

Chapter 14

Community-Academic Partnerships and Social Change

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Abstract Too often, there is a schism between social epidemiologists who train and work in academic institutions to identify the factors influencing health and program planners and policy makers who work in the field as part of government or non-profit organizations to deliver public health services. Program planners and policy makers need academic partners with scientific expertise to help them make sound evidence-based decisions on the broad array of mechanisms affecting health. The complementary potential of collaborations between the discipline of social epidemiology and the real world service implementation experience of program planners and service delivery staff is vast, but this potential can only be realized if the two cease to work in isolation from one another. From a program planner and policy maker perspective, what is needed from the field of social epidemiology are solution-focused research initiatives – investigating an intervention to understand for whom does it make a difference, in what circumstances does it make a difference and in what respects does it make a difference. In becoming familiar with programs over a period of time, during which technical assistance is provided, knowledge is

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gained, trust is built, and social epidemiologists begin to shed the limiting strictures of their formal training. The transfer of knowledge between community and academics becomes unrestricted for the benefit of both parties and for the benefit of the communities whose health problems form their common focus.

Abbreviations

NICHHD National Institute of Child Health and Human Development

14.1 Introduction

Too often, there is a schism between social epidemiologists who train and work in academic institutions to identify the factors influencing health and program planners and policy makers who work in the field as part of government or non-profit organizations to deliver public health services. Program planners and policy makers need academic partners with scientific expertise to help them make sound evidence-based decisions on the broad array of mechanisms affecting health. However, productive community-academic partnerships are too rare in the field of social epidemiology. The purpose of this chapter is to address two questions from the perspective of a community-based health program planner:

1. What kinds of evidence should social epidemiology produce to be of use in community-based practice?
2. What are the relational characteristics of a community-academic partnership that produces actionable evidence for social change?

One of the ongoing frustrations from a policy maker or program planner perspective working within distressed communities to improve health and well-being is that much of health research is focused on describing health problems and associated risk factors in the biomedical tradition; this research does little to inform practice premised on an understanding of health issues that are largely the consequence of socioeconomic and environmental factors. Too often, identified risk factors suffer from their immutable nature (e.g., race viewed as a biological risk factor rather than a social construct) or from a conceptualization of an individual behaviour that pays little regard to the fact that the “problem” behaviour is often significantly influenced by the social and economic parameters of the individual’s life (e.g., poor diet as a risk factor) (Dunn 2010).

The limitations of the predominant biomedical model and the appropriateness of a community-focused approach become apparent (if not clearly established through rigorous scientific methods – a schism discussed more fully below) when viewing the geographic clustering of poor health indices, such as poor pregnancy outcomes and other measures of maternal and child health in areas of Baltimore, Maryland. Many unique factors might be contributing to the observed clustering, and from an

intervention point of view, the clustering presents an opportunity to deliver services in an efficient manner to those who are in greatest apparent need. A community-focused conceptual framework that seeks to account for the observed geographic clustering of poor outcomes would not only look to commonalities among the community's residents but also at community-level factors. At this junction, the factors that have the greatest potential for intervention in a community may emerge. The fact that communities, at least urban communities in the United States, are often racially segregated and are internally homogenous with respect to socioeconomic status suggests that relationships between residents and the larger society must be accounted for in a conceptual framework describing the mechanisms by which the health of a community's residents are influenced. For example, food insecurity is commonly assessed among individuals and households, but if it is determined also to be a community-level factor (i.e., a factor prevalent across households within a given community determined by a community's disadvantaged geographic, economic or political relationship to the larger society), then possible interventions take on a different shape and scope.

At the other end of the spectrum from approaches that rely on individual characteristics described in biomedical terms, analyses and the resulting prescriptions that would require wholesale change to a society's political and economic systems to address inequities in health are not very helpful in improving the lives of people in the short-term. Such changes in political and economic systems are rare and, to the extent that they do occur, are generally long-term projects and often quite incremental in nature, especially in the United States. Public health and social service practitioners work, and the residents of impoverished communities which suffer the worst health live, in the middle ground where individual biology and behaviour interact with and are influenced by social, environmental and economic structures. It is here that social epidemiology can be most useful in contributing to perspectives, which not only describe health problems but reveal paths to amelioration.

Throughout this chapter I draw upon my experience and that of colleagues, notably Maxine Reed-Vance and Julia Hayman-Hamilton of the Baltimore Healthy Start program, who worked together with Patricia O'Campo in Baltimore. This working relationship was a partnership between a service delivery program and an academic researcher.

The Baltimore Healthy Start program, an infant mortality reduction program in which the American federal government provided funding directly to local communities, began in 1993 as a demonstration project to develop promising approaches to reduce infant mortality. During the development of the Baltimore Project, the predecessor and model program to the Baltimore Healthy Start initiative, the Baltimore City Health Department was fortunate to have technical assistance from the National Institute of Child Health and Human Development (NICHD). Dr. Heinz Berendes, a senior researcher at NICHD, suggested that in order to measure the success of the Baltimore Project it would be critical to create defined geographic areas from which to recruit clients and to establish a goal of high recruitment rates of pregnant women. This approach would ensure that the population served by the project would be representative of the population in the target geographic area. Dr. Berendes explained

that most infant mortality reduction programs of the past had achieved penetration rates of less than 50%. Most programs served large catchment areas, making it impossible to determine if apparent program successes, if any, resulted simply from participation of the most motivated or easiest to find women.

