Unfortunately, relatively little literature exists that focuses on the content and efficacy of training programs for HIV researchers, particularly with respect to training in ethical issues or ethical issues arising in the context of that training. As a result, much of this chapter draws on what has been reported regarding training programs for clinicians that may also be relevant to researchers.

The Need for Training

Studies consistently suggest that individuals preparing for research and clinical careers receive inadequate training with respect to HIV/AIDS. Campos and colleagues (1989) surveyed 92 doctoral programs in psychology that were approved by the American Psychological Association (APA), as well as 169 predoctoral internship programs. They found that 75% of the doctoral programs and 40% of the internship programs did not systematically provide information about HIV/AIDS and slightly less than half of the graduate programs even offered training in human sexuality. Those that did provide HIV/AIDS training on a systematic basis often failed to include critical issues within their programs. For instance, 68% offered little training on behavioral medicine, 30% did not include training related to substance abuse, 67% failed to address primary prevention of HIV/AIDS, less than half (41%) provided instruction on urban or minority issues, and more than two-thirds (67%) failed to provide training in community psychology. A survey of training in 115 APA-approved clinical psychology doctoral programs found that AIDS was identified as a specialized area of training in only 7% of the programs (Sayette and Mayne, 1990). Only 15 faculty members were identified as conducting research related to HIV/AIDS.

As recently as 1998, another survey of 585 practicing psychologists found that more than half had not received any formal training or education about the clinical presentation, treatment, or transmission of HIV/AIDS (Schmeller-Berger, Handal, Searight, and Katz, 1998). The majority of respondents received their HIV-related information through radio, television, and newspapers. Although the survey related to practicing psychologists, it is
likely that at least some psychologists engaged in research would have undertaken similar programs.

A study of health care providers in Mexico found that 75% had received some training related to HIV/AIDS (Infante et al., 2006). Despite this training, however, almost one-quarter of the respondents indicated that they would not buy food from an HIV-infected individual and 16% thought that HIV-infected persons should be banned from public services. More than one-third believed that employers and administrators should have the right to know the HIV status of employees, and many distinguished between “innocent victims” and “guilty” ones, thereby justifying delays and stigmatization in the context of health care. The extent to which the providers also engaged in HIV research was not indicated.

It has been suggested that it may be particularly important to train minority researchers in the field of HIV (Marin and Diaz, 2002). Although access to minority populations for research may be particularly difficult, it may be somewhat easier for minority researchers to develop collaborative relationships with these communities. However, minority researchers in this field are relatively scarce (Marin and Diaz, 2002).

The training of researchers is critical not only to facilitate needed research, but also to develop a cadre of individuals sufficiently familiar with principles of research to review research protocols, both for potential funding and in the context of ethics review committees. For instance, although many ethics review committees in parts of Africa will likely be required to review protocols for HIV vaccine trials, most have no or only moderate capacity to do so, both with respect to the ethical issues and the scientific aspects involved (Milford, Wassenaar, and Slack, 2006).

Developing Program Content

Researchers, like clinicians, must have basic knowledge about HIV, its epidemiology, its prevention, and its impact on individuals, families, and communities. Table 17.1 presents the various domains that a comprehensive HIV/AIDS training program would include, together with a listing of some elements encompassed within each such domain.

Mechanisms for Training

Research training grants may be available to fund training programs for HIV researchers in a variety of disciplines. The Fogarty International Center, part of the National Institutes of Health, has partnered with several institutions in the United States to fund training programs for HIV researchers based in a number of countries (United States Department of Health and Human Services, 2004). These and other NIH-funded programs have trained individuals at the master’s...
and doctoral levels (National Institutes of Health, 2006). Depending upon the specific program, training has focused one or more of the following areas:

- animal models
- applied mental health research
- behavioral sciences
- bioethics
- clinical trials
- communicable disease control
- cultural and social factors
- epidemiology
- family structure and dynamics
- HIV vaccinology
- human rights
- immunology
- qualitative research methods

