Monitoring the Worker and the Community for Chemical Exposure and Disease: Legal and Ethical Considerations in the US

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Biomonitoring of workers and communities raises important legal and ethical concerns, but the two contexts are different. Monitoring workers is usually done by, or at the instigation of, the employer who, in law, is responsible for their health and safety. Whenever worker monitoring leads to the removal of workers, difficult issues emerge affecting labor-management relations, labor law, and discrimination law. Resulting legal and ethical questions are usually framed within the context of the employment contract or labor relationship. In contrast, public health or environmental officials may be the driving force behind biomonitoring of the community. No employer-employee relationship exists, and the doctor-patient relationship may be tenuous. The community may often request biomonitoring, but the situation is no less contentious. On the basis of an historical view of monitoring events within the US, mechanisms are suggested to promote positive interactions between employers and workers and among agencies, individuals, and groups in the monitoring of chemically contaminated communities.

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Biomonitoring of workers and of communities at large raises important legal and ethical concerns, but the two contexts are different. Monitoring workers is usually done by, or at the instigation of, the employer who, in law, is responsible for their health and safety. Whenever workplace monitoring leads to the removal of workers, difficult issues emerge affecting labor-management relations, labor law, and discrimination law. In contrast, public health or environmental officials may be the driving force behind biomonitoring of the community. No employer-employee relationship exists, and it is doubtful whether a doctor-patient relationship is present. The local community itself may initiate the request for biomonitoring, but the situation is no less contentious.

The identification of DNA–protein–carcinogen adducts and other markers of exposure to chemicals and disease raises new and challenging questions for the emerging science of molecular epidemiology in the workplace and community. Most of the attention for possible applications has been focused on the workplace, but the eventual use of biomarkers in the context of contaminated communities or consumers exposed to chemicals can also be anticipated. The new science may well have relevance for chemical regulation, workers' compensation, and damage suits in the courts.

Here I bring together two research efforts that I and my colleagues conducted at the Massachusetts Institute of Technology. The first has focused on monitoring in the workplace (1) and the second on monitoring in the contaminated community (2). The emphasis and the examples refer to the US, but the underlying principles have general applicability.

Human monitoring in the workplace, sometimes referred to as medical screening, focuses on workers to assess indicators for (a) disease resulting from exposure to a toxic substance, radiation, or other traumas (medical surveillance); (b) absorption of a toxic substance into the body (biological monitoring); (c) predisposition of a particular worker to certain diseases (genetic screening or other probes of sensitivity); and (d) existence of a preclinical disease state, indicating that potentially harmful exposure has occurred (genetic monitoring). These monitoring practices, especially when required or carried out by a government agency or the employer, raise serious and complex legal and ethical concerns (1, 3).

Monitoring in the context of the contaminated community is unlikely to involve genetic or sensitivity screening, but may go beyond physical examinations or the collection and analysis of biological samples to include surveys of self-reported symptoms or searches of medical records.

The legal and ethical problems of disease detection and the communication of information in the context of the patient–physician relationship are thorny enough; workplace and community monitoring complicate the issue even further. In this article, I seek to construct a philosophic framework for examining the adequacy of law as an embodiment of ethical values concerning worker and community monitoring and for identifying possible solutions to the attendant legal and moral dilemmas. In the workplace, the analysis necessarily focuses on three sets of activities involving distinct participants: workers; employers; corporations; physicians, either in-house or under contract; and the government. The sets of activities deserving separate consideration are as follows: (i) requiring the worker to submit to monitoring tests, (ii) disseminating the results of the tests, and (iii) using the test results.

Community monitoring involves a different set of actors and activities than is encountered in the workplace. Community residents and public health/environmental officials are the key players. Monitoring the community for chemical exposure and disease involves eight stages: (1) recognition of a potential hazard to health; (2) decision to monitor a particular population for exposure or
for particular health endpoints or indicators; (3) design of the monitoring study; (4) actual conduct of the monitoring; (5) evaluation and interpretation of the scientific data, i.e., the scientific study; (6) dissemination of the results; (7) decisions to act, or not to act, in response to the results; and (8) actions (or inaction). While workers may have little potential choice in participating in decisions related to workplace monitoring, community residents can in principle demand participatory roles in all eight activities in exchange for their agreement to be the subjects of monitoring.

Toward an Ethical Theory for Human Monitoring

Moral and legal inquiry in human monitoring addresses the behavior of particular actors deciding to undertake monitoring tests, designing and conducting the evaluation and disseminating the test results; and using the information. Ladd (4) argues that it is important to distinguish ethics from law, custom, institutional practices, and positive morality (the body of accepted popular beliefs): Ethics is concerned with what ought to be. Moral problems concerning human monitoring may be categorized as (a) conflicts arising from differences in legitimate interests of different actors/institutions; (b) conflicts in moral and legal duties of each actor/institution; and (c) conflicts among actors/institutions arising from different perceptions of what is right or wrong, fair or unfair. In addition to conflicts, there is the perennial problem of how much (information, safety, precaution, etc.) is enough to justify intervention, and the difficulty of responding responsibly to events and information when people are experiencing stress and misperception.

Individuals possess certain rights, and those rights impose (moral) obligations on others. Rights and obligations must be viewed together in the context of particular relationships (5). Ladd and others argue that people have a general duty to support the fulfillment of the moral requirements of relationships, whether their own or those of others. Some of this is embodied in rights and obligations, which is sometimes given the force of law.

The delineation of rights and duties gives rise to certain expectations or hopes on the part of society concerning human behavior. The law often embodies societal attitudes, values, and expectations. Sometimes, but not always, this occurs when a significant societal consensus has been reached on a particular moral question. The law establishes legal rights, whose violation may be illegal, and the law provides remedies to correct their violation. But the law also recognizes that conflicts of legitimate interests, conflicts of legal duties, and differences in perception of what is right or wrong, fair or unfair, require a balancing in the fashioning of remedies. Indeed, there are both legal remedies (usually of statutory origin) and equitable remedies that give great discretionary power to the courts or adjudicating institutions, such as the Equal Employment Opportunity Commission in the US. Rules are embodied in legislation and regulations; legal principles guide, but do not unequivocally settle, other conflicts. The law does indeed view behavior in the context of relationships. One party's justifiable expectations of another are translated into the legal concept of reliance. Thus, the law will sometimes find a physician–patient relationship between worker and company physician—when none was intended by the physician—because it was reasonable that the worker expected certain behavior or information from the physician. Similarly, although personal liability by corporate officers or employees is limited (6), the courts will "pierce the corporate veil" when corporate behavior violates the ethical norm. Discrimination law is replete with discretionary justice (7).

