Health Activism, Participatory Action Research and Cancer Prevention and Control Services in Three Eastern Kentucky Area Development Districts

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Introduction

Cancer prevention and control research represents a significant arena where social inequalities have an inter-relationship with culture and personal responsibility. The prevalence of social inequity in healthcare indicates that there are barriers making it difficult for certain populations of persons to receive the care they need. Though policy solutions and outreach are common methods used to address inequality and the barriers that sustain it, this paper focuses on other means through which groups make themselves heard. Health activism (Zoller, 2005), whether promoted as part of community development projects or through social movement activity, is an alternative means groups use to assure their needs and grievances are heard. The purpose of this paper was to conceptualize health activism as an area of research and examine how that conceptualization might be applied to cancer prevention and control research three area development districts in eastern Kentucky. I also seek to examine how different mobilization potentials in various communities might affect efforts to implement a community-based participatory mapping project designed to support cancer prevention and control efforts in the same area development districts.

Brown and Zavestoski (2004) say that a central reason for the emergence of health social movements in the past decade or so is that science and technocratic decision-making have become increasingly dominant in shaping social policy and regulation. The increased use of science and expert opinion has come to exert control over debates regarding costs, benefits, and potential risks of new technologies and industrial

production as scientific experts work to ensure that battles over policy-making remain scientific, 'objective' and effectively separated from the social milieu in which issues unfold. Habermas (1987; 1989; 1996) has discussed this issue in terms of 'decline of the public sphere' whereby, "What was once an exemplary forum of rational-critical debate became just another domain of cultural consumption, and the bourgeois public sphere collapsed into a sham world of image creation and opinion management in which the diffusion of media products is in the service of vested interests (Thompson, 1993, p. 178)". Mayhew (1997) has gone as far to argue that the institutions providing forums for good-faith, two-way discourse no longer exist as professional specialists, using market research and promotional campaigns, have come to dominate public communication.

In the first section I want to make some distinctions between health activism and health advocacy. Such a distinction is significant because it distinguishes between attempts to work within current health systems, which rely on expert knowledge and the dominance of commodified service forms, to advocate for limited, system-defined health benefits for *at-risk* or other *deserving* populations and activism led by those outside existing power arrangements who define their own health needs. I also want to make a distinction between health activism that arises as part of or in reaction to community development efforts and social movement activism. This distinction helps clarify the context under which health activism arises, and, as a result helps us to clarify the nature of the public and private spheres as well as the intermediate domain of civil society. In particular, I want to make concrete the notions of an enabling and protest sector where activist activities can emerge, gather momentum, and result in forms of collective action (Scrambler & Kelleher, 2006). Social movements and health-related organized resistance

to community development projects mobilize populations in different ways in part because they engage local forms of oppositional culture differently (Morris & Braine, 2001).

From there I want to outline the methodologies that are required to carry out the study. This approach will start from a basic conceptualization for doing formative research in rural communities, then use a variety methods to expand that approach to address the kind of themes that are related to identifying and studying health activism. Briefly, I will outline a basic community assessment approach which will constitute phase I of the research, making amendments to the method to clarify the team approach used, define the place of local media in the community, and discuss how to gather and analyze the range of health-related discourses in the communities of interest. Phase II of the approach discusses how to incorporate the assessment data into doing a participatory community mapping project with local health navigators.

The value of this project is derived primarily from its attempt to conceive holistically the relationships among various forms of advocacy and activism in the communication environment that can affect health promotion. I consciously focus on health activism and the presence of oppositional cultures and related oppositional consciousness (Morris & Braine, 2001) that has the potential of resisting health promotion efforts. It also suggests a means to allow bottom-up influences to shape the nature of health promotion before efforts are taken to encourage cancer prevention and control efforts from only an expert point of view.