This advice to set high recruitment goals within a defined geographic area was applied in the Baltimore Project in 1990 and then carried forward with Baltimore Healthy Start in 1993. Effective recruitment of the eligible population to participate in Healthy Start was critical, both in terms of assessing whether any benefits from Healthy Start participation were actual benefits opposed to an artefact of selection bias and in terms of demonstrating the program's effectiveness for high risk as well as relatively low risk populations and, consequently, its effectiveness in terms of reducing perinatal health disparities for the geographic project area as a whole.

Since the project area communities at large suffered from high rates of poor pregnancy outcomes and since no reliable one-time risk assessment instrument existed that would lead the program to confidently exclude "low risk" women from services, the program attempted to enrol as many women as possible and employed ongoing early identification of risk factors as they emerged as a fundamental strategy to have an impact on community-wide measures. In practice, depending on funding over the years, the enrolment rate ranged from 60% to over 80% of all pregnant women in the community.

An example of the limitations of an individual risk factor approach to targeted interventions is the recommended use of scientifically-validated risk assessments to determine eligibility for, and level and intensity of, case management services that a pregnant woman should receive in order to achieve the program's goal of reducing the incidence of poor pregnancy outcomes. One-time risk assessments at program enrolment, beyond identifying women with a history of prior fetal or infant loss, are poor predictors of subsequent circumstances that could negatively affect pregnancy outcomes, such as eviction or other forms of housing instability or emerging symptoms of preterm labour among women with no history of preterm labour. As a result, the approach taken by Baltimore Healthy Start was to provide case management services with the premise that all clients are potentially high risk in order to be in position to assist with and, if possible, prevent such events. This approach was seen in both the minimum contact standard of bi-weekly contact and monthly home visits and the repeated home visit checklist assessments that were employed, which focused on signs and symptoms of preterm labour, changes in interpersonal relationships and social support and changes in personal economic situation. Many of the circumstances that might have a significant effect on the life of a pregnant woman and influence the course of her pregnancy cannot be reliably predicted for an individual woman at the pregnancy's outset. It was the prevalence of these "hard to predict" destabilizing events, which affected the lives of individuals in certain communities, that led to the intervention design of not excluding women from services on the basis of an assessed one-time, "low risk" status.

The above is an example of a situation where the academic-community partnership provided mutual intellectual and experiential support. The understanding of the limited utility of risk assessments from past research along with the statistical

challenge inherent in reliably predicting rare events, coupled with community experience of the often changing circumstances and rapidly emergent stressors in the lives of women, led the academic and community partners to use their shared knowledge to reach a common conclusion. The resulting conceptualization, which recognized environmental and community-level factors, removed interventions from a clinical setting and placed them in a community setting. It recognized community-based interventions working in tandem with formal clinical systems of care as an integral facet of effective clinical care for many marginalized populations. The approach of prioritizing high enrolment rates within the community and employing regular home-based monitoring of emerging needs and perinatal health along with a community-based centre, which allowed women to avail themselves of services when they determined that they need assistance outside of the program-prescribed schedule of home visits (i.e., exercising autonomy with regard to their health and well-being), evolved not from formal research but from program experience.

Originally conceived as a social support and health education program, early program experience led Baltimore Healthy Start case managers to realize that emerging clinical issues, particularly regarding preterm labour, demanded an immediate and coordinated clinical response. The fact that clinical prenatal care services were available to the community from a geographic and health care coverage (i.e., Medicaid) perspective did not obviate the need for a proactive systematic schedule of home-based assessments to identify signs and symptoms of preterm labour. Incorporating such assessments into the regular schedule of home visits – which occurred more often than regular clinical prenatal care visits and were followed by internal nurse review and immediate medical referral for stabilization as indicated – became a key enhancement of the original social support program model. This recognition of the need to coordinate clinical practice with community-based, social support-oriented home visits illustrates the intersectoral nature of both the health problems and the effective means to address those problems. The reason that a program such as Baltimore Healthy Start has a role in making clinical care more effective is the manner in which it compensated for the deficits in other sectors, such as income inequity, poor public transportation, lack of affordable child care, poor education and all the other areas by which poor pregnant women face stressors and demands that both directly contribute to clinical risk and that take their time, focus and energy away from their health and pregnancy. The role of Baltimore Healthy Start in the communities it served is largely one of being a liaison between the community and formal systems of care.