The law, of course, does not always serve the ethical interests of the society so nobly. Legislation and legal institutions can be compromised by powerful special interests. Moreover, if societal consensus or interest about a moral issue is lacking, the law may either not address that issue or fail to give helpful guidance concerning the boundaries of fair or equitable behavior. This is currently the case concerning the problems encountered in community monitoring.

In the context of the transfer of medical information resulting from workplace monitoring and discrimination resulting from its use, the legal and ethical norms are in a great state of flux. Conflicts of interest and conflicts of duty (for example, for the company physician or government officials) abound. The worker would rather be safe and keep his or her job; the employer wants to limit his or her legal and economic liability. In the face of great uncertainty, the actors generally prefer to take few chances, so that very different policies are preferred regarding the transmission of uncertain information, possibly derived from imperfect screening tests, and its use.

Workplace Monitoring

Requiring Workers to Submit to Human Monitoring

Privacy. Personal privacy is an important issue. An employee may always refuse to be the subject of human monitoring. Thus the US Occupational Safety and Health Administration (OSHA), the US National Institute of Occupational Safety and Health (NIOSH), and the employer have no authority to compel employees to cooperate. Refusal to participate, however, may mean loss of a job, so that the relevant enquiry is the extent to which the employer may predicate employment on such cooperation. For example, may an employer require a prospective employee to submit to genetic or biologic screening as a precondition to employment? May he or she require a current employee to submit to periodic biologic monitoring or medical surveillance? These questions raise important issues of confidentiality and discrimination.

Monitoring in response to agency directive. A distinction must be made between the human monitoring that OSHA, NIOSH, or the US Environmental Protection Agency may require and the monitoring that the employer implements on his or her own initiative. When a

\[1\] Nonstandard abbreviations: OSHA, Occupational Safety and Health Administration; NIOSH, National Institute for Occupational Safety and Health; OSHAct, Occupational Safety and Health Act; and MRP, Medical Removal Protection.
federal agency requires that monitoring be done, the worker may validly object only through asserting a statutory or constitutional violation. The US Congress specifically acknowledged the need to balance interests when an employee asserts a religious objection to a monitoring procedure. Human monitoring can also impinge on the worker's constitutional right to privacy, i.e., the right to physical privacy, and the right to withhold information likely to prove detrimental to one's self-interest.

If an employee does not wish to comply with a monitoring procedure required by agency regulation, imposing that procedure as a condition of employment may invade that employee's constitutional right to physical privacy. In some cases, it may infringe the right to be free from unwelcome physical intrusions and the right to make decisions regarding one's own body. The former is grounded in the Fourth Amendment's proscription against unreasonable search and seizure, whereas the latter is closely associated with the rights of personal privacy commonly identified with the Ninth and Tenth Amendments. Although protected by the Constitution, these rights of privacy are not inviolate.

US courts have recognized a general need to balance the privacy interests of the individual with the public health interests of society. To date, no reported judicial decision has mentioned an asserted constitutional right to refuse participation in human monitoring as a condition of employment. Nevertheless, one can identify the factors that would be considered in an evaluation of that right.

The public health significance of human monitoring, when properly used, is difficult to deny. Gathering information through human monitoring to develop standards for the protection of workers' health, or for the enforcement or evaluation of existing standards, serves an important public health purpose. The fact that this public health interest parallels the affected worker's own interest in a healthy workplace may make monitoring a less onerous invasion of privacy than it would be otherwise. Indeed, Bayer (8) raises the question of whether workers may actually have a moral obligation to cooperate in such monitoring for the collective good; he also argues that, without safeguards, coercive monitoring is unfair. To the extent that monitoring serves a legitimate public health purpose, a limited intrusion of physical privacy appears constitutionally permissible. The less the accuracy, reliability, or predictive value of a particular intrusion, however, the weaker the case for violating physical privacy.

Some forms of human monitoring may simply be too risky or too intrusive to be constitutionally permissible. Furthermore, the worker may have a right to insist on an alternative, less intrusive procedure that adequately fulfills public health purposes. To survive constitutional challenge, a regulation requiring human monitoring should be reasonably related to a legitimate public health goal and should impose the least intrusive method necessary to achieve that goal.

A critical question is whether the employee may refuse to participate in a program of agency-directed monitoring when he or she believes that the employer may use the resulting information as a basis to terminate employment. For example, the worker who suffers chromosomal damage as a result of workplace exposure may fear that medical screening will reveal this condition to the employer and thus induce job loss or reassignment. Thus participation in a monitoring program can be tantamount to self-incrimination.

This form of self-incrimination conflicts with the right to personal privacy. If there is a constitutional right to preserve the confidentiality of information pertaining to one's health, there may also be a right to retain that information within one's body. Stated differently, there may be a limited constitutional right to refuse to comply with physical procedures that result in the initial disclosure of confidential information. Although this right is not absolute, damage to the employee can be substantial if health data are likely to affect employment status adversely. A worker's interest in preserving his employment status may rise to the level of property protected by the Fifth Amendment.

In developing monitoring requirements, an agency should seriously consider the constitutional dimensions of human monitoring; e.g., OSHA and NIOSH might consider including mandatory Medical Removal Protection (MRP) programs as part of their human monitoring requirements to provide earnings protection and employment security during medical removal.

Monitoring in the absence of agency directive. Under common law, employers can require their employees to comply with reasonable programs of human monitoring. The US Congress did not intend the Occupational and Safety and Health Act (OSHAAct) to preempt the field by authorizing the implementation of human monitoring requirements. One of the Act's express purposes is to "stimulate employers . . . to institute new and to perfect existing programs for providing safe and healthful working conditions." As long as it promotes "safe and healthful working conditions," therefore, employer-initiated human monitoring would appear to be allowed. Similarly, nothing in the Act precludes employers who are subject to OSHA monitoring requirements from implementing additional programs. Further, employers may have a moral obligation to initiate monitoring if they suspect their employees are at risk. To date, however, this moral obligation has not been translated into a legally enforceable duty to undertake medical screening.