Defining Health Activism and Its Relationship to Civil Society

Advocacy versus Activism

Brown, Zavestoski, McCormick, Mayer, Morello-Frosch, and Altman (2004) discuss differences between health advocacy and health activism. For these authors, advocacy involves groups that work within the existing system and biomedical model, uses tactics other than direct disruptive action, and tend not to push for lay knowledge to be included into expert knowledge systems. Activism involves activist-oriented groups that engage in direct, sometimes disruptive, action, challenge current scientific and medical paradigms, and pursue increased democratic participation in scientific or policy knowledge production by working largely outside the system.

Health activism, according to Zoller (2005), also involves contextual questions of scope and time. The scope of activism points to the place of social movements as a means for political groups to act outside institutions, engage in unconventional actions, and use protest and other forms of disruptive activities to ensure their grievances are addressed. As far as time is concerned, social movements differ from isolated protest events because they develop a shared vision of their purpose, evolve collective identities that facilitate collective action and give that action meaning, and create and sustain linkages among movement members and other allies that serve to sustain the movement through time. Still, social movements do not exhaust the range of activities that can be considered health activism. Zoller (2005) also discusses community organizing as a form of health activism.

Community organizing is yet another way persons and groups challenge existing power relations to address health concerns. Often thought of as a specific process of empowering individuals and building relationships and organizations to affect social change at the community level, community organizing can be conceptualized as bottom-

up versus top-down (Zoller, 2005). Bottom-up, or grassroots, organizing are often driven by community memberships, creating critical dialogues about local conditions to mobilize groups for change, with the expectation that dialogue can lead both to improved individual health behavior and to changes in the collective identity of community members. Top-down organizing by local elites may be initiated by an outside organizer. The focus is often on development of local housing and transportation infrastructures and community "capacity building". Such projects often fail to engage community ownership of the project results and also fail to address important barriers to participation.

According to Zoller (2005), many community development projects fail to empower the community to negotiate for needed resources and end up leaving the community worse off than it was before the project's inception. In terms of the issue of scope previously mentioned, community organizing is focused on a particular community while social movements tend to not only involve local communities, but can range across region, national, and even global levels of social organization.

Civil Society, Oppositional Cultures and Oppositional Consciousness

According to Scrambler and Martin (2001), Habermas has accounted for the emergence and changing nature of the public sphere by first describing its development in England in the eighteenth-century. It provided a sphere in which state activities could be examined and criticized through the public use of reason, articulated by private individuals engaged in argument, that was at least in principle open and constrained. The public use of reason was mediated in part through a parallel rise in the availability of the periodical press and through the development 'centres of sociability', like clubs and associational groups, and places like salons and coffee houses where people could meet

and discuss issues of interest among political equals. Habermas (1989) suggests that as the state became more capitalist and interventionist, the public sphere experienced a kind of ‘re-feudalization’. Salons and coffee houses declined during the same period and the periodicals were absorbed into an increasingly commercialized systems of mass communications.

Habermas (1987) understands the decline of the public sphere in relation to a broader social process whereby social differentiation under modern capitalism has gradually lead to an uncoupling of system (which he defines as the economy as it generates money and the state as it generates power) from the lifeworld (which he defines as the private sphere which generates commitment and the public sphere which generates influence). As delinguistified steering media (money and power) come to more and more drive the social world, strategic action, narrowly focused on achieving a narrow range of instrumental goals, comes to supplant discursive meaning making in the lifeworld. As such, commitment and influence no longer connect everyday cultural experiences. Communicative action, or action oriented to understanding is not called upon to legitimate activity. The ensuing ‘legitimation crisis’ is precipitated by the gap between the economic and occupational strategies of the state and the cultural mores of the lifeworld (Scrambler & Kelleher, 2006). Society continues to become progressively ‘juridified’, or managed by statutes and bureaucratic regulations which attempt to govern social behavior.

Traditionally, the concerns and arguments raised in families, pubs, and other meeting places (what Scrambler & Martin (2006) call civil society’s ‘enabling sector’) are to be taken up by community organizing, particularly through the use of participatory

democratic forums of various kinds, and by social movements (Scrambler & Martin's (2006) 'protest sector') (see Figure 1 in Appendix I). Media systems are supposed to compete to bring these concerns to the attention of state. In the "New Public', as Mayhew (1997) describes the current state of the public sphere, a number of 'systems of dominance' (Morris & Braine, 2001) can act to promote a 'culture of subordination' by manipulating media to maintain a hegemonic view of the current state of affairs as opposed to airing the grievances arising from some location within the enabling sector, and hence, acknowledge the presence of an 'oppositional culture' afoot in areas of the lifeworld.