Our academic partners respected what was learned by Baltimore Healthy Start's service providers in the course of providing services, and our service model was adjusted and enhanced in light of this experience. However, the task of evaluating the program and determining which program components contributed to the outcomes of interest was complicated. The dynamic nature of a service demonstration project potentially offered a number of conflicts with an academic researcher trained to control as many variables as possible in order to isolate and discover truth. However, to conduct such analyses entails imposing artificial restrictions on practitioners

who are striving to learn from their experiences and apply the lessons that those experiences bring. Rather than stand in the way of these changes, which made their job of evaluation more difficult, program staff were instead buttressed by new data collection procedures that were introduced with the assistance of our academic partners..

14.2 The Role of Social Epidemiologists

Social epidemiologists have the rigorous scientific training for assessing needs and measuring effectiveness of interventions that program planners usually lack. The complementary potential of collaborations between the discipline of social epidemiology and the real world service implementation experience of program planners and service delivery staff is vast, but this potential can only be realized if the two cease to work in isolation from one another.

Of the valuable functions social epidemiologists can offer to the field is movement away from further *describing* the problem of poor health toward *action* to ameliorate the problems of poor health. These functions are rooted in social epidemiologists' research training and experience to: (1) assist community-based programs to develop the tools and institutional capacity to monitor programmatic processes and outcomes, thus enabling programs to identify and promptly address the deficits in their program design and effectively meet the needs of communities they serve; and (2) test, validate and refine the programmatic responses.

With regard to technical capacity to monitor programmatic processes and outcomes, input from social epidemiologists in the development of a data collection system, which serves multiple purposes and constituencies, is key. A number of major purposes each with their respective constituencies must be served by a single data collection system. First, case management staff needs ready access to individual client characteristics and service utilization data to inform and monitor adherence to individual client care plans. Second, supervisory staff needs individual and caseload aggregate client tracking and service utilization data to monitor adherence to program protocol by supervised staff. Third, program planners need aggregate process and outcome data to report progress on goals and objectives to funders. Fourth, program planners and direct service staff need process and outcome data sorted by various client characteristics to understand varying levels of program participation and for whom an intervention makes a difference with respect to outcomes. Finally, independent evaluators need individual-level data across client characteristics and service utilization to conduct more rigorous analyses.

In the case of Baltimore Healthy Start, the development of the Client Tracking System, which served all of the above noted purposes and constituencies, originated from the needs of a social epidemiologist charged with conducting the local independent evaluation. However, unlike in many such scenarios, Patricia O'Campo recognized that the data collection system that she needed for program evaluation also could serve as the data collection system that program planners and operational

staff needed to effectively monitor and operate the program. In a very simple and elegant conceptualization of the challenges in collecting quality data, the data collection system development process ensured the participation of the people who would be collecting the data (i.e., the direct service staff). Rather than have a set of data collection requirements imposed on them from an outside entity, the direct service staff, upon whom everyone depended for quality data, determined to a large extent which data the system would collect as a result of what they needed the system to report in order to do their jobs.

Capacity in data management extends beyond the design of the original data system, data collection forms and reports, and should include the capacity to continually modify and improve these systems. This flexibility is necessary to ensure the forms and reports maintain their utility for all parties involved and is fundamental for direct service staff who collect the data. Thus, capacity is not only the hardware and software of a data system, but it is also the human resource capacity to modify and improve the software.

Once this technical capacity is established, ongoing collaboration between social epidemiologists and program staff is needed. This approach might pose challenges to the ideal of scientific objectivity, which is a part of the culture and training of social epidemiologists, but then this whole chapter is intended to be such a challenge (Box 14.1).

Box 14.1

Peter Schafer asked Patricia (Pat) O'Campo to address many of the issues raised in this chapter from her perspective as a social epidemiologist. Excerpts from their conversation follow:

Peter: "You had the evaluation contract for Baltimore Healthy Start, but, unlike a typical scenario where the evaluator came in and imposed a bunch of data collection requirements on a pre-existing operational protocol, you helped to design a system and create the technical capacity within the organization to monitor itself from a very early stage."

Pat: "I think that was a unique feature – that we were all starting together. We were all learning about what we had to collect. Recall that, from a very mainstream perspective, we had this so-called 'minimum data set' required by the federal government. Many of the elements were not useful at all, but because they were required and because the only people who could collect them would be the case managers and outreach workers, they were forced to get involved. In other words, they wouldn't have a future if they didn't collect those data because if you didn't collect the minimum data set then you wouldn't have a program."

(continued)

Box 14.1 (continued)

Peter: “Yeah, the minimum data set was an externally imposed requirement by the national evaluators, not locally generated, and therefore a requirement of the program’s federal funding.”

Pat: “That’s right. So direct service staff got involved in the data collection process. They were in a way forced to participate in research, maybe not in an ideal way, but they were forced to think about the ways in which they collect data and how it could be used for science. They asked a lot of really good questions about the validity of some of the data elements that were in this minimum data set, which we all knew had nothing to do with giving better services to the client. I knew from a scientific perspective that, for example, knowing whether somebody had a tuberculosis test or not was probably not going to make a difference to infant mortality, but feeling like we were all part of a team in shaping the data collection system and commenting on the data elements that we were forced to reply to, I think, helped to empower the local evaluators to give feedback to the national evaluators about the problems with many of the required items. And I think that because there was a view that I was a bit of an open researcher, I wasn’t put in the same category as the national evaluators.”