If an employer institutes a human monitoring program in the absence of agency directive, he or she is still subject to applicable restrictions under state common law, state statute, and federal labor law such as the National Labor Relations Act. Common law requires that human monitoring be implemented in a reasonable fashion, balancing the benefits gained by monitoring against the risk, discomfort, and intrusiveness involved.

Informed consent. Consent is an important issue in the context of workplace monitoring. Those performing monitoring procedures have a duty to perform those procedures properly and will face liability for damages caused by the negligent administration of a monitoring procedure.
A troublesome question arises, however, with regard to the applicability of the doctrine of informed consent. Strictly speaking, informed consent is a medico-legal concept, and stems from a belief that persons have a right to make decisions governing their bodies and health. Thus, a medical professional is said to have a duty to inform the patient honestly and accurately of the potential risks and benefits of a proposed medical procedure so that the patient can make an informed choice whether to consent to that procedure. All human monitoring procedures are medical or quasi-medical in nature. Commonly, they are performed by medical professionals: physicians, physician assistants, nurses, or nurse practitioners. Thus the concept of informed consent appears at first glance to be applicable. The differences between human monitoring and medical treatment, however, are not insignificant, and they raise serious questions as to whether and to what extent the traditional doctrine of informed consent has meaning in the occupational setting.

One issue is to what extent the relationship between the worker and the medical professional who administers the monitoring procedure can be characterized as a physician–patient relationship. Usually, the employer selects and often directly employs the occupational physician. Accordingly, some courts have held that the performance of a physical examination, which would clearly establish a physician–patient relationship in a purely medical context, does not create that relationship if it is a preemployment examination requested by the prospective employer. If the physician–patient relationship does not exist, traditional notions of informed consent may not be applicable in the occupational setting.

Similarly, the doctrine of informed consent is tied closely to the concept of medical treatment. It assumes that not only is the patient being requested to submit to a procedure designed for his or her own benefit, but also that the patient is in a position to make a voluntary choice to participate. Human monitoring calls both of these assumptions into question. Not only may monitoring not be “treatment” in the conventional sense of the word but also in many cases, it benefits the employer more than the employee and is usually compulsory (i.e., a condition of continued employment). It may be meaningless to speak of “informed consent” if the worker/patient is not free to reject the proffered procedure without jeopardizing his or her job. The applicability of informed consent thus appears particularly dubious in the case of agency-directed monitoring, for neither the employee nor the employer has the discretion to discontinue monitoring.

A complete and accurate disclosure of risks seems advisable in a program of human monitoring. Whether or not a physician–patient relationship exists, imposing a medical procedure on a person not fully informed of the risks of that procedure may still be regarded as physical battery and may give rise to legal liability. In addition, prudent social policy requires full disclosure of risks. If the employer is required to disclose all risks inherent in a program of human monitoring, employee and union scrutiny will act as an incentive for the employer to develop programs that use the safest and least intrusive techniques possible. Indeed, unions may have a right to demand such information as a part of the collective bargaining process.

A final question concerns the scope of the required disclosure of procedural risks. The employer should, of course, disclose all material physical risks. The most significant risk of all, however, may be dismissal from employment. The Code of Ethical Conduct (9) adopted in 1976 by the American Occupational Medical Association and the American Academy of Occupational Medicine states that physicians should:

...treat as confidential whatever is learned about individuals served, releasing information only when required by law or by over-riding public health considerations, or to other physician at the request of the individual according to traditional medical ethical practice; and should recognize that employers are entitled to counsel about the medical fitness of individuals in relation to work, but are not entitled to diagnose or details of a specific nature.

Under this formulation, although the physician may not disclose to the employer the specific results of human monitoring, the employee’s job security may be endangered nonetheless as a result of “counsel about the medical fitness of individuals in relation to work.” A preferable alternative practice (10) would involve the worker in such discussions between the physician and the employer.

Dissemination of Monitoring Results

Employee’s right of access. An employer may not limit or deny an employee access to his or her medical or exposure records, according to the OSHA regulation promulgated on May 23, 1980. Furthermore, the employer is required to reserve and maintain these records for an extended period of time. [In the absence of OSHA regulation, employees would arguably still have a right of access under common law or state statute in many jurisdictions (11).] There appears to be some overlap in the definition of “medical” and “exposure” records, because both may include the results of biologic monitoring. The former, however, is generally defined as those records pertaining to “the health status of an employee,” while the latter is defined as those pertaining to “employee exposure to toxic substances or harmful physical agents.”

The regulations provide that, upon any employee’s request for access to a medical or exposure record, “the employer shall assure that access is provided in a reasonable time, place, and manner, but in no event later than fifteen (15) days after the request for access is made.” In addition to the right of access, there are duties to inform workers of exposure to occupational hazards (12).

Employees’ right to confidentiality. Of all of the issues raised by human monitoring, employee confidentiality may have received the most attention (13). An employee’s right to maintain the confidentiality of information regarding his or her body and health places a significant limitation on the ways in which others can use that information. As programs of human monitoring are developed, mechanisms must be found that maximize both the employee’s interest in privacy and society’s interest in promoting general workplace health and safety. In
the final analysis, this may be more a technological challenge than a legal or ethical one.

In a broad sense, private citizens do have a right to protect the confidentiality of information about their personal health through the US Bill of Rights and state law. In the medical setting, this right grows out of the confidential nature of the physician–patient relationship, although it exists outside this relationship as well. In essence, the recognition of a right of privacy reflects an ongoing societal belief in the need to protect the integrity of the individual.

This right to privacy, however, is not absolute and may be limited or waived. US courts nonetheless remain vigilant in their attempts to protect individual privacy. They prefer an approach that permits both the use of health information for a socially useful purpose and the protection of the privacy of the individual. The key is the development of information-based technology that will make that approach more readily available.

Notification of workers at high risk. Caldart (14) and Ashford and Caldart (15) have addressed the worker's right to information and the employer's duty to provide information concerning occupational risks. Recently, there has been increasing attention to the government's responsibility to notify workers if they have been identified as being part of a high-risk group based on epidemiologic studies. The excellent works of Schulte and associates (16–18) deal with the multitude of legal and ethical problems arising out of the right-to-know.