### Table 17.1 Recommended content for comprehensive HIV/AIDS training programs for researchers

<table>
<thead>
<tr>
<th>Domain</th>
<th>Elements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Overview</td>
<td>HIV transmission, epidemiology, testing, and prevention, disease course, treatment, and progression; symptoms</td>
</tr>
<tr>
<td>Cultural and Historical</td>
<td>History of disease “discovery” and identification; disease impact on subgroups; changing demographics of epidemic; population and governmental response to HIV/AIDS in various countries and localities; discrimination and scapegoating;</td>
</tr>
<tr>
<td>Historical Context</td>
<td></td>
</tr>
<tr>
<td>Psychological and</td>
<td>Responses to HIV testing; psychiatric and other medical comorbidities; human sexuality; coping strategies; chronic and terminal illness; death and dying; impact on caregivers; family composition and dynamics; impact of HIV treatment; substance use; identity issues; suicide risk; stigma and stigma management;</td>
</tr>
<tr>
<td>Psychosocial Aspects</td>
<td></td>
</tr>
<tr>
<td>Community Aspects</td>
<td>Local community response to HIV/AIDS; impact on local community; type and extent of community services available to HIV-infected and -affected persons; local economic impact of disease;</td>
</tr>
<tr>
<td>Legal and Ethical Issues</td>
<td><strong>Participant-focused issues</strong>: Evolution of legal and ethical issues over time; confidentiality and privacy; informed consent; mandatory reporting (infectious disease; unprotected sexual relations, etc.); contact tracing; duty to warn; protection of vulnerable research participants; risks and benefits of study participation; obligations to community and research participants; legal vulnerabilities of/risks to subgroups (e.g., prisoners, sex workers, undocumented immigrants) <strong>Profession-focused issues</strong>: Data ownership, sharing, storage, and retention; professional boundaries; obligations to colleagues;</td>
</tr>
<tr>
<td>Human Rights</td>
<td>International protections for HIV-infected persons; stigmatization and discrimination</td>
</tr>
<tr>
<td>Research and Methodology</td>
<td>Study design; quantitative data collection methods; sampling; statistical analysis; qualitative data analysis; preparation of manuscripts, presentations, and grant proposals;</td>
</tr>
</tbody>
</table>
Marin and Diaz (2002) described a program developed through the University of California San Francisco Center for AIDS Prevention Studies (CAPS) to train scientists of color, with an emphasis on preparation for the successful submission of grant applications. This program included the following elements:

- Summer 1, at CAPS: emphasis on development of the research question, literature review, and conceptualization of the problem
- Academic Year 1, at home institution: conduct of preliminary studies
- Summer 2, at CAPS: analysis and synthesis of preliminary data, draft of research proposal
- Academic Year 2, at home institution: revision and submission of research proposal to potential funding source
- Summer 3, at CAPS: revision of proposal in response to reviewer comments, or preparation to begin conducting research

Other program components included training on research with human subjects; seminars related to qualitative research, intervention planning, recruitment and retention, and grants management; internal peer review; and individualized mentoring (Marin and Diaz, 2002).

Long-term collaborations between countries and institutions may be critical to the professional development of HIV researchers. One such example is provided by the Ethio-Netherlands AIDS Research Project (ENARP), which was developed in order to strengthen both international HIV/AIDS research and the research capacity of Ethiopia (Sanders et al., 2000). Components of this collaborative effort included the addition and renovation of research facilities; the extension of electrical resources; the provision of equipment and materials; degree programs at the master’s and doctoral levels; technical programs for laboratory technicians, maintenance engineers, and computer staff; and short-term fellowships abroad for Ethiopian scientists. Ph.D. programs were established in the fields of epidemiology, virology, immunology, and parasitology. Research resulting from this program has included the identification of HIV subtypes in Ethiopia, a study on HIV infection progression, the evaluation of laboratory markers to aid providers in initiating antiretroviral therapy, and a study of the relationship between HIV and intestinal parasitic infections (Sanders et al., 2000).