Peter: “Well, this is really important here. I want to pursue this. It’s important because in terms of the interpersonal dynamics, and the baggage that certain people bring, such as an academic outside evaluator who is naturally seen as someone who is looking – I mean, this is the way it is in programs – an outside evaluator is someone who is looking to find something wrong, things to criticize. But the fact that you were similarly critical and frustrated with the apparent irrelevance of a lot of these national evaluation requirements, which did not conform with what the Baltimore Healthy Start program was about, I think, did a lot to help people view you not as this outside threatening person but as someone who was understanding, and that’s important. I mean, this happened in Baltimore and you were from Johns Hopkins...”

Pat: “...which is bad...”

Peter: “...which is a bad thing. [Laughter] I mean, you know?”

Pat: “From the community perspective...”

Peter: “From the community perspective, Johns Hopkins is a bad thing. They [Johns Hopkins] just want to do research on black people and are not really concerned...”

Pat: “...negatively label them...”

Peter: “Negatively label them, and just find out all the things that are wrong with them and blame them for their problems. That’s basically the perception, and there are good reasons that that is a perception.”

(continued)

Box 14.1 (continued)

Pat: “Having those discussions about whether these data elements were relevant, useful or irrelevant and having the discussions with the staff I think helped engage them in kind of a critical look at research as well so they could then understand that, gee, there are choices here: we could have good research that helps us or we could have not good research that doesn’t. And I think it empowered them to comment further on some of the data elements that we ended up liking and retaining going forward.”

14.3 Orienting Research to Address the Needs of Public Health Practice

From a program planner and policy maker perspective, what is needed from the field of social epidemiology are solution-focused research initiatives – investigating an intervention to understand for whom does it make a difference, in what circumstances does it make a difference and in what respects does it make a difference.

Multisector programs require multidisciplinary epidemiologic approaches that measure impact across all the areas that a given program aims to affect. In other words, useful social epidemiology does not restrict itself to looking solely at health outcomes; it also considers outcomes in areas such as housing insofar as housing is recognized as a significant factor affecting health. Already, mental health, particularly depression, and substance use are recognized as factors affecting maternal and child health directly, as typically measured, and influencing health care utilization. However, the factors that influence mental health and substance use, like social isolation, community and family violence and unsafe and unstable housing, are generally not examined.

Programs need timely, actionable evidence that provides explications of the underlying mechanisms affecting both program outputs and health outcomes. What programs often need is corroborating evidence to anecdotal observations of changes and new trends, or evidence of changes and new trends absent of any anecdotal observations, so that the programs can respond appropriately and with confidence. The evidence does not need to meet the traditional standards of “evidence” in peer-reviewed scientific journals – it simply has to be “good enough,” which is a variable concept dependent upon a variety of factors, including the costs and feasibility of possible interventions and the nature of the leadership within a community organization (Box 14.2).

The type of evidence that is most valuable to programs is information that suggests an enhancement of services or an improved way of delivering services. Community direct service programs are all about doing something about a problem, so further dissections of a problem, which have no practical impact in the realm of

Box 14.2

Peter: “I know that you were frustrated with the reception in the scientific community received by your analysis of the Baltimore Healthy Start program, which was not based on a randomized clinical model. Then you talked among your colleagues and said, okay, if that’s not going to be accepted then at least the contribution that can come from this, from this experience, is in methods. You were developing new innovative methods to deal with this problem, this predicament, of not wanting to distort the program by applying the standard randomized assignment approach. Instead you applied other scientifically valid methods to evaluate the effectiveness of the program. But even that wasn’t well received. So I want you to talk a little bit about, I guess from your perspective as a young professional at that time, how this wasn’t paying off in terms of how, I think, an academic young professional would expect it to pay off. You weren’t getting stuff published from this, yet you persisted in it. Can you talk about how you dealt with that?”

Pat: “Sure. You make it sound, Peter, like I got the raw end of the deal and that I had to compromise a lot. You’re alluding to the fact that I got very few publications from our almost decade long, at that point in time, collaboration. We still collaborate now, which means something, it says something about the partnership. Those markers are often viewed – and I am sorry – maybe they are the only things that are important when you are thinking about promotion, that is, the number of publications. So, it’s true, I didn’t have a lot of publications to show for all of the work that I did. Healthy Start would take up about 35% of my time, more than a day a week of time, and even a day a week is a lot for a project to take up for me to get, you know, two publications [Laughter]. But I think one thing that is again not talked about in academic training is that what I got out of that partnership was not only good partners to do transdisciplinary research right – and not just social epidemiology research but transdisciplinary research – I also learned what the real priorities of the community were, and I could then go on to have that perspective impact the research that I did afterwards. If I just sat in my office and I looked at the existing literature and I said ‘Hmm, what are the problems facing inner city populations?’ and if I relied solely on what other researchers who came before me had written about, I would be way off, right?”