Employer's Use of Human Monitoring Results

Even if an employer obtains human monitoring data through a legitimate exercise of right of access, the right to use such data is not absolute. In the US, employers may not use health information to discriminate against employees on a basis deemed impermissible by federal or state law. Beyond discrimination, however, a more essential—and perhaps more difficult—question arises: To what extent may an employer use health or exposure information to limit or terminate the employment status of an individual employee or to deny employment to a prospective employee? Further, to what extent and under what conditions does the employer have an obligation to remove the worker? If removing a worker and rotating another employee to take his or her place reduces each worker's individual risk but increases the total number of diseased workers, what should the employer do?

Common law limitations. In early common law (court-developed law through successive cases), an employer had the right to take an employee's health into account in determining whether to continue to employ that person. If the employment contract was "open," with no definite term, the employee could be discharged for any reason, including health status, at the will of the employer. If the contract of employment was for a definite term, the employee could be discharged for "just cause." Typically, significant illness or disability constituted "just cause." Although federal labor law, workers' compensation, and recent common law limitations on the doctrine of "employment at will" have profoundly affected the nature of employee–employer relations in this century, courts continue to recognize an employer's interest in discharging employees who cannot perform their work safely. Thus, if a worker has no statutory or contractual protection, an employer may retain a general common law right to discharge a worker whose health status makes continued employment dangerous, or whose health status prevents him or her from performing the job. Workers' compensation legislation, of course, facilitates termination of permanently disabled workers.

Human monitoring, however, places the issue in a somewhat different light. Monitoring designed to reveal whether an employee has been, or in the future may be, harmed by workplace hazards raises the question of whether the employer may discharge an employee merely because the employee was, or may be, harmed by a situation created by the employer. The rights of the employer to discharge the employee might not be as broad then as in the general case.

Suppose an employer is complying with an existing OSHA standard for a particular toxic exposure, and monitoring reveals that one of the firm's employees is likely to suffer serious or irreparable health damage unless he or she is removed from the workplace. In this situation, the employer is complying with public policy as enunciated by OSHA and, in the absence of a mandatory MRP provision, is arguably free to discharge the employee. If an employer fails to comply with applicable OSHA standards, however, or if no standard exists, and the employer permits workplace exposure levels that violate state and federal requirements to maintain a safe place of employment, then the employer is violating the public policy embodied in the OSHAct. Workers are only infrequently able to obtain compensation for disability due to occupational disease. In this case, to permit the employer to discharge the employee is to permit a further violation of public policy. An employer's use of human monitoring data for this purpose may well be impermissible as a matter of public policy, and employers may be obliged by common law to find safe assignments for the workers at comparable pay or bear the costs of their removal.

Limitations under the OSHAct general duty clause. The use of monitoring data to limit or deny employment opportunities raises other issues under the general duty clause of the OSHAct. When monitoring information reveals that an employee risks serious health damage from continued exposure to a workplace toxicant, it may also indicate that the employer is in violation of the general duty clause. When a workplace exposure constitutes a recognized hazard likely to cause death or serious physical harm, an employer violates the general duty clause if he or she does not take appropriate steps to eliminate the hazard. In the case of a toxic substance, this would appear to require reduction of the exposure, not mere removal of presumptively sensitive employees from the site of exposure.

The issue is amenable to regulatory solution, such as the implementation of mandatory MRP standards for exposure to toxic substances in general, as OSHA has
done with its lead standard (19). An employer's compliance with a mandatory MRP provision for a particular exposure would remove the threat of a general duty clause citation.

Limitations under the antidiscrimination laws. An employer who uses monitoring information to limit employment opportunities may also face liability under antidiscrimination laws. Although not all workplace discrimination is prohibited, US state and federal laws forbid certain bases for discrimination. Many of these may apply to an employer's use of human monitoring information. A detailed discussion is beyond the scope of this article, but their potential impact on human monitoring is outlined below.

Section 11(c) of the OSHAct prohibits employers from discharging or otherwise discriminating against any employee "because of the exercise by such employee on behalf of himself or others of any right afforded by this chapter." If an employee insists on retaining a job in the face of medical data indicating that continued exposure to a workplace toxicant will likely pose a danger to health, the employee may well be asserting a right afforded by the OSHAct. The Act's general duty clause imposes on employers a duty to maintain a workplace that is free of "recognized hazards" likely to cause death or serious physical harm. Inherently, then, the Act vests employees with a concomitant right to insist that their workplace be free of such hazards. Accordingly, an employer who discharges or otherwise discriminates against a worker because of perceived susceptibility to a toxic exposure arguably violates the prohibition of section 11(c). When an employer asserts that an employee cannot work without injury to health, the employer tacitly admits that the workplace is unsafe. That admission triggers the remedial provisions of the Act.

An OSHA regulation, issued under section 11(c) and upheld in a unanimous US Supreme Court decision (20), gives individual workers a limited right to refuse hazardous work when there is a situation likely to cause "serious injury or death" (21). The employer may not take discriminatory action against the employee by discharging the employee or by issuing a reprimand to be included in the employment file. Withholding the employee's pay during the period in which the employee exercises the right is also prohibited.

Because a worker may be absent from a hazardous work assignment under certain conditions without loss of pay or job security, it seems anomalous to allow an employer to discharge or remove the employee without pay because of the same hazardous condition.

Handicap discrimination. Congress and most states have passed laws barring discrimination against handicapped/disabled individuals in certain employment situations. The laws, which vary widely among jurisdictions, all place potential limitations on the use of human monitoring data. Although the courts have adopted a case-by-case approach, a worker denied employment opportunities on the basis of monitoring results often falls within the literal terms of many handicap discrimination statutes. In general, two issues determine disability: whether the workplace in question is covered by a state or federal handicap act, and, if so, whether the worker in question is handicapped/disabled under the act.

At present, the general applicability of handicap/disability discrimination statutes to the use of human monitoring information remains unclear. The US National Rehabilitation Act of 1973 as well as the Americans with Disabilities Act of 1990 defines a handicapped/disabled individual as "any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment."

In the great majority of cases, persons facing reduced employment opportunities as a result of human monitoring data do not at present have a substantially debilitating medical condition and thus do not satisfy either the first or second clauses of the federal definition. Rather, they are perceived as having an increased risk of developing such a condition in the future. The acts' wording is broad enough to cover discriminatory practices based on data obtained through human monitoring.