Other models of HIV training that have been utilized with health care professionals may also be useful in training researchers. These include: short-term training sessions over several days, in-service training for a period of a few months, didactic sessions on a regular basis, mentoring visits by experienced professionals, refresher courses, off-site clerkships, consultation systems, case conferences on a regular basis, and institutional exchanges of information and resources (McCarthy, O’Brien, and Rodriguez, 2006).
Training is also available via the internet (McCarthy, O’Brien, and Rodriguez, 2006). For instance, PLoS Medicine provides free access to all readers (Eisen, Bowen, and Varmus, 2004). The endeavor is supported by charging the authors of manuscripts a publication fee to cover the costs of peer review, editorial oversight, and publication. In addition to providing access to researchers and researchers-in-training, this mechanism also allows access to providers, patients, and research participants because it is “open access.” Additionally, courses can be developed that are web-based and permit learners to progress at their own pace (McCarthy, O’Brien, and Rodriguez, 2006).

Evaluations of specific training programs for health professionals have found them to be efficacious. Various studies have found that training may resulted in an increase in providers’ knowledge (Wertz, Sorenson, Liebling, Kessler, and Heeren, 1987), a reduction in their level of anxiety about having contact with HIV-infected patients (Sherr and McCreaner, 1989), an increase in their comfort level in dealing with substance users (Mejita, Denton, Krems, and Hiatt, 1988), and an increase in their level of professional responsibility towards HIV-infected individuals (Ezedinachi et al., 2002). However, it is unclear to what extent such findings would be equally applicable to HIV researchers, in contrast to individuals in clinical practice.

The Training Process

Often, training is reduced to a focus on the substantive content, without regard to the process of training or the process by which researchers are socialized into the field of research. It is critical to the development of professional researchers, however, that attention also be paid to these issues.

Training, for instance, can be accomplished both on an informal basis, through direct supervision of training activities, through formal meetings to review progress and accomplishments, and by role modeling. The mentor should be prepared to assist the trainee not only in the development of his or her research skills, but also in the development of scientific integrity, the formation of professional networks and relationships, the choice of a career path, and the development of a “thick skin” that allows the trainee to persevere in the face of professional disappointments. Trainees will also need guidance on such critical issues as time management, the development of skills for grant writing and manuscript preparation, and the preparation of a curriculum vitae.

Ethical Issues

Numerous ethical and legal issues may arise in the context of developing and implementing training programs. Because many of these issues are addressed in the following case study, they will not be discussed in detail here. These issues include access to and ownership of data; confidentiality and privacy concerns
related to research participants and to the trainees themselves; ethical obligations owed by trainees to their colleagues; responsibilities of the training mentors to the trainees; and ethical obligations of the mentors/administrators of the training program to the program, their colleagues, and their institutions.

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References


Case Study Eleven
Ethical Issues in Training the Next Generation of Researchers

Oscar Grusky, Ph.D.

Introduction

Faculty and staff have a responsibility not only to prepare students for the technical aspects of their work but also for providing them with ethical guidance and monitoring the learning process. This essay builds on experiences with the author’s National Institute of Mental Health (NIMH) supported multidisciplinary research training program on service systems for persons living with HIV/AIDS (PLA) (T32 MH19127, 1989-present). Hence, this is a case study of some ethical issues that arose in the context of a training program (an organization) rather than the case of a single individual.

Although the program is based primarily at UCLA, it also draws upon the Drew University of Science and Medicine and the RAND Corporation for faculty resources and works cooperatively with the Los Angeles Health Department and community-based HIV organizations throughout Los Angeles County to attain shared objectives.