Oppositional cultures contain frameworks of oppositional ideas and worldviews that are part of much of the larger culture of subordinate communities (Morris & Braine, 2001). The frameworks contain partially developed critiques of the status quo, knowledge of isolated rebellious acts, and historical accounts or prior episodes of collective action. As such, the frameworks can shape and crystallize the collective identities imposed by dominant groups on oppressed groups. They become important filters through which collective identities become internalized and experienced subjectively by members of an oppressed group. Still, oppositional cultures rarely provide shared understanding that clarify the need for collective action nor do they provide directions and strategies necessary to overcome oppression. Thus, though oppositional cultures establish a shared basis among cultural members for critiquing the larger dominant culture, their ability to recognize the shortcomings of the dominant culture may slip by them and lead instead to periods or resignation. Cultures of subordination and opposition become intertwined and it is as likely that recognition of the negative consequences of rebellion may win out as

does encouragement to acknowledge one's frustration at one's current status.

(Morris & Braine, 2001) defines a system of domination as 'that constellation of institutions, values, and practices which successfully enables one group to achieve and maintain power and privilege through the control and exploitation of another group (p. 25)'. Most commonly in the United States, such systems include the systems of class, race, and gender. Balshem (1991) provides an interesting example of the class-based cleavage as it manifested in relation to cancer prevention in two working-class neighborhoods in Philadelphia. She frames the notion of working-class 'fatalism' as a form of noncompliance that centers on a community's loss of autonomy to medical professionals. The central dispute in this case had to do with who has the power to define illness as well as to define appropriate responses to that illness. Balshem illustrates how members of the two working-class neighborhoods she studied resisted scientific authority by being skeptical of proposed links between cancer and lifestyle, denying that scientists definitively can know the causes of cancer, then complaining of various forms of victimization by the healthcare as a means to undermine provider claims. Instead of accepting medical authority, many community members legitimated their resistance by reference to a 'defiant ancestor' who maintained a lifestyle that indulged any number of risk behaviors and did not experience cancer:

> The defiant ancestor, a golden age figure of the grandparental or parental generation, was often invoked by community residents during informal discussions following health education programs. The figure was introduced by eight out of 25 interview respondents, and recognized eagerly by others when I myself introduced it. Respondents stated proudly that they themselves had many of the attributes of these ancestors. The defiant ancestor, so goes the story, smoked two packs of cigarettes a day, ate nothing but lard and bread, never went to the doctor, and lived up to the age of 93. The natural questions that followed during the interviews were: What do you think these people did right? Why do you think they lived so long?

> Above all else, the defiant ancestor was a hard worker. Physical labor, at work and at home, was the backbone of her existence…Moreover, the defiant ancestor did not dwell on disease. Keeping a positive attitude is an important part of staying healthy; refusing to acknowledge symptoms is a way of keeping sickness at bay (p. 162).

Continuing medicalization, as it feeds the cleavage between working-class communities, aspiring middle-class professionals like health educators and other health advocates, and upper middle-class professionals like physicians, tends to block professionals' view so that they see such disputes over authority in adversarial terms. It also makes it likely that professionals will over-sell their viewpoint even when it is unlikely to result in the benefits initially promised, In turn, the same health professionals can ignore the insights of entire communities concerning the nature of the experience of cancer. By importing a moralistic tone to health education, the role of health educator is constructed tightly within a limited set of parameters and not allowed to expand to incorporate a greater repertoire of social action beyond basic compliance characteristics. Physicians maintain their expert status as well as defend themselves against ongoing critiques of their practices. Community members find themselves at odds with professional experts who appear to misunderstand their efforts to survive cancer in an unpredictable universe.