“So, what I learned was what’s written in the literature is very far away from what’s actually going on in a community like that, one of the highest risk communities in Baltimore. I learned that approaches that are often talked about in the literature for how to address those issues are way off, so it opened my eyes. I also gained important information about the limitations of, again, the standard measures that are used to measure risk or resilience

(continued)

Box 14.2 (continued)

in a population. So it totally affected my whole research career going forward, and so I rarely ever do research without doing partnerships now because I know that if I rely again on what other mainstream epidemiologists do I would not be helping the population. I would not be characterizing them correctly. I would be wrong and I didn't want to be wrong. So, it's true I didn't gain publications *per se*, but I did gain a new perspective and a new approach to doing research.

"That experience affected the rest of my career. I feel like I am doing better research than I ever did, and I am also about to get more publications out of this new research [Laughter] because I am also smarter about how to do that. I wasn't as smart when we first did CBPR [Community-Based Participatory Research]. I don't know if it was a matter of being inexperienced. I don't know if it was a matter of the timing. But when we did CBPR, it was not widely recognized, so neither were we necessarily encouraged to write about our experiences nor was there any place to publish it even if I did write about our experiences. So if a young person is starting out now, even if they can't get as many publications as they like, I still think it's a worthwhile experience because you learn to do research in a way that is not taught to you when you go to a place like Johns Hopkins for training. The only way I have a chance of improving health in inner city Baltimore with the evidence that I generate is to partner with the community."

Peter: "That's encouraging because I feel bad. The way I am writing this it sounds like I am asking the social epidemiologists to give up a lot, so it's good to hear that."

Pat: "We gain a lot."

service delivery at either the operational or strategic (or political or advocacy) level, are not particularly valued.

Such an example of a programmatic intervention based on internal monitoring evidence is the Family Planning Nurse Practitioner component added to the Baltimore Healthy Start case management model. Family planning interconceptional care services – which includes family planning education, individualized counseling and home- and community centre-based contraceptive method prescriptions and method dispensing in accordance with the client's education, employment and family size goals – have been provided to West Baltimore Healthy Start postpartum clients by a certified registered nurse practitioner, who has been fully integrated into Healthy Start case management operations, since 2004.

The intervention was initiated in response to an alarming increase, sustained over 3 years, in the rate of short inter-pregnancy intervals (i.e., <12 months from

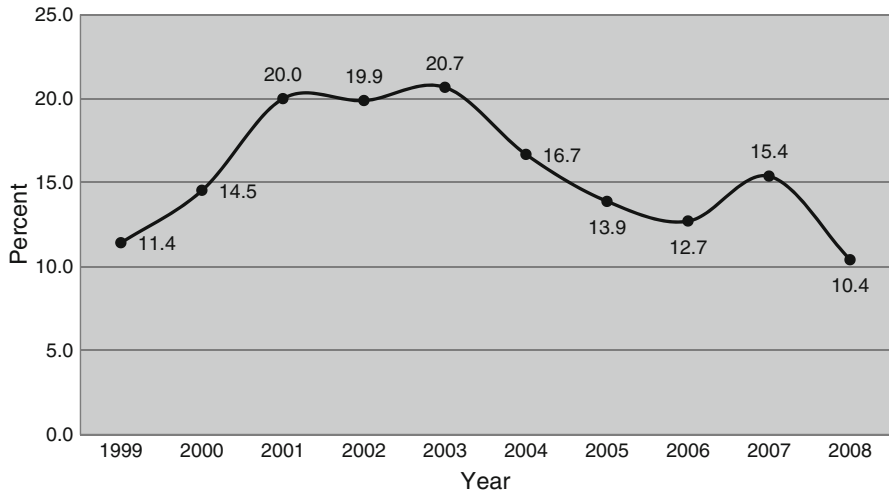


Fig. 14.1 Percent of Baltimore Healthy Start pregnancies with an inter-pregnancy interval of <12 months among clients whose prior pregnancy resulted in a live birth

prior delivery to subsequent conception) among Healthy Start clients in the West Baltimore project area. While internal tracking statistics strongly suggested the extent of the intervention’s effectiveness (Fig. 14.1), it also showed that there were still a significant number of pregnant women who continued to have births within short inter-pregnancy intervals.

Those who worked in the program generally believed that some Healthy Start program services, such as the individualized family planning counselling and contraceptive method dispensing included in the intervention, while designed to be effective among all clients, were in actual practice more readily adopted and utilized by the relatively more stable clients (e.g., non-substance users). The result of this practice was that only those relatively low risk pregnancies were being prevented through the intervention, leaving higher risk births to represent a higher proportion of all births. The implication of this underlying phenomena occurred not only at the operational level where direct service staff worked to meet the needs of the clients they served but also at the level of policy and program evaluation where multi-year trends were often analyzed without the benefit of insight that program operational staff (i.e., the community) can provide.