The basic objectives of the program are to instruct trainees about social science behavioral and psychiatric and public health theories and methods in areas such as organizational analysis, health services research, health psychology, epidemiology, and biostatistics, so that trainees will be equipped to undertake research careers in HIV-related research. The training is designed to give participants the conceptual and methodological tools needed to conduct rigorous research.

The program focuses on psychosocial issues and health/mental health service systems for Persons Living with AIDS (PLA). It is led by scholars from medicine, psychiatry, psychology, sociology, health services, epidemiology, social policy, social welfare, nursing, and community health sciences. Each year 6 to 10 students are trained. Four to six pursue the Ph.D. in the social sciences, public health, or psychology and undertake a three-year sequence of courses and supervised research on mental health/HIV/AIDS. Two to four are postdoctoral trainees who already hold a Ph.D. degree and undertake a two-year sequence of courses and advanced research on mental health/HIV/AIDS. All trainees participate in a core seminar on HIV/AIDS that is offered the year round, mentored HIV research, and a carefully designed set of courses and field experiences.
To train persons in services research for persons living with HIV/AIDS, it is essential that they be taught fundamental knowledge of the organization of community service systems and the methods and models of HIV service systems research. Trainees must work closely with faculty engaged in ongoing research in this area so that they can master the fundamentals of theory and research design, identify and comprehend potential ethical issues and issues of research responsibility, and learn to deal with the administrative realities of behavioral health sciences field research. There are 24 faculty-HIV scientific mentors associated with the training program.

Since the program’s inception in 1989, a total of 75 individuals, 38 predoctoral and 37 postdoctoral fellows, have been trained. Over two-thirds are currently engaged in HIV research, and over half have submitted an HIV-related grant application. Almost 4 out of 10 predoctoral and two-thirds of postdoctoral trainees in the 2000–2005 funding cycle have published jointly with HIV faculty mentors. The program is closely connected with the NIMH-supported Center for HIV Identification, Prevention, and Treatment Services (CHIPTS) and has links with numerous other UCLA units engaged in HIV behavioral health research.

All identifying individual case information presented in this essay is fictional. Pseudonyms and other devices are used in the cases presented in order to prevent identification of any persons who may be involved. Although the situations are real, any similarity to actual persons is coincidental and is not intentional.

Ethics Training

Formal ethics training came about in the program because it was mandated by the NIMH. The primary manner in which trainees are formally instructed about research ethics and the responsible conduct of scientific research is by means of a special required course on this topic, Sociology 284, which is specifically designed for the program and is offered by the Program Director in alternate years. This seminar is designed to foster sensitivity and understanding of biobehavioral ethical issues in mental health/HIV/AIDS and health services research. The course provides researchers with the kinds of analytic tools needed to anticipate, understand, and hopefully resolve appropriately ethical conflicts and issues of scientific responsibility and integrity that emerge in social research. Course participants are required to complete the on-line program in protecting human research subjects of the UCLA Office for the Protection of Research Subjects. Students learn about the consent process and many other issues that relate to obtaining institutional review board approval for their research projects. Of course, a number of the issues raised in this course may also arise and are discussed in other courses taken by trainees such as in the required course on health services evaluation taught in the School of Public Health and the program’s core seminar. Faculty mentors also provide significant supervised albeit less formal training in this area by serving as role models for trainees.
Ethical Aspects of Social Influence in Organizations

The AIDS research training program has goals, a core technology, and boundaries, and, therefore, by definition is an organization (Aldrich, 1999). A major feature of organizations is hierarchy. A hierarchy refers to a pyramid of influence whereby those at the top of the power structure (superordinates) have the opportunity and rights and privileges to influence those at lower levels in the organization (subordinates). Training program faculty are superordinates and students or trainees are subordinates. For example, the faculty and staff develop rules and requirements that trainees are required to fulfill. The organization’s norms and values serve as limits on the process by which superordinates can influence subordinates and subordinates can influence superordinates. The AIDS research training program exists within a larger academic organization, UCLA, and consists of faculty, staff, postdoctoral students, and graduate students. The faculty may influence students directly and indirectly by transmitting information to them. The relationship between faculty and students is asymmetric as faculty generally have greater direct influence over students than students have over faculty. Nevertheless, it is a two-way influence process.