Even in cases in which handicap/disability discrimination is established, an employer may escape liability if the discriminatory practice is reasonably necessary for efficient operation of the business. The US National Rehabilitation Act provides employers with no affirmative defense, but does require the handicapped/disabled individual to prove that he is "qualified" for the job. Most state handicap statutes include some form of affirmative defense.

Civil rights and age discrimination. Title VII of the Civil Rights Act prohibits employment discrimination on the basis of race, color, religion, sex, or national origin. With a scope substantially broader than that of the federal handicap discrimination act, the Civil Rights Act protects the great majority of American employees. In addition, many states extend similar protection to employees not covered by the federal act. The Age Discrimination in Employment Act of 1967 and some state acts provide protection of comparable breadth against discrimination on the basis of age.

As with handicap discrimination, the applicability of these laws to the use of human monitoring information is not yet clear. The practical impact of an exclusionary practice, however, may fall disproportionately on a particular race, sex, ethnic, or age group. The US Supreme Court has long held that a claim of disparate impact constitutes a viable cause of action under the Civil Rights Act. A similar rationale has been applied in the area of age discrimination. A 1975 decision held that job applicants denied employment on the basis of a preemployment screening can establish a prima facie case of racial discrimination if they demonstrate that "the tests in question select applicants for hire or promotion in a racial pattern significantly different from that of the pool of applicants." Proof of disparate impact thus requires statistical analysis demonstrating a "significant" disproportionate effect on a protected class. The cases
provide no clear guidance, however, as to the level of disproportion deemed significant.

The potential for disparate impact is inherent in many uses of human monitoring data. A genetic screen for sickle cell anemia, for example, will disproportionately exclude blacks and certain ethnic groups because they have a much higher incidence of this trait than does the general population. Similarly, tests that consistently yield a higher percentage of positive results in one gender than the other may give rise to exclusionary practices that discriminate on the basis of sex. [Fetal protection policies, which exclude women of childbearing capacity from the workplace to avoid exposure to reproductive hazards is held not to involve discrimination on the basis of monitoring data; for a brief discussion of this issue, see Ashford and Caldart (12).]

Finally, a wide variety of exclusionary practices based on monitoring data may have a disparate impact on older workers. Older workers are likely to have been in the workforce longer, with greater cumulative exposure to hazardous work environments than their younger colleagues. Their prior exposure may have impaired their health or left them more vulnerable to current workplace hazards, e.g., with a preexisting illness as a result of previous workplace exposures or on account of age alone.

When a plaintiff establishes a prima facie case of disparate impact, the employer, to withstand a charge of disparate impact discrimination, can justify the alleged exclusionary practice by showing that it constitutes a "business necessity." The US Supreme Court has characterized the defense of business necessity as requiring "a manifest relation to the employment in question," meaning that the practice must be "necessary to the safe and efficient operation of the business." If the plaintiff can establish that another, less discriminatory practice will accomplish the same purpose, the defense of business necessity will not stand.

If a practice is discriminatory on its face or involves disparate treatment, the employer may avoid liability only by demonstrating that the basis of the discrimination constitutes a bona fide occupational qualification. This defense is available under the Civil Rights Act for discrimination based on sex, national origin, or religion (but not for discrimination based on race or color) and under the Age Discrimination in Employment Act. The defense requires the employer to establish that the discriminatory practice is "reasonably necessary to the normal operation of business." However, the US Supreme Court has characterized the defense as an "extremely narrow" one.

There are two principal reasons why business necessity may be difficult to establish for exclusionary practices based on human monitoring data. First, most of these practices are not designed to protect the health and safety of the public or of other workers. Instead, their business purpose is the protection of the excluded worker and, not incidentally, the protection of the employer from the anticipated costs associated with the potential illness of that worker (22). As noted in one analysis, "the courts are usually skeptical of an employ-
ier's argument that it refuses to hire qualified applicants for their own good, and they often require a higher level of justification in these cases than in cases in which public safety is at stake" (23). Another, and potentially more serious, obstacle to the successful assertion of a defense of business necessity is the unreliability of the screening procedures themselves. If the exclusion of susceptible (high risk) individuals truly is a business necessity, the rationale disappears if the test used as the basis for such exclusion cannot provide reasonable assurance that those excluded are actually at high risk. Without such assurance, the test only adds to the discriminatory nature of the exclusionary practice. Given that many screening tests are currently far from reliable, the business necessity defense is questionable.

The foregoing discussion has presupposed that the screened worker will be excluded from the workplace. Employers, however, may have another option, to provide these workers with other jobs in workplaces that do not involve exposures to the substances from which they may suffer adverse health effects. If such alternative positions were supplied, at benefit levels comparable with those of the positions from which exclusion was sought, employers might avoid the proscriptions of the various discrimination laws. Providing an alternative position would certainly remove much of the incentive for filing a discrimination claim. Further, even if such a claim were filed, courts might find that an adequate MRP program obviated the charge of discrimination. This could be one area in which good law and good social policy coincide.

Use of Monitoring Data in Tort and Workers' Compensation Cases

From a legal perspective, the most important impact of human monitoring information may be its use as evidence in tort and workers' compensation cases to address how we know whether a particular exposure caused a particular person's medical condition. At present, the problem remains a major one, except for exposure to a few substances, such as vinyl chloride and asbestos. Human monitoring has the potential to bring about a change in the nature of the evidence used in these cases.

Typically, the evidence offered to prove causation in chemical exposure cases is premised on a statistical correlation between disease and exposure. Whether the underlying data are from epidemiological studies, from toxicological experiments, or from the output of a complicated risk-assessment model, they are usually population-based. This places the plaintiff at the mercy of the attributable risk (expressed as the percentage of cases of the disease attributable to the exposure) for the study population. Unless the attributable risk exceeds 50%—that is, unless the incidence rate among those exposed to the chemical is more than double the background rate—the plaintiff cannot prove on the basis of the available statistical evidence, that his or her particular case of the disease, more likely than not was caused by the chemical exposure.

The developing science of human monitoring may offer a way to distinguish individual claimants from the
population at risk. Conceivably, the data generated by various human monitoring procedures will: (a) increase our knowledge of the "subclinical" effects of toxic substances, thus permitting us to track the effect of a chemical exposure over time, and also expanding the universe of "medical conditions" for which compensation may be provided; (b) eventually enable us to establish that a particular person has been exposed to a particular chemical (or class of chemicals); and (c) eventually enable us to establish that a particular person's medical condition (or subclinical effect) was caused by exposure to a particular chemical (or class of chemicals).