Naturally, funders of programs are very interested in the efficacy of their efforts and dollars spent in improving community-wide health status. How is the effect of a programmatic intervention to be evaluated on the basis of community-wide data without these kinds of underlying influences explicated? The effect of Healthy Start services, in particular the Family Planning Nurse Practitioner intervention, may have had a direct effect on the risk profile of the remaining births as a result because it succeeded in significantly reducing the rate of short inter-pregnancy interval births. In this case, when looking at aggregate statistics at the community level as a

measure of program impact, relying on rates of poor outcomes is inadequate because the total number of births may be reduced as a result of the program, and this reduction may have occurred unevenly in terms of the risk status of women. That social epidemiologists have the training and interest to delve into these issues in order to fully understand the underlying dynamics to community-wide health statistics, including the effect of program interventions, is an important contribution to the work of program planners, policy makers and funders.

14.4 Collaboration Between Social Epidemiologists and Program Planners and Policy Makers

The barriers to productive relationships between social epidemiologists and direct service providers often originate in a clash of cultures but not necessarily of values (see Chap. 3). Addressing the culture clash directly, from a common set of values, is the first step toward establishing a transparent and productive relationship. As in many cross-cultural relationships, addressing cultural issues often constitutes a challenge to norms and practices and contributes to the misunderstanding of peers operating under the traditional parameters.

Community-based service programs are often interested in a number of research questions that derive from their experience, with internal monitoring of services and health outcomes providing a focus for those questions. However, programs face an ethical problem in testing programmatic interventions by rigorous scientific methods in that those approaches generally require denying available services to a segment of the population served (i.e., the control group). This approach runs counter to the mission of a community-based organization dedicated to serving its target population. When internal monitoring evidence suggests that a new intervention is effective, a program's natural response is to make it available to all program participants as soon as possible in order to be consistent with its mission to serve.

Resolving the conflict between rigorous scientific research methods (e.g., random assignment to treatment and control groups) and ethical and effective community-based service delivery is, perhaps, the most challenging barrier to collaboration and represents a fundamental difference in cultures between the direct service and scientific research communities. From the point of view of a community-based direct services program, the artificial conditions imposed upon community-based services in order to meet the standards of peer-reviewed research – for example, requiring random assignment of pregnant women into services and not allowing *all* pregnant women to enrol into services in a community when that very practice is integral to the trust built between program and community and, therefore, may be integral to the success of the program – are conditions that act to distort the intervention purportedly being investigated (Box 14.3).

Instead of randomized controlled trials (RCTs), Baltimore Healthy Start relied on evidence generated from “natural experiments,” which were generally the product of funding constraints, in order to assess the effectiveness of new intervention designs.

Box 14.3

Peter: “I raise in the chapter the idea of a culture clash between social epidemiologists on one side and program planners and policy makers on the other. What has to happen in order for there to be useful collaboration between the social epidemiologists trained in the academic traditions and program planners out there working in the field?”

Pat: “I think the culture clash stems from the fact that program planners and scientists have very different goals in mind. The scientists’ goals and objectives will be to produce work that is scientifically rigorous, and the program planners are interested in evidence that enables them to do their job better and essentially have a successful program. But the two objectives are different, and so the scientists and the program planners are not necessarily working toward the same objectives, and I think that leads to a clash. Some of the culture clash comes from different use of language, but I think the root cause is that they have different objectives.

“The way in which I handled that in our partnership is that, I guess, I kind of threw away what I was trained to prioritize. I was trained to prioritize rigour and methodological aspects toward doing research, and I adopted the goal of trying to ensure that the program was the best program. So my role became to generate evidence, whether it’s existing evidence from the literature or trying to ensure that there were good data collection systems as part of the program. But the priorities of all of those activities were consistent with the program planners. It doesn’t mean there was perfect alignment, but I did not prioritize scientific rigour.

“The other thing I wanted to say about that is that I believe that training of scientists could take place in a different way to minimize the culture clash you mentioned. Too often the way in which social epidemiologists and epidemiologists are trained is with an emphasis on method, but the context is not mentioned when the method is taught, and epidemiologists aren’t trained to understand that methods should be adapted to the context in which they’re being applied. So, in a community partnership that is trying to do an evaluation, the methods might be different or modified from how they would do an evaluation, say, in a clinical context where there is a lot more control over both the intervention and the circumstances in which the intervention is being administered. In a community context, especially one that involves home visits like Healthy Start, the context in which you’re administering interventions is going to vary. It could be at the centre, it could be on the street corner, it could be in the house.”

Peter: “And every house is different...”

Pat: “And every house is different and so you don’t have much control over the environment and things that affect the delivery of the intervention. So the fact that methods are often taught without regard to context is really problematic, and it means then that epidemiologists tend to be rigid and inflexible about their methods. They are not encouraged to innovate or adapt to this kind of environment, and I think that contributes to the culture clash.”