The underlying theme of this essay is the relationship between organizational power imbalance, social influence processes, and ethical issues. Many years ago, Lipset, Coleman, and Trow (1956) argued that despite a deep commitment to democracy in the U.S. most of the nation’s complex organizations are oligarchies. This is because incumbent elites have a disproportionate amount of power, are able to stay in power for a long time, and ordinary members of the organization tend to avoid participating in its internal political processes. The UCLA training program to some extent fits this model. The faculty has overwhelming power compared to students, maintain their power over time, and lower level members such as students often avoid direct internal political participation. Lipset and his colleagues argue that this power imbalance contributes to the development of flawed social influence processes including misunderstanding and mis-communication that inhibit the effective transmission of information. Consequently, less than ideal ethical decisions may result in these systems.

This essay is concerned with selected ethical aspects of the influence process that characterize training in the program. Kelman (2001) has identified four moral principles in evaluating organizational social influence processes:

1. Autonomy. Is the influence attempt respectful of the values and concerns of the person being influenced?
2. Nonmaleficence. Is any harm involved in the influence attempt?
3. Beneficence. Is the welfare of the person being influenced promoted?
4. Justice/fairness. Are the rights of the person being influenced respected?

As Kelman (2001) points out, there is a continuum varying from persuasion to coercion along which social influence processes may be evaluated. Overall, persuasive methods such as conversation, dialogue, and discussion, superficially,
at least, may often represent approaches to social influence that are respectful of the subordinate, non-harmful, considerate of the person’s welfare, and are respectful of the person’s rights. In contrast, coercive social influence tends to be none of these and is associated with perceived disrespect, is harmful to the target person’s self-esteem, and involves very little dialogue. However, appearances may be deceptive. A finer and more nuanced analysis requires careful examination of the specific social and organizational context within which each aspect of persuasion and coercion occurs. There may be situations such as enforcement of racial desegregation decisions in the U.S. where coercion is both legitimate and justified. Likewise there may be situations where persuasion, or what appears to be persuasion, is quite similar to manipulation and coercion. Only an intensive examination of the context within which the influence process takes place and the changes that occur in the social situation and in the characteristics of the participants can provide the information needed to assess accurately where it should be situated on the persuasion-coercion dimension.

The Ethical Dilemmas

Letters of Evaluation and CVs As Influence Devices: A Need for Evaluative Neutrality?

The Ethical Issue

The first issue to be examined is faculty and students’ ethical responsibility for describing themselves and others accurately in documents such as resumes, curriculum vitae (CV), and letters of evaluation. Two ethical questions are considered: To what extent are faculty and students obligated to be accurate in framing a personal document such as a CV or letter of evaluation? Should faculty and students strive for evaluative neutrality?

The Thompson case is one where a trainee candidate seriously misrepresented the status of her publications and apparently incorrectly described her teaching skills in her CV. In addition, faculty letters on Thompson’s behalf stated only positive aspects of the student and omitted serious weaknesses in her performance despite the likelihood that the evaluators were aware of the candidate’s deficiencies in teaching, publication, and other areas. Faculty may feel obligated to help their student gain employment by accenting their positive attributes in letters and omitting negative ones. Framing a letter in a generally positive rather than a negative manner is not uncommon. Although it may be understandable and admirable for a faculty member to try to help a student, the question is how far should a faculty member go in positively framing an evaluation of the candidate’s characteristics? To what extent should a candidate’s glaring weaknesses in fundamental areas such as teaching, research, and collegial relationships be downplayed or overlooked?
The Factual Situation