Human monitoring data are already being used in some situations to identify subclinical changes thought to be associated with particular chemical exposures. In the long term, evidence of subclinical changes occurring between the time of exposure and the time of disease may be a way of distinguishing those whose disease was caused by the exposure from those who contracted the disease because of other factors. Such evidence may also give rise to more immediate legal relief. There is a growing trend toward allowing those who can establish that they have been exposed to a toxic substance—and thus that they have been placed at increased risk of future harm—to recover the costs of medical surveillance from the responsible party. Proof of certain subclinical effects, such as DNA damage, would tend to support an allegation of increased risk, and would make the claim for medical surveillance all the more compelling. Further, such evidence may support a separate claim for damages for having been put at increased risk of future harm.

Finally, some evidence of subclinical effects may give rise to a right to recover compensation for those effects themselves. For example, human monitoring can detect certain changes in the immune system, which—according to a large body of literature—can be harmed by various chemical exposures (24), and evidence of immune system damage has been offered in recent cases involving toxic substance exposure (25). Thus far, allegations of immune system damage have met with mixed success in the courts, both because the relationship between chemical exposure and immune system damage is not yet clear, and because the evidence of immune system damage was not always considered persuasive. Although human monitoring may not be able to tie particular immune system deficiencies to particular exposures, it should be able to establish with greater certainty whether immune system damage has, in fact, occurred.

It is quite possible that further developments in the science of biomarkers will permit the identification of "chemical fingerprints"—a distinctive change in the DNA that can be linked with exposure to a particular chemical or class of chemicals. At the very least, this should make it much easier to distinguish those who have been exposed to a particular chemical in the workplace from those who have not, and to identify which of the many potential defendants was responsible. More importantly, it should eventually permit the correlation of particular cases of diseases such as cancer with exposure to particular chemicals (or classes of chemicals).

Possible Solutions in the Workplace

With legal and ethical norms in flux, it is important to examine the policy options for dealing with future and continuing ethical workplace dilemmas. Possible strategies include:

1) Encouraging ethical enquiry in the conduct and use of medical screening, i.e., educating workers, management, and health professionals to think more seriously about the problems. Indeed, ethicists should be consulted in designing the screening programs.

2) Using legislative and regulatory means to clarify rights and duties, such as encouraging OSHA to promulgate a generic earnings and job security protection requirement for all cases of medical removal, or enacting legislation that requires workers to be notified of occupational risks and prohibits discrimination outright.

3) Encouraging the use of self-help techniques by workers, e.g., union bargaining, the filing of discrimination complaints, and the right to refuse hazardous work.

4) Encouraging better disposition of conflicts by improving procedural fairness in attempts at resolution, such as full and complete disclosure of information to workers, the better maintenance of confidentiality of worker records, or the use of corporate ombudpersons.

5) Sharing decision-making through encouraging development of joint health and safety committees.

The choice of options at any one time reflects the seriousness with which society wishes to address the moral and legal dilemmas. Thinking about the problems is a first and necessary step (26–29).

Legal and Ethical Problems in Community Monitoring

Experience with three contaminated communities—Love Canal, NY; Woburn, MA; and the state of Michigan—reveals a rich picture of conflicts and problems.

The trench that was Love Canal was filled with municipal and industrial wastes before it was covered in dirt and sold, as part of a larger parcel, to the Niagara Falls Board of Education. The Board built a school on the site and sold other portions to real estate developers who, over the next two decades, constructed single-family homes along its borders (2). In 1978, the landfill oozed toxic chemicals into the environment of a middle-class community.

A relatively high incidence of leukemia among children in the neighborhood of Walker Pond initiated the episode at Woburn, MA. Residents quickly focused on the sometimes malodorous drinking water as the probable culprit; two wells that contributed to the supply in recent times had been closed when found to contain toxic organic compounds (2).

Deforested and dying cattle led to the discovery of toxic contamination in Michigan. Inadvertent mixing of a flame retardant with cattle feed, leading to production of contaminated dairy products, eggs, and meat, exposed virtually the entire population of Michigan to a variety of brominated organic compounds. The continuous, although decreasing, toxic exposure of a variety of live-
stock and of human consumers persisted for several years after the initial mishap (2).

Conflicts of Interest

There were conflicts of legitimate interests at every stage of monitoring activity, both early and late, in the three contamination episodes. The conflicts generating the most hostility occurred between government agency personnel and community residents, often due to the agency's concern for the overall health of the entire public within their jurisdiction, vs the community's more parochial and environmental concerns and individuals' private concerns. Similarly, agencies and citizens often had different interests with respect to the distribution of costs and benefits. Conflicts of interests also existed between the government and the entity responsible for the contamination—which were significant sources of discord during the first two monitoring stages ("hazard recognition" and "decision to monitor"), the next two stages ("decision to act" and "action"), and the fifth stage ("evaluation of monitoring data"). Conflicts of interest between citizens who were activists (in favor of monitoring and remedial action) and people affiliated with the entity responsible for pollution were substantial during the same five stages. Finally, the conflicts of legitimate interests between scientists and government (especially public health agencies) were prominent, beginning with the stage "design of the monitoring study" and ending with the "decision to act" stage.

In anticipation of possible criticism for omitting discussion of conflicts of interest with the news media, let me note that I have included local media in the category of people affiliated primarily with the contaminated community. These individuals were indeed influential and helped to shape the course of events; however, their role appeared to be investigative and (or) supportive of community activists rather than independent in character. The regional and national media were not observed to initiate conflict, and actually did not appear on the scene until late in the episodes. The exception to this rule occurs when a community is ignorant of the potential hazard and informed by media coverage, e.g., as happened with the pesticide ethylene dibromide. In such cases, the national media actually assumes the more activist role of the local media in service of the potentially exposed community, which includes the entire population of the US.