The differences in causal explanation alluded to here are related to the issue of oppositional versus subordinate cultures (Morris & Braine, 2001). Oppositional consciousness is 'an empowering mental state that prepares members of an oppressed groups to act to undermine, reform, or overthrow a system of human domination'. This includes identifying with a subordinate group, concluding that the mechanisms that have produced at least some of the group inequalities are unjust, opposing the injustice and

seeing a common interest with the subordinate group in eliminating the injustice. Oppositional consciousness can range form a minimal level that actually expresses little about a person or their interests to a fully mature state of oppositional consciousness.

Mature oppositional consciousness tends to not only be able to ask for what it wants, but also provide coherence, explanation, and moral guidance for actions. In the case of Balshem's (1991) working-class communities, we see defiance as an empowering state that allows persons living in communities where they are vulnerable to exposure to carcinogenic agents that has resulted from industrial development in their parts of the larger urban landscape. Medical professionals' claims that lifestyle factors cause cancer challenge valued personal attributes that manifest as part of the individual's efforts to adapt to the local ethnopsychology (Shaw, 1994) that defines a person as tough, hard working, and willing to maintain a positive attitude under conditions of deprivation and stress. More general claims by medical professionals to knowing the causes of cancer ignore local perceptions of environmental hazard that accompany the need to work under dangerous conditions. Community members do not want to make lifestyle changes, but instead want the environmental risk reduced so they can maintain steady employment and sustain their traditional way of community life. In the case cited by Balshem, community members have not achieved a mature oppositional consciousness that manifests collective action to change environmental conditions, but they are aware of their collective identity as a community and their loyalty to that community is reflected in their comfort and satisfaction with maintaining their way of life where they know who they are and how things get done.

New Social Movements, Infrastructure, and Boundary Objects

Social movements, according to della Porta and Diani (1999, p. 16), are described (1) informal social networks, based on (2) shared beliefs and solidarity, which (3) mobilize around conflictual issues, and (4) deploy frequent and varying forms of protest. Scrambler and Kelleher (2006) point out that as there has been a historic change from industrial/organized capitalism to a global/disorganized capitalism, so to have the nature of social movement activity. Habermas (1987) claimed this shift in movement activity is one away from class-based labor movements toward identity-oriented movements focused on lifestyle and the environment, which he called 'new social movement' (NSMs). Many feminist, Gay rights, ethnic identity, and environmental movements have been less involved with working-class efforts to achieve equitable distribution of income and benefits (which originally arose out of processes of production) and have focused on matters of personal and social identity (which shifts the focus to processes of consumption).

Brown et al (2004) has identified three types of health social movements, each of which can fit the NSM framework. *Health access movements* seek equitable access to healthcare and improved provision of healthcare services. Examples include movements seeking national healthcare reform, increased ability to choose specialists, and extension of health insurance to uninsured people. *Constituency-based health movements* address health inequality based on race, ethnicity, gender, class and/or sexual differences. Women's health movements and gay and lesbian health movements that address the disproportionate outcomes and oversight by the scientific community are examples. The third type of health social movement the authors call *embodied health movements*. These movements address disease, disability or illness experience by challenging science on

etiology, diagnosis, treatment and prevention. Movements focused on ‘contested illness’ unexplained by current medical knowledge or have environmental explanations fit this type.

Embodied health movements represent a kind of ‘boundary movement’ because they blur the boundaries between lay and expert knowledge and between activists and the state. In recent efforts to promote mandatory vaccination of the human papillomavirus in Kentucky and other states, activists from groups concerned about mandatory vaccination by a medication not tested for long-term effects, other groups concerned about the growing power of pharmaceutical companies to market products with little oversight, and the Christian Right concerned about parental rights to control female children’s reproductive behavior is an example of a ‘boundary movement’ that challenged professional definitions of the vaccine as a ‘cure’ and forced legislators to reconsider the effort to make vaccination mandatory for pre-adolescent girls.