Thompson was accepted into the training program by the program’s review committee to a considerable extent because of her extensive publication record. This included a book listed as in press with a major publisher, six peer-reviewed journal articles, and uniformly strong faculty letters of evaluation. The mentors asserted that she was an outstanding researcher, an excellent teacher (she had been an assistant professor for several years), and a very helpful colleague. For example, the faculty letters stated:

“Thompson is among our very best Ph.D. recipients in the last decade. She has a good balance of theoretical, substantive, and methodological strengths that enable her to engage in a broad range of teaching and research activities. . . . I feel that I know her very well . . . She had considerable teaching and research experience during her years at the university and since joining the faculty of R University as an assistant professor, where she has added many new courses to her portfolio. She has reported to me many times the very positive teaching evaluations she has received from students.”

“I’ve known Thompson since 1988 when she came here . . . One of her strengths is her level of maturity. During her first couple of years at the university, she seemed to be devoting most of her time to teaching, which she enjoys and apparently does well. She has changed now how she uses her time, so that she has several papers and a book published in the last few years.”

“Of the faculty in our department, Thompson has consistently had the highest student evaluations . . . I am quite familiar with her research publications since we share an interest in her discipline . . . I highly recommend Dr. Thompson to you. She is highly regarded by her students and . . . has a promising research program.”

Unfortunately, Thompson’s experiences as a trainee were largely unsuccessful. She produced no research publications. Her PowerPoint conference presentations were poorly organized and sometimes were almost incoherent. Unlike other trainees, she refused to practice her presentation in a training session prior to her first yearly student conference on the grounds that she was a highly experienced teacher and did not need the practice. Unfortunately, her presentation at the annual conference was dismal. It was by far the worst of over 20 student oral presentations made at a conference in front of an audience of about 80 persons including graduate and postdoctoral students, staff, faculty and representatives of community-based HIV organizations. The low point in her presentation occurred when she presented a slide with a table. The slide was so poorly constructed that it was indecipherable even to those in the first row. Worse yet, she seemed at the time completely unaware that the audience could not comprehend the table and could not understand anything that was said about it. When the Director discussed her presentation with her after the conference was over, she was contrite. She said she appreciated the honest feedback about the weaknesses of her presentation and she acceded to the request that prior to her next conference presentation she should this time give a practice presentation so that she would be better prepared. One year later she did present at a practice session. As was standard
for all trainees, the Director worked with her before and after the practice presentation to improve her slides and her presentation style. The result was a conference presentation that was somewhat better than her previous effort and was judged to be adequate.

Thompson also delayed for several months selecting an HIV scientific mentor until pressured to do so by the Director. She finally selected a mentor. However, she had a very unsuccessful relationship with the mentor, a very prominent HIV behavioral scientist. The problem as described by the mentor was that Thompson kept reporting by email on her progress, but avoided face-to-face meetings and never produced promised drafts of a joint manuscript. The mentor sent the Director an email: “I have been meaning to write you for some time. I am concerned because I haven’t seen Thompson in several months. I have emailed her about her progress and she keeps saying she is busy with presentations and writing. To date, I haven’t seen a draft of her paper based on the data I provided her. Please advise.”

Each year trainees are required to prepare a plan for the forthcoming year of research training. At the end of the year they are asked to evaluate their accomplishments in light of that plan. Thompson summarized her final year in the program by asserting that her goals for publication and training were “exceeded.” However, when she first applied for her postdoctoral position she claimed that she had a book with a respectable publisher dated 2000 that was “in press.” Two years later, at the completion of her postdoctoral training, the same book was still listed as “in press,” but the date was changed. When the Director asked Thompson how she could claim that her expectations had been exceeded when she completed the year with no manuscripts and no publications, she was unable or chose not to respond. Thompson spent two years in the program and did manifest some modest improvement in her ability to communicate with others. However, overall she was unable to work effectively with her fellow students, with the program director, and with her HIV scientific mentors.