Internal conflicts among duties in these incidents led to psychological distress and sometimes to unethical behavior, particularly in community residents torn between a duty to be well informed (so as to anticipate and respond appropriately to danger) and a duty to maintain their own peace of mind (being conducive to rational thought) and a calm exterior for the benefit of their families. The latter duty prompted many residents to avoid distressing information or to deny its significance. Public health professionals experienced internal conflicts between their duties to prevent panic in the community and to warn the public of potential danger, as well as between the duties associated with their various roles as scientists, wage earners, public servants, and employees of a particular branch, unit, and level of government. Other individuals who worked for governmental agencies experienced conflicts as a result of multiple roles as defenders and regulators of a particular client group—e.g., farmers. Private physicians were faced with the sometimes conflicting desires to help community members cope with their fears, to protect the health of their patients, to maintain their professional standing in the community, and to avoid taking responsibility for decisions with regard to issues beyond their expertise. People affiliated with the entity that caused the contamination also faced conflicting duties—loyalty to the entity; obligation to the community (because of their special knowledge); and obligations to families, friends, and the community as a whole if they resided locally. Most of these internal conflicts permeated all stages of monitoring activity, both early and late in the episodes.

Conflicts among values of different key actors centered around the relative significance of "subjective" vs "objective" information and the nature and degree of uncertainty, error, and risk that is tolerable or that should be addressed by the managers of hazards. Residents and agency professionals disagreed about which of these issues should be addressed by the managers. They even disagreed about which of these issues was more important—i.e., problem definition—and therefore about what were appropriate solutions. Residents worried about experts' ability to assess and control risk, while "experts" fretted about citizens' unreasonable demands for certainty. The views expounded were not universally held by all actors affiliated in the same group. Rather, conflicts occurred between those who were trained and socialized in a technical field and those who identified more with humanistic traditions. These conflicts drove a wedge between actors, initially when they considered the need for monitoring and later when they considered the need for acting in response to monitoring results and in evaluating the monitoring data, but the conflicts also influenced the other monitoring stages.

The problem inherent in dealing with complex issues that are surrounded by scientific uncertainty—that has been encapsulated by "How much information is enough?"—fueled disputes during the stages of "design of monitoring studies" as well as, to a lesser extent, during "hazard recognition," "decision to monitor," "evaluation of monitoring data," "dissemination of information," "decision to act," and "action." Tied to this issue, in every case, is the related question, "Who should decide?"

Stress afflicted key actors faced with unprecedented situations, scientific uncertainty, and a need to make decisions quickly. Before the discovery of contaminated communities became common, people in government were subjected to enormous political and personal pressures and placed in a no-win position. Today, professionals have the benefit of past experiences and specialized training. Nevertheless, in view of the crisis mentality that often prevails, the political controversies that develop, and the continuing scientific uncertainty, people in government still find their personal moral integrity...
threatened. For residents of contaminated communities, although they may have read about the events in other contaminated communities, their own episode usually is a novel personal experience. They generally are not prepared to cope well and can be expected to respond emotionally and with confusion. In such an aroused state, their behavior may be abusive or otherwise inappropriate. In short, they need to be regarded like any other victims of natural disasters or of crimes—with understanding, patience, and counseling. They also need to be provided with adequate resources and a meaningful role in monitoring activities. Stress is a problem throughout contamination episodes, but it is most acute when residents first learn about potential adverse health effects. The “conduct of monitoring” stage in the first round of monitoring is particularly sensitive because inevitably, no matter how wide the press coverage, some residents will have not heard about the contamination or not accepted the threat as real. To be asked for a biologic sample is a convincing but frightening way to learn about one’s possible exposure to a toxic substance.

Finally, there is the problem of misperceptions and misunderstanding when actors observe the activities of people whose frame of reference differs from their own. People afflicted within each group may misconstrue the meaning of events, misinterpret verbal and written communications, and attribute negative motives to silence or to an unexpected absence of apparent activity. Each may be acutely aware of his or her own responsibilities and attitudes but quite ignorant of the responsibilities and attitudes of others. The obvious solution is to increase opportunities for actors to get to know one another and to interact in a positive way. They need to discover common goals, to realize constraints that shape the attitudes and actions of other groups, and to form realistic expectations with regard to the timing and substance of monitoring activities. Ideally, communication between agencies and citizens would commence before a problem occurs, but, in any case, communication should be initiated with vigor as early as possible, even before a hazard is given official status. Only through a convincing display of openness and respect for the abilities and trustworthiness of others will trust be reciprocated.

Resolution of Conflicts

Four factors emerged as significant influences on the emergence and evolution of conflicts and problems in contaminated communities: resources, information, openness, and trust.

Limitations on resources—time, money, and (knowledgeable) personnel—too often constrain the options available to key actors in contamination episodes. Agencies and community residents alike are forced to address the concerns that are immediate and critical while ignoring other concerns of almost equal importance. Often, the relative availability of a particular resource determines what aspect of a multisided issue the actors are willing to address (30). Thus, managers of prosperous industries (e.g.) are more willing to define an issue in terms of its complexity because that aspect emphasizes the value of the two resources most available to industry—money and expertise. Individuals such as the residents in contaminated communities, however, are more apt to characterize issues as value conflicts over the distribution of costs and consequences, thus emphasizing the importance of public opinion and political input.

Information, particularly its existence and availability to different groups, is power. Biased or selected information or the lack or unavailability of information frustrates attempts to resolve disputes and forces opponents to rely on personal values in making judgments. Scientific uncertainty also clearly influences perceptions of risk.

Openness, in fact and in appearance, of the actors’ minds and of decisionmaking procedures is the antithesis of secrecy. Citizens in a democratic society insist on their right to observe government in action and, therefore, to hold public servants accountable for their part in decisions (31). Although the majority of citizens may never exercise their right, the knowledge that they may do so, and that some other citizens do watch over government, gives reassurance to everyone that democracy is safe. In contrast, the merest hint of secrecy by elected or appointed public officials enrages many citizens, absent a strong and reasonable argument that secrecy protects some other more basic right—e.g., to privacy for individuals. Demands for access to information about activities in the past asserts a citizen’s right to retroactively “observe” decision-makers.

Trust and trustworthiness are key attributes. A breakdown in trust between people or groups does not occur without reason; the behavior or communication of the party who is judged is at least as instrumental in destroying trust as is the tendency of the judge to pass judgment precipitously. To learn from experience, one must evaluate the available information. If the only information available is a gesture or an ambiguous situation, one can either defer judgment and wait for more information or pass judgments based on previous analogous experiences. The circumstances in episodes of contamination strongly favor a decision to act and to dispense with more waiting. To avoid loss of trust, actors must learn to radiate an aura of trustworthiness as well as to maintain their integrity in fact. Placing the blame on others for drawing inaccurate conclusions is counterproductive and unfair itself.