Scrambler and Kelleher (2006) critique the Brown et al (2004) typology by suggesting that such a typology short changes the dynamism and adaptability of many social movements. They also suggest that the movements run the risk of understating the ‘protean’ character of health social movements in general, and health-related new social movements in particular. They offer instead a typology of ‘mobilizing potential’ which help to elaborate the Habermasian framework outlined previously (see Figure 2 in Appendix I). They want to recognize that the imposition and sponsorship of expert cultures like medicine might be judged as a kind of lifeworld colonization. For the authors, the ‘voice of medicine’ has become pervasive in American culture, coming to dominate the ‘voice of the lifeworld’.

For Scrambler and Kelleher (2006), Habermas has also been concerned with democracy and rights. The extension of political rights has grown to include a number of cultural and civil rights which have been struggled for through various feminist and ecological movements. The non-hierarchical organizational structures of NSMs have been recognized as carriers of communicative rationality through forums of participatory democratic discussion.

Rights as a mobilizing potential are concerned with categories of cultural and civil rights such as those demanded by the disability movement. These movements often challenge definitions of normal and abnormal, understanding such labels as forms of oppression which deny selected groups of persons access to many domains of life experience. *Users* as a mobilizing potential have sprung up in response to dissatisfaction with local or national treatment options, as well as the institutional controls exerted by the medical system. Mental health user's movements have been one example of such a movement mobilized to voice user's issues. *Campaigns* and *campaigning* focus on specific interventions in civil society and the public sphere, often seeking government regulation civil legal actions against powerful interest groups. The anti-smoking campaigns of recent years are an example of the fruition of this mobilizing potential. *Identity* potential focus on segments of society differentiated by gender, age, ethnicity, or sexual preference. This potential is the heart of Morris's (Morris & Braine, 2001) oppositional consciousness and 'third wave' feminist health movements which forced the scientific community to recognize women's control over their own bodies is an example of this potential in action. Finally, politics refers to the subsystems of economy and/or state and is often linked to environmental concerns, but can also impact forms of material

or psychosocial deprivation. Environmental movements that seek to protect natural and social environments from corporate or other exploitation and degradation, whether or not the state sponsors that exploitation.

The challenge here is to develop a methodology that can allow for both the range of phenomena as well as the complex ways that culture, politics, science, and morality intertwine at a community and regional level, as well as how regional and community organizations reach out to national or even global groups, while attempting to address local threats and grievances. I want to propose a two phase methodology that would involve using a team of researcher to first analyze community relations in the three area development districts of interest for their mobilizing potentials for health activism. A second phase would then draw on the participatory action research tradition to develop a series of workshops that would allow the researchers to see how community members from the different area development districts would draw on the mobilizing potential of their communities to address a particular health issue.

Methodology

Setting

The Cumberland Valley, Lake Cumberland, and Kentucky River Area Development Districts (ADD) in southeastern Kentucky encompass 27 counties all of which are also understood to be part of the Appalachian Regional Commission's definition of an Appalachian county. All three ADDs have traditionally poor and medically underserved counties, with Kentucky River ADD having not only some of the poorest counties in the state, but also in the entire United States. On the other hand, the Lake Cumberland ADD, with its central community of Somerset is experiencing significant economic growth. Its

traditional history as a Republican stronghold in Kentucky has ensured new political clout as state representitive in congress, Hal Rogers, has become a member of the House Appropriations Committee. Cancer rates in many of these counties are above the national average, with lung cancer and cervical cancer being among the most dangerous risks for members of these district communities.

Community Assessment

Nettekoven and Sundberg (1985) have proposed a training model designed to prepare doctoral students to carry out mental health promotion projects in rural settings. I chose to draw on this model as a methodological starting point because it suited the nature of my current status as a researcher, as well as the likely status of fellow research team members. The authors suggest that training be done in a team approach allowing the students to draw on one another for both support and expertise. The team would consist of the author, three additional student investigators/workshop facilitators and a student GIS expert. Together the team would assess the ADDS in terms of the mobilizing potential that exist in the various communities in the first phase of the project, then, in the second phase, organize and implement a series of three workshops with community members from each of the ADDS. This would allow the research team to examine how regional differences in mobilizing potentials affect the workshop participants ability to work collectively in the workshops.