Analysis

The Thompson case reveals the possible harm that can result from the gross misrepresentation of a candidate’s qualifications. One recent report cited the reprehensible behavior of a famous scientist who routinely wrote very negative letters of evaluation for his best postdocs so that they would remain in his laboratory for a long time (De Vries, Anderson, & Martinson, 2006). Although Thompson succeeded in obtaining a postdoctoral fellowship, her flawed performance in the program undoubtedly contributed to her inability to obtain a position once she completed the program. Thompson’s CV and supporting faculty letters, viewed as influence attempts, violated the moral principles of autonomy, nonmaleficence, beneficence, and justice/fairness. The documents were disrespectful of the values and concerns of the target. Because they were misleading they were harmful to the training program staff and students. Indeed, the program faculty and students were publicly embarrassed by Thompson’s poor teaching skills. Hence, the welfare of the program’s members was reduced. Still another injustice or unfairness
occurred by appointing Thompson since her appointment meant that a more highly qualified applicant did not receive an appointment.

Some constructive changes did emerge from the Thompson case. One of the positive developments of the Thompson experience was the institution by the program’s leadership of improved trainee selection and evaluation procedures. Selection procedures were improved by the addition of telephone calls to faculty evaluators of the top candidates. The program leadership also decided to institute a Quarterly Evaluation of Trainee Performance Form which consists of an evaluation of each trainee by their HIV scientific mentor(s) every three months. This procedure has helped provide the program leadership with up-to-date information on the process and outcomes of the relationship between the HIV scientific mentor and the trainee.

Evaluative neutrality in CVs and letters of evaluation is fundamentally an ideal rather than a practical standard to be implemented. Injustice and unfairness are often difficult to discern because one’s values impact on perceptions of injustice and unfairness. Also, often there are structural issues associated with the social influence process such as elite control over the agenda, the availability of information, and consequently the manner with which controversial issues are framed. Those with the most power may also be better able than others less well-positioned to give the impression of fairness even when undeserved. Hence, an individual or organization may appear to be neutral, but actually have unnoticed preferences which are demonstrated in subtle and non-obvious ways.

Space limitations preclude a fuller and more comprehensive discussion of letters of reference. For example, it would be useful to examine the potential influence on such letters of lawsuits by terminated employees (such as postdoctoral fellows) against their former employers for failure to provide positive references to subsequent prospective employers (Salter, 2002; Sayko, 2004). Concern over possible defamation lawsuits has apparently led to a practice by some employers of providing only dates of employment, salary, and title (McCord, 1999). The possibility of these lawsuits illustrates the potential tension that may exist between legal realities, on the one hand, and ethical obligations, on the other.

Data Ownership, Acknowledgement of Assistance, and Authorship: A Need for Guidance?

Background

When research is conducted with the financial support of the federal government, the university holds legal title to the data collected and the principal investigator is generally delegated to be the person with ownership rights to their use (Fishbein, 1991). The National Institutes of Health, the largest U.S. supporter of research, and other federal agencies now request that grant applicants propose a plan for data-sharing including a timetable, mode of data-sharing, whether a data-sharing agreement is required, and other issues. Although it appears that the legal issue of data ownership is relatively clear, the case of Mark demonstrates that a
number of students and perhaps faculty as well may be unaware that principal investigators own the data from their projects. In addition, there remain many ethical issues associated with the complex problem of data access, data use, and authorship.

Students in training programs are frequently deeply interested in developing their research careers. The prime method of doing this is through publication, preferably in top peer-reviewed journals. Access to datasets and authorship are obviously important elements in the publication process. Postdoctoral and advanced Ph.D. students also view their position as an opportunity to strengthen their attractiveness in the academic and non-academic market by generating publications. At the same time, a primary index of a training program’s success is effective mentorship. A key index of program research effectiveness is the number of student publication authorships or co-authorships produced under the aegis of the program. Since authorship is so vital to the careers of students and faculty alike, it is not surprising that this ethical area is potentially volatile. We turn next to Mark, a case where data ownership was a significant concern.