Such was the case with the Family Planning Nurse Practitioner intervention discussed above, which was introduced in the West Baltimore Healthy Start Project Area in response to a huge upsurge in short inter-pregnancy interval births in West Baltimore. As the intervention was introduced and significant reductions in short inter-pregnancy interval births occurred in West Baltimore, the East Baltimore rates were monitored and remained moderate throughout. Funding priorities were adjusted, and the services were expanded to East Baltimore acting on the evidence of the effectiveness of this new home visit component. While Baltimore Healthy Start would have liked to subject that intervention to rigorous scientific methods to firmly establish its effectiveness, it could not ethically deny services to any subgroup currently not being served if it believed those services were effective. Here is an example, perhaps, of the level of evidence that a program finds sufficient (i.e., internal monitoring of inter-pregnancy interval rates among clients who re-enrol with a subsequent pregnancy) being quite different from what an academic and academic journals would consider adequate evidence of an intervention's effectiveness.

In the future, Baltimore Healthy Start might choose to expand services into new project areas in a limited fashion (e.g., without the Family Planning Nurse intervention) in accordance with funding limitations. Of course, this approach does not utilize random assignment within a community. As alluded to above, programs have concerns that the standard method of scientific research distorts the program purportedly under study by undermining the integral component of trust between the community resident and the program and prefers comparisons of varying services' availability to be conducted between communities rather than within communities. The scientific community views this approach as far from ideal because of the presumed differences between the communities involved. However, this presumption is buttressed by a fallacy derived from aggregate statistics of communities that overlooks the heterogeneity that exists in all communities and that overstates the differences between communities. It is the methodological challenge to the research community to develop scientifically rigorous approaches that do not distort the programmatic intervention being studied, and the failure of the research community to meet the challenge with regard to the design of many community-based programs, that is a potentially fatal obstacle to community-academic collaboration.

Case studies are a promising avenue with which to introduce scientific rigour into how programs often view the evidence available to them, including both qualitative and quantitative experiential evidence. Recent advances in case study methodology designed to address its weaknesses are promising in their potential to bridge the gap between clinically-derived methods, which are best suited to uncomplicated regimented interventions, and methods that embrace and fully account for program complexity as well as those that respect and do not distort the reality of community-based interventions (Yin 2009).

Communities are complex, open systems that are subject to change. This fact needs to be accepted when designing research and accepted and accounted for in analyses of data that will likely result in statistical strength at a lower level than the "gold standard" of biomedical research. In other words, researchers and academic

institutions interested in conducting meaningful research that provides evidence to service programs as to which interventions are effective, and why and for whom they are effective, need to reject the biomedical research paradigm. Rather than considering this paradigm as the method by which “truth” is revealed, researchers should consider it to possibly be either not applicable or not useful. In many circumstances, in fact, biomedical research paradigms are the methods by which the “truth” is obscured or overlooked.

With regard to the non-generalizability of results, another oft-cited weakness of non-RCT study design (e.g., case studies, natural experiments or other forms of quasi-experimental design), experience in program planning suggests that the purported generalizability of results from an RCT approach may be illusory. Since the results of an RCT approach derive from a study design that seeks to isolate, through both actual and statistical means, an intervention from the various multisectoral influences that affect the individual lives and communities of the population studied, and through those mechanisms have an impact on the outcome of interest, the real world validity and value of the results need to be scrutinized. Multisectoral influences need to be explicated and understood, not isolated away and controlled for, because in the real world they cannot be set aside. Research based on case studies, natural experiments or other forms of quasi-experimental design might offer conclusions not as statistically strong or methodologically sound as the biomedical tradition, as with an RCT approach, but they may get closer to the truth in that they more fully embrace the real world complexity in which multiple sectors interact on multiple levels to affect health.

The role of differing cultures and career and economic imperatives of the academic and community partners need to be discussed candidly so that conflicts can be addressed openly and strategies jointly developed and pursued that meet both the needs of the social epidemiologist and the program. A fruitful research approach for program planners and policy makers is one that sheds light on the interactions of the multisector influences on a health issue and on possible interventions to address the health issue. One way for social epidemiologists to be informed of these influences is to learn directly from the affected individuals and communities.

14.5 Community Participation in Research

Complementing the social epidemiologist, who reorients research in order to conduct investigations that bridge problem-focused and solution-focused research, are community direct service providers and community residents who take an active role in initiating and shaping research. While many researchers recognize the value of community participation in research implementation – for example, by increasing recruitment and retention rates, reducing reporting bias and reducing measurement error from survey and interview questions that are not culturally aligned with study participants (Cargo and Mercer 2008) – there is less recognition within research institutions of the value of community participation in shaping the purpose and

scope of research. Underlying the principles and processes of Community-Based Participatory Research (CBPR) is an implicit recognition that the community context of research has a meaning beyond the setting in which research occurs to also include the community in which the research is designed and conducted (i.e., the community of researchers). To the extent that the community of researchers includes members of the communities that are researched, higher quality and more relevant research will result. A large body of evidence demonstrates that “insider knowledge can enrich academic partners’ understandings of the needs, priorities and health concerns of communities, organizations and the public health system and lead to refined and new research questions” and “[e]ngaging with nonacademic partners in shaping the research purpose has the advantage of enhancing contextual readiness for research implementation” (Cargo and Mercer 2008).