For me, this fits with a larger commitment to participatory action research philosophy. Participatory action research can be defined as "collective, self-reflective enquiry undertaken by participants in social situations in order improve the rationality and justice of their own social...practices" (Kemmis & McTaggart 1988). It occurs in four basic

moments – reflection, planning, action, and observation (see figure 3, Appendix I). According to Seymour-Rolls and Hughes (2000), the four moments can be defined as an iterative cycle. Reflection is that moment where participants examine and construct, then evaluate and reconstruct their concerns. Reflection includes the pre-emptive discussion of participants where they identify a shared concern or problem. The research team will interact through time in the PAR cycle as they apply the assessment methods in the first phase of the research project, then continue to work within the framework as they engage the community groups in the workshops during phase II.

The purpose of the assessment process itself is twofold (Nettekoven &Sundberg, 1985). It enables the student researchers to enter the respective ADDs and begin establishing a presence, while also assisting student researchers to gain familiarity with the given communities in the counties of each ADD to begin to design workshop materials for phase II. The use of assessment instruments (see Appendix II for example tools suggested by Nettekoven and Sundberg, 1985) can be thought of as the action phase of the PAR Cycle. Use of ethnographic observation within communities and community organizations also are forms of action within the PAR cycle. In later cycles of the assessment, after key informants have been identified and the student/researchers have established a presence in the communities, each ADD will provide members for three focus groups to discuss health concerns in the respective ADD.

Prior to actually entering the community and on an ongoing basis as the research team works in its respective ADDS, reflection would involve reviewing secondary and archival data on community features, such as census data, health statistics, but also local examples of newspapers, newsletters, community calendars, and other regional media as examples

of community media related to health, community development projects, local politics, and other manifestations of the social cleavages discussed by (Morris & Braine, 2001) as indicative of oppositional cultures. Group discussions will examine secondary data for patterns of hegemonic dominance in framing community issues and examples of local resistance to that hegemony.

Planning will involve contacting and interviewing key informants from each county, as well as developing what Nettekoven and Sundberg (1985) call Leadership Diagrams and Organizational Maps of various ADD communities. Planning discussion will seek to prioritize which communities appear most salient in affecting ADD mobilizing potentials as well as identify health-related organizations like physician's offices, public health clinics, hospitals, and other community agencies that are involved in cancer related services. Members of these organizations constitute the most likely possible key informants, though other opinion leaders and other community members may emerge as possible key informants as well.

The last moment in the PAR cycle, observation, will occur in two basic ways. Most basically, the team will have a research mentor from the Cancer Prevention and Control Research Program at University of Kentucky who will meet periodically with the team to discuss team progress and the barriers they are experiencing. Also, since each student/researcher will have their own research focus as well, they will meet periodically with an academic mentor from their department, likely a committee member, to discuss progress on the project and consider how to adapt the project's progress to their own research interests.

Specific Issues Related to Identifying Oppositional Culture and the Extent of Oppositional Consciousness

The Scrambler and Kelleher (2006) system-lifeworld model (Figure 1, Appendix I) suggests graphically an interface between the instrumentally driven system and the communicatively driven lifeworld with a broken line separating the two domains. In concrete terms, I draw on the communication infrastructure approach (Ball-Rokeach, Kim, and Matei, 2001) as a starting point to operationalize the interface of the system with the lifeworld and the rural communication contexts in which cancer-related barriers arise. This exploration would focus on two inter-related components of local communication infrastructure: the story-telling neighborhood and the communication action context (Ball-Rokeach, Kim, and Matei, 2001). The storytelling neighborhood is made up of the various links between community residents, community organizations, and the local media enabling storytelling about the community as well as about health issues in the community. A strong storytelling network would involve integration of local support networks that carry information and emotional support in times of health need, organizational ties that reach into communities to spread information about services through local churches, neighborhood associations, and other formal and informal networks, as well as local media, including newspapers, newsletters, free local bulletins, and other genres, that provoke conversation and storytelling about services, service providers, and the needs of local persons.