The Factual Situation and Ethical Dilemma

Mark was a graduate student research assistant hired to work as a participant observer on a multi-year National Institute of Health (NIH) research project. During the orientation session for the ethnographers and interviewers, the Principal Investigator (PI), who was an HIV scientific mentor in the training program, and the Project Manager explained in detail the nature of the project to the group of graduate research assistants with whom they met weekly over a period of many months to train them in the use of the project protocols and to supervise data collection. Copies of the narrative of the NIH research application were also provided to the students. The issue of data ownership was addressed and it was stressed that all project data, including the observational and interview data, were the property and responsibility of the project and the PI. At the same time, joint authorship and possibly first authorship, was described as a possibility depending on who actually takes the main leadership role with regard to manuscript conceptualization, writing, and other duties. Later, one of the research assistants (not Mark) was granted first authorship on a published project paper. All of the project research assistants including Mark were given co-authorship on a publication that involved, in part, a comparative analysis of the numerous sites that were studied. The NIH study compiled both qualitative and quantitative datasets. To date there have been a dozen peer-reviewed publications produced by the project with most involving current or former graduate students as co-authors. Two students are currently using the project’s quantitative dataset for a Ph.D. thesis and three others are working on manuscripts based on that dataset.

Meanwhile, Mark was taken ill and was unable to continue working on the project. After about two years had passed, April, a postdoctoral trainee working under the PI’s supervision, was asked to prepare an abstract and paper with others based in large part on the observational and interview data collected mostly by
Mark, but processed and analyzed by several others. April planned to submit the abstract and present it at a conference. The PI suggested and April agreed to send the paper abstract to Mark to see if he would be interested in participating in the writing of the manuscript and being a co-author with April, other graduate assistants, the PI, and the Project Director. Mark replied that he would be uncomfortable having his name on the paper because it was in an area in which he had already presented a sole-authored paper at a national conference and he was concerned that there may be a lot of overlap. Mark also insisted that he had obtained the PI’s prior approval to work solely in the conceptual area of the paper and hence to write and present this paper.

The PI was sent a copy of the email. The PI promptly informed Mark that his understanding was incorrect. He reminded Mark (and the Project Director confirmed) that Mark had been informed at the outset of his work as had the other graduate research assistants that the data were the sole property of the NIH project and the PI. Moreover, the PI stated that no agreement was ever made with Mark or with any other research staff member assigning sole rights to any conceptual area. Also, the PI expressed concern that he was not previously informed of Mark’s manuscript or of Mark’s paper presentation at a national meeting based on data from the NIH project. He noted that the NIH project was funded for this work and that all resources, IRB approvals, and permissions to undertake the ethnographies were obtained by the PI. He also requested a copy of the paper. Mark replied by sending a copy of the paper. He apologized for not informing the PI of the paper that was presented one year previously. However, he continued to insist that he received oral consent to produce a single-authored paper and that he had discussed the topic with the PI in advance.

When the PI read Mark’s paper he discovered that the material in it was directly related to the NIH project’s specific aims. Also, he learned that Mark had even failed to acknowledge that the data were collected with the support of the project. The manuscript never mentioned the NIH study, the PI, the Project Director, or the other research staff who contributed to the research. Since Mark had been ill for some time and was in poor health, no other actions were taken other than informing him of the situation as described above,

Analysis

This case illustrates a major communication breakdown regarding data ownership and acknowledgment responsibilities. It suggests that other graduate students may have serious misunderstandings about data ownership. It is likely that a number of students and faculty would benefit by PIs presenting them with written statements that discuss clearly who owns the data, authorship issues, responsibilities with regard to acknowledgement of assistance (including sample wording of acknowledgements), and the need to keep the PI informed of working manuscripts. Such a document could be used as the basis for a comprehensive group discussion of these and other ethical issues and issues of scientific responsibility.
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