Possible Solutions in Community Monitoring

Major US legislation during the 1970s and 1980s addressed some of the issues that emerged at Love Canal, Woburn, and in Michigan. Funds for emergency response actions were established at the federal level and in many states. Citizens were granted the right to petition the federal government to perform health studies of populations exposed to chemical wastes, and the Environmental Protection Agency now screens requests of industries that plan to produce, distribute, or use newly synthesized chemicals. If the chemical is determined to potentially pose an unreasonable risk, toxicity tests are
required before executing the intended plans. Toxic chemicals presenting an unreasonable risk may be banned, or their use may be strictly regulated.

Other issues have been resolved, or at least managed, as agencies gain experience in dealing with releases of toxic substances. Training programs for staff provide constructive suggestions to improve community relations. Some citizens, too, have gained experience and have formed organizations to provide advice to others.

Problems and conflicts and the external conditions that give rise to hostility still exist, however. Some unresolved legal issues include: definition and protection of the right to privacy for residents of monitored communities; lack of assurances that citizens are adequately informed before being asked for their formal consent to be monitored; agreement about the conditions that justify decisions to withhold research results or information about research methods; and confidentiality of individuals' and groups' test results. Ethical issues that require attention include: the need for counseling and support for individuals who experience stress in monitoring situations; the lack of sensitivity and respect among the various groups affiliated with the potentially responsible party, government, and the community; the perception of undue delays and secrecy in government's response to citizens' concerns; the quality and quantity of public involvement in the decision-making stages of monitoring activities; and lack of knowledge about the substance and format of information that is needed or desired to empower residents to make personal and political decisions related to the local problem of contamination and to the broader social issue of chemical controls.

Participation by members of the affected communities was seen as an essential element in constructing solutions. The use of advisory panels warrants particular attention in the context of a participatory model for problem solving. Establishment of the following five different types of committees, each with a different mission or purpose, level of involvement, and degree of public representation, is recommended for different purposes:

1) For each state-level agency involved in monitoring, a permanent, statewide, institutional science advisory board of independent experts to evaluate and advise generally on monitoring policies, protocols, and priorities on a regular, periodic basis (e.g., The Agency for Toxic Substances and Disease Registry's obligation to utilize "disinterested experts").

2) A permanent, statewide, advisory board of interested (or affected) parties and citizens to evaluate and advise generally on monitoring policies, protocols, and priorities on a regular periodic basis.

3) A permanent, statewide, fact-finding, technical board of experts (from multiple disciplines) with balanced representation, including citizens or their nominees, to review research, hold hearings, draw conclusions, or evaluate studies at particular sites, i.e., a permanent, open "Blue Ribbon" review panel.

4) An ad hoc citizen (or worker) advisory board or citizen (or worker) panel to represent citizen (or worker) concerns in each putatively contaminated community. [This has been advocated as a separate committee so as to avoid citizens' concerns of possible intimidation and the divulging of health-sensitive information to industry, insurance companies, or employers.] Arguably, this citizen panel would be involved at an early stage, i.e., "hazard recognition" or "decision to monitor," and continue throughout the monitoring stages.

5) A permanent advisory board of interested and affected parties to represent all concerns in each community. This might be an expanded Local Emergency Planning Committee, but it must include representatives of the contaminated area as well as workers involved in remedial activity. Terms should be staggered and limited, to prevent cooptation.

The distinction between the first committee and the second is that the first is restricted to "independent experts," whereas the second is representative and need not be "expert." Both are permanent and statewide and perform the same functional tasks. The third committee is an expert review or evaluating committee that operates statewide but reviews studies at many particular sites. The fourth and fifth committees operate at the community level and perform similar functions but differ as to composition.

Even with regard to citizen panels, there is wide variation in type. Renn et al. (32) advocate using 20–25 randomly chosen citizens. Despite the "democratic" nature of this approach, it may not ensure that serious differences within the community are sufficiently aired. Administrative selection, carefully overseen; inclusion of a range of affected groups (33); or election by community groups might be preferable in the monitoring context. Of course, a given "group" may not be homogeneous; i.e., divergent views can exist there, too.

Obviously, it may not be necessary to appoint all five types of committees. For example, a state could ensure that the first committee includes recommendations for technical experts from the community or industry, thus making the need for a second committee less compelling. The different types of committees may be utilized in different ways at different stages of the monitoring process; the third committee would evaluate the results of the monitoring studies.

In each case, committee membership should be balanced appropriately to reflect the range of reasonable political and scientific viewpoints. Members should be required to disclose any allegiances or relationships that could suggest bias or that might influence their ability to function independently. In general, several citizen members, not just one, should be on the committees. Citizens who serve on advisory committees, at every level of government, should be provided with training to participate effectively and with compensation for their time, effort, and child-care expenses. We and others (34) argue that participation should occur as early as possible in the decisionmaking process.

In addressing the issues raised in this study, keep in mind that a variety of possible interventions is available, from specific laws to administrative processes. In
suggesting the greater use of advisory panels, community monitoring impact statements, and other measures, we are mindful of the danger of creating greater bureaucracy and paperwork requirements. Obviously, these measures should be utilized in such a way as to not unduly impede rapid and timely action.

Both new laws and institutions as well as ad hoc or informal mechanisms are needed to more fully involve the affected public and other key actors in monitoring. In general, the earlier that key actors are involved in the activities comprising human monitoring, the more effectively can adverse effects and loss of trust be avoided or minimized. Specific policy initiatives can be conveniently grouped into areas that build skills and capability in the community; build skills and capability in the agencies; increase specific authority for (and obligations of) government; provide increased community participation through access to governmental decisions; provide adequate incentives and motivation to agency personnel; and provide for more, more predictable and better communication.

Communities are just beginning to explore ways to address the above activities. Law provides little structure at this time. Finally, community demands for health studies should be recognized as a community's means of getting governmental attention—and perhaps action—either to relieve the community of its concerns or to assist the community in dealing with a bona fide health problem. Many monitoring studies are unlikely to yield scientifically significant results because they involve a small population, low-dose exposures, indeterminate latency periods, etc. This problem partly explains the reluctance of some community residents to participate in monitoring. The proper response of government, then, is to decide either that it is willing to take remedial action even if a study does not reach statistical significance, or that it will take action on the evidence of significant exposure alone.

References

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