Communication action context is the second component of local communication infrastructure. This is constituted by the environment in which residents, community organizations, and media operate. Comprised of the important factors in a community that influence whether storytelling about critical health issues occurs, the communication

action context includes the availability of affordable screening services in the area, but also other factors like safe gathering places where storytelling about health issues can occur and the availability of transportation or telephone service which can allow persons in a rural area to engage such storytelling.

According to Ball-Rokeach, Kim, and Matei (2001), a strong, integrated communication infrastructure facilitates a sense of belonging within the community that allows community members to unite with others to address healthcare problems. "Sensitive issues", those issues that necessarily and involuntarily reference inherited status inequalities of speakers as a part of the content of speech in ways that destabilize efforts to conduct public deliberation about issues of concern (Warren, 2006), are more likely to arise in poorly integrated communication infrastructures because the stories persons tell are less likely to reflect collective sense of community that recognizes the rights of different members to take part in the discussion. Sensitive issues mark the presence of social cleavages and identify the basis for dominant and subordinate relations that characterize the inter-relationship between hegemonic and subordinate/oppositional culture.

Boundary object are objects that inhabit several intersecting worlds and satisfy the informational requirements of each of them (Star & Griesemer, 1989). Boundary objects are both plastic enough to adapt to local needs and robust enough to maintain common identity across sites. They are embedded in social infrastructures and exist at the interface between different social communities (Gal, Yoo, & Boland, 2004). Because of this placement, they also impact the ways that different social communities mark both their boundaries in relation to other groups, but also constrain how internal positioning of

group-based and individual identities unfold through time.

> At first glance the Pap smear is very simple, including some kind of stick, swab, or brush for obtaining the cells, a slide and slide holder, and a microscope. But we now understand that this is not the whole technology in any meaningful way. In the new frameworks of technoscience studies, the technology of the Pap smear in the United States includes female bodies. Cytologists, pathologists, an array of medical and technical practices, the obstetrics and gynecology infrastructure, most family and community medicine infrastructures, family planning clinics, and community and other hospitals, county public health departments, laboratories, shipping facilities, computers, and so on – in short, all the people, places, things, and activities that can produce a classified pap smear. It is the initial integration and subsequent inextricability of the Pap smear from its larger domain that makes it especially interesting in terms of classificatory and related issues, such as prevention and treatment (Clarke & Casper, 1996).

The Clarke and Casper (1996) quote points out how an apparently simple medical procedure, the pap smear, can operate as a boundary object, and thus establish an interface between a complex variety of social actors and expert and lay discourses. Figure 4 (see Appendix I) draws on Gal, Yoo, & Boland's (2004) discussion of how social identities emerge in the interaction of different professional and lay communities in a particular setting. Social infrastructures, as have been discussed before, support various forms of discourse and storytelling. It is in these stories that student/researchers will identify the 'frameworks of oppositional ideas and worldviews that are part of much of the larger culture of subordinate communities' mentioned earlier. I am using Figure 4 here to illustrate how student/researchers can attend to the routine medical and prevention practices in their communities of interest to identify significant, relevant boundary objects and begin to sort out the following:

- Community A – Local networks of communication and support from which someone will enter the healthcare system(s) in a particular eastern Kentucky county.
- Community B – The organizational networks that structure Kentucky Homeplace in the three focal area development districts in eastern Kentucky.

- Community C – The organizational networks that structure Public Health in the three focal area development districts in eastern Kentucky.
- Community D – The organizational networks that structure community and family medicine and/or hospital access in the three focal area development districts in eastern Kentucky.

A fifth community is not depicted in the figure. That community is the community of researchers at the University of Kentucky in which the student/researcher interact. This constitutes an additional layer of complexity that project researchers must negotiate and include in their reflections and observation.

The model in Figure 4 allows the researchers to begin to sort the 'on-the-ground' conversations they observe in communities and begin the process of reflecting on the structure of the interactions and planning how to further how to trace outward to the contextual conditions that sustain local social cleavages and the oppositional consciousness that exists in relation to that cleavage.