Gaining the value of “insider knowledge” through basing and structuring the research process on an equal and collaborative process between community and academic partners, and simultaneously building research capacity within communities typically studied, is a hallmark principle of CBPR. One example of “insider knowledge” might be a greater appreciation of within group differences, opposed to a focus on racial disparities, as the endpoint of investigation and analysis. Community members, and those who work in communities delivering services, are exposed each day to the great heterogeneity among class and racial groups, and it is this heterogeneity that might suggest fruitful areas for solution-focused research (as opposed to reducing a complex system to an oversimplified “racial disparity” in health status). Community participation in research will not only provide the motivation to explore solution-focused research but will also provide insights into how to discover the mechanisms underlying potential solutions (Box 14.4).

Box 14.4

Pat: “I want to add to what you said earlier, because in my opinion Baltimore Healthy Start was more than a cultural liaison. Healthy Start, although it started out in the precursor program going out into the community and telling pregnant women ‘You need to get to prenatal care. Let’s go!’ women often didn’t go. Why? Because the program wasn’t addressing their top priorities. So the program had to learn that in order to engage this population they had to first address the top priorities of the women. Then there was not only a level of trust built, but also the case managers could give advice and have their clients be responsive to the advice given, some of the advice being that you should go to prenatal care. That enabled the staff to act as cultural liaisons, and I think that’s a really important point to make.”

(continued)

Box 14.4 (continued)

Peter: “Again I think that’s where there is an analogy. The analogy is the program staff wasn’t just telling clients that they needed to get to prenatal care, and you weren’t telling program staff that they needed to collect this data for the evaluation. You listened to their needs first, just like the program listened to the women’s needs first. A real signature aspect of the Baltimore Healthy Start Program is this thing we call emergency needs, and it’s assessed at the beginning, at recruitment, through door-to-door outreach. What are those families’ emergency needs, in terms of food, in terms of clothing, in terms of shelter, that is, Are they in danger of being evicted? How stable is their housing situation? What type of assistance do they need now? It was recognized that prenatal care and a healthy pregnancy outcome are the program’s priorities and not necessarily priorities shared by a woman who’s got a lot of other more pressing issues confronting her. And similarly, from a social epidemiologist’s point of view, the priorities of finding the ‘truth’ by following this rigorous scientific method are not the priorities of the program.”

Pat: “Yes, so, yes! You read my mind [Laughter]. So I set that up because I was going to say that I think in many ways we can identify commonalities – common interests that the program staff has and that someone like me who has training and privilege and all of that has. As I mentioned before, I had to kind of give up my priorities and adopt the priorities – or at least be on board with the priorities – of the program itself, and then, having done that, we had much more in common. The program staff and I, no matter what colour, no matter what class, no matter what training, no matter what background, had much more in common, and we could move forward together. We could find our common ground, and I think that’s really what it boils down to. So to me that suggests, too, that what we identify superficially as racial differences, you know...I think those can kind of disappear if you can identify common ground to work on, and common goals to work toward, and then I think then those other more superficial barriers can just break down.”

Peter: “It reminds me of another important point in order to realize that potential, and that is the relationship be an ongoing relationship over time, which includes continuity of partnership and technical assistance. Because part of the presumption about academic researchers is that they’re self serving. They just want to publish something. They want to do some research and just publish. They swoop in, get out and are never to be heard from again. You get written about somewhere in some journal that you don’t even know about it until you hear someone talk about it later on, about all the

(continued)

Box 14.4 (continued)

bad stuff that was written about you. I mean that's kind of... that's sort of the...[Laughter]"

Pat: "...That's the model."

Peter: "That's the model. So there's this other aspect of what you just said that for it to really work it does require a long term relationship, a long term interest, and I think that that's consistent with an interest of an academic researcher and their career because I mean they invest so much in this project initially upfront that they would hope to – and it's reasonable that they would to be able to – gain something from an intellectual perspective, from a career perspective, from an ongoing relationship. So much of this is interpersonal relationships, interpersonal trust, and breaking down presumptions about where people are coming from and what their priorities are."

14.6 Conclusions

A fruitful partnership between academic social epidemiologists and community-based direct service programs requires a long-term investment in the relationship by both parties. Early and ongoing collaboration can take many forms, including conducting an assessment of a community's needs and strengths as well as its deficits and sources of resilience and community member views of the health problem targeted. It can also include technical assistance, for example, in building a data collection and reporting system that serves client case management, program monitoring and evaluation purposes (and one that also builds capacity in community-based organizations to effectively monitor emerging needs and changing trends and to respond accordingly in a timely manner with appropriate service initiatives). As the partnership collaboratively designs intervention research according to CBPR principles, the social epidemiologist needs to bring a flexible methodological approach that respects the service mission of service delivery programs. Interpretation of findings and involvement in the development of program modifications and enhancements is an area where the benefits of familiarity with a program and with the individuals who operate the program are substantial. In becoming familiar with programs over a period of time, during which time technical assistance is provided, knowledge is gained, trust is built, and social epidemiologists shed the limiting strictures of their formal training. The transfer of knowledge between community and academics becomes unrestricted for the benefit of both parties and for the benefit of the communities whose health problems form their common focus.

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