callahan D, Pavlock D, Leviton LC, Talbott E, Hemstreet G. 1990. A protocol for bladder cancer screening and medical surveillance among high risk groups: The Drake Health Registry experience. J Occup Med 32:881–886.

McKnight JL, Kretzmann JP. 1990. Mapping community capacity. Evanston, IL: Center for Urban Affairs and Policy Research, Northwestern University

Miles MB, Huberman AM. 1994. Qualitative data analysis. 2nd edition. Thousand Oaks: Sage.

Millar JD. 1989. The right to know in the workplace: The moral dimension. In: Landrigan PJ, Selikoff IJ, editors. Occupational health in the 1990s: Developing a platform for disease prevention. Vol 572. New York: New York Academy of Sciences, Annals. pp 113–121.

National Institute for Occupational Safety and Health (NIOSH). 1983. Interim Report #1, Augusta Chemical Company. Unpublished internal document. Cincinnati, OH: NIOSH. pp 81–122.

Needleman C. 1990. Notifying the high-risk worker: A literature review. Unpublished internal document, 90-0110. Cincinnati, OH: NIOSH.

Needleman C. 1993. Worker notification: Lessons from the past. Am J Ind Med 23:11–23.

Needleman C. 1997. Applied epidemiology and environmental health: Emerging controversies. Am J Infect Control 25:262–274.

Needleman C, Needleman ML. 1996. Qualitative methods for intervention research. Am J Ind Med 29:329–337.

Omang J. 1981. Augusta: Case study of difficulties of telling workers of old job perils. Washington Post, September 3. p A2.

Patton MQ. 1990. Qualitative evaluation and research methods. 2nd edition. Newbury Park, CA: Sage.

Patton MQ. 1997. Utilization-focused evaluation. Thousand Oaks: CA: Sage.

Pavey R. 2000. October 10, 2000. EPD violations cost factory $125,000; Employees to relocate. Augusta Chronicle, 10/10/2000. p 1.

Pinkham J. 1988. Hazard Notification legislation loses ground in Senate battle. Occup Health and Safety News Digest 4(June):1–3,6.

Ruttenberg R, Powers M. 1986. Economics of notification and medical screening for high-risk workers. J Occup Med 28:757–764.

Schulte PA. 1983. Worker notification pilot study: Epidemiologic considerations and development of a conceptual Model. Dissertation, University of Cincinnati.

Schulte PA. 1986. Problems in notification and screening of workers at high risk of disease. J Occup Med 28:951–957.

Schulte PA, Ringen K. 1984. Notification of workers at high risk: An emerging public health problem. Am J Public Health 74:485–491.

Schulte PA, Ringen K, Altekruse EB, Gullen WH, Davidson K, Anderson SS, Patton MG. 1985a. Notification of a cohort of workers at risk of bladder cancer. J Occup Med 27:19–28.

Schulte PA, Ringen K, Hemstreet GP, Altekruse EB, Gullen WH, Patton MG, et al. 1985b. Risk assessment of a cohort exposed to aromatic amines: Initial results. J Occup Med 27:115–121.

Schulte PA, Boal WL, Friedland JM, Walker JT, Connally LB, Mazzuckelli LF, Fine LJ. 1993. Methodologic issues in risk communications to workers. Am J Ind Med 23:3–9.

Stern FB, Murthy LI, Beaumont JJ, Schulte PA, Halperin WE. 1985. Notification and risk assessment for bladder cancer of a cohort exposed to aromatic amines: III. Mortality among workers exposed to aromatic amines in the last B-Naphthylamine manufacturing facility in the United States. J Occup Med 27:495–500.

Strauss A, Corbin J. 1998. Basics of qualitative research: Techniques and procedures for developing grounded theory. 2nd edition. Thousand Oaks, CA: Sage.

Tillett S, Ringen K, Schulte P, McDougall V, Miller K, Samuels SW. 1986. Interventions in high-risk occupational cohorts: A cross sectional demonstration project. J Occup Med 28:719–727.