Workshops

In this phase, the research team will work with Kentucky Homeplace Staff in a series of three workshops to develop and answer research questions the staff develop with their respective team facilitators. Each area development district will work with a facilitator to pose problems related to cancer screening and control in their respective area development districts and use the PAR plan-act-observe-reflect cycle to explore solutions to the problems. The research team will include a GIS specialist who will help area development district groups to map assets and barriers as they are identified throughout the project. This section is intentionally vague because it is understood that many features of the workshop will be negotiated between workshop participants and the student/researchers they engage with.

Workshop 1 – Conducted separately within each of the Area Development Districts involved in the project. Facilitators will engage KY Homeplace staff and other participants in social mapping of their respective counties to locate local media sources, service outlets, area cultural activities, transportation resources, and other community assets that characterize the local environment and its ability to support or inhibit cancer prevention. Develop a set of relevant questions about each county for further research and a plan to follow-up answering those questions. Also, basic guidelines for evaluating the success or failure of workshop efforts will be decided among workshop participants.

Workshop 2 & 3 - The second and third sessions will continue to bring all the participant groups together. The second session will include discussion of the mapping activities and the results of the research process for the different groups involved. Groups will identify how regional differences and similarities emerge from the activity. Participants will develop a network diagram of their respective counties; will use the Johari Window activity to discuss knowledge differences among network participants, particularly in relation to what each participant in the network understands about cancer screening; will use a force field analysis to identify and analyze forces affecting their ability to identify and motivate persons eligible for cancer screening. Completion of the activities will be followed by reflecting on the meaning of the results, with participants again generating a list of questions to research before the next workshop. They will again design a plan for gathering that information. Research results will be documented and brought to the next workshop for discussion. The last session will attempt to summarize results and develop a plan for further action based on the identified needs of respective counties. Finally, workshop participants will observe the results of their efforts and use

the evaluation guidelines they developed in the initial session to assess the success or failure of their efforts in accomplishing their goals.

In Closing

As discussed, the purpose of this project is to investigate the existing and potential health activism in three area development districts in eastern Kentucky. It then seeks to examine how the different potentials available in the three area development districts affect efforts to implement a community-based participatory mapping project designed to support cancer prevention and control efforts in the same area development districts. I have defined health activism and its relationship to social movements and community organizing. I have also discussed the place of oppositional culture in developing the oppositional consciousness necessary to mobilize persons to collective action./

Methodologically, I have discussed a framework that combines basic community assessment in a team approach with participatory action research principles to outline how student/researchers would carry out assessments of three area development districts in southeastern Kentucky. The purpose of the assessment process itself is twofold (Nettekoven &Sundberg, 1985). It enables the student researchers to enter the respective ADDs and begin establishing a presence, while also assisting student researchers to gain familiarity with the given communities in the counties of each ADD to begin to design workshop materials for phase II.

I also addressed a means to start with ethnographic observation in health setting for identify boundary objects that organize communication within a particular setting and from there, allowing the researcher to ‘work outward’ to identify what communities interface around the boundary object and how the social relations at that interface come

to shape the social identities of group members. This basic observational method of social interaction becomes a starting point for tracing the presence of social cleavages manifesting in and around the particular instantiation of the social infrastructure.

Additionally, I made a general outline of the workshops that would constitute the second phase of the research. Three workshops would be conducted for each of the three area development districts, focusing on the use of community mapping practices to produce desired outcomes for the workshops. Groups would develop criteria and guidelines for evaluating their outcomes and use these in the third workshop to assess their results.

As previously stated, the value of this project is derived primarily from its attempt to conceive holistically the relationships among various forms of advocacy and activism in the communication environment that can affect health promotion. I consciously focused on health activism and the presence of oppositional cultures and related oppositional consciousness (Morris & Braine, 2001) that has the potential of resisting health promotion efforts. It also suggests a means to allow bottom-up influences to shape the nature of health promotion before efforts are taken to encourage cancer prevention and control efforts from only an expert point of view.

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