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Résumé

L'autonomie du secteur bénévole relativement à l'évaluation des programmes de santé publique : une exploration, selon la perspective d'une coalition pour le VIH/sida

Hélène Laperrière

Tel que recommandé par la Charte d'Ottawa, les agences gouvernementales canadiennes s'appuient sur les organismes communautaires pour mettre en œuvre des programmes de santé publique fédéraux à l'échelle locale. L'imposition aux organismes communautaires d'un rôle prédéfini les obligeant à fournir des services est un enjeu central. La logique hiérarchique descendante qui régit les pratiques structurées en promotion de la santé constitue un problème important pour les services infirmiers de santé publique. L'auteure réalise une analyse réflexive, ancrée dans le cadre de la colonisation interne pour explorer le cas d'un programme de santé publique canadien et ses liens avec une coalition provinciale d'organisations bénévoles travaillant sur des questions relatives au sida. La mise en vigueur de la Charte d'Ottawa met en lumière les défis liés à l'interprétation et aux actions inhérentes à la notion de partenariat entre les agences de santé publique et les organismes communautaires bénévoles. La notion de participation suggère la mise en place d'organismes sociaux plus démocratiques et égalitaires, avec des structures hiérarchiques basées sur une vision plus large d'une société moderne.

Mots clés : promotion de la santé, santé publique

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Autonomy of the Volunteer Sector in the Evaluation of Public Health Programs: An Exploration From the Perspective of an HIV/AIDS Coalition

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As recommended in the Ottawa Charter, Canadian government agencies are counting on the involvement of grassroots organizations to implement federal public health programs at the local level. At issue is the forced acceptance by community organizations of the predefined role of suppliers of services. Because of the top-down issues of health promotion practice, the problem is crucial for public health nursing. The author uses reflexive analysis, grounded in the internal colonization framework, to explore the case of a Canadian public health program and its relations with a provincial coalition of volunteer organizations working on AIDS issues. Implementing the Ottawa Charter highlights the challenges of the meanings and actions inherent in the notion of partnership between public agencies and community organizations of volunteers. Participation suggests more democratic and egalitarian social organizations, with hierarchical structures in a broader image of a modern society.

Keywords: AIDS/immune system, Community Health Nursing, health promotion, population health, psychometrics and evaluation, public health

Introduction

The Ottawa Charter (World Health Organization [WHO], 1986) and the Bangkok Charter (WHO, 2006) oriented regional AIDS Community Action Programs (ACAPs) towards cooperating with civil society and the public and private sectors to include an economic development perspective within health promotion practices. This movement in the health sector follows the prescription, by the World Bank and the United Nations Development Program (UNAIDS/UNDP/WB, 2006), of intersector cooperation and local responses. In line with those recommendations, the New Canadian National Strategy on HIV/AIDS advocates for the mobilization of local community organizations (Canadian Public Health Association, 2006). The federal initiative is aimed at increasing engagement with the volunteer, professional, and private sectors as well as people living with and vulnerable to HIV/AIDS by choosing "long relationships with Non-profit Organizations and community partners" (Public Health Agency of Canada [PHAC], 2007).

Within the National HIV/AIDS Voluntary Sector Response Fund, ACAP finances more than one hundred community-based AIDS groups across the country (PHAC, 2006). It supports community-based organizations (CBOs) in "delivering HIV/AIDS prevention education, creating supportive environments for those infected with and affected by HIV/AIDS" and health promotion (PHAC, 2009). The federal initiative is guided by three policies: partnership and engagement, integration, and accountability (PHAC, 2007). The decision to finance a project by an HIV/AIDS CBO is directly influenced by the inclusion of these three policies in its proposal.

A participatory research study was conducted in cooperation with CBOs affiliated with a provincial coalition in Canada, to better understand the tensions, caused by evaluation, between HIV/AIDS CBOs (volunteer sector) and the regional ACAP (public sector). The study took place over a 2-year period, with collective discussions and sustained volunteer work among people living with HIV/AIDS. The in-depth participatory character of the research meant that each actor was invited to take part at all stages of the research process, including planning and evaluation.

The Problem

The research fostered reflexive analysis to generate insights into the socio-historical process of developing and evaluating public health programs. The theoretical background for the study was provided by Latin-American studies of internal colonization as a critique of "programmed development." Programmed development puts forward an abstract model of a "modern" society that assumes the right to impose itself on any culture that does not meet its standards (Casanova, 2002). In public health, programmed development means that the context of action is taken for granted in the proposed program; it is up to the local setting to comply with the imposed standards. In programs, planning, evaluation, and intervention logic is organized to facilitate the analysis of all of its components from the perspective of the managerial actor; formalization leaves little room for intuition and emerging strategies (Mintzberg, 1994). The study explored a broader problem in public health philosophy and programming approaches (Rose, 1992) when government public health initiatives involve volunteers. In order to mobilize the volunteer sector, "programmed actions," such as described in this article as general aims and actions to be followed in all local experiences, are often transmitted using language taken from the Ottawa Charter (WHO, 1986), such as "partnership," "participation," and "empowerment."

More and more, education in public health nursing is taking a program evaluation approach based on the Logic Model (Budgen, Cameron, & Bartfay, 2010; Edwards, Etowa, & Kennedy, 2008). Mintzberg (1994) sets out three premises of the Planning School Model with regard to strategy. First, strategic action should be controlled as well as being part of a formalized and elaborated process, broken down into steps, each delineated by checklists and supported by techniques. Second, responsibility for the overall process rests with the chief executive. Third, strategies emerge from this process fully developed, typically as generic positions to be explained so they can then be implemented. Mintzberg emphasizes the possible costs to those who must adhere to these guidelines.

There have been few critical examinations of the top-down issues in health promotion practice with "objective centralized and institutionally controlled set of criteria" (Potvin & McQueen, 2008, p. 28). It is crucial to analyze the pervasive presence of vertical relations of control in the use of the Logic Model for public health nursing practices that require local participation. A centralized, top-down hierarchical strategy of implementation clearly threatens to crush the logic of local participation and empowerment and make the program the victim of its contradictory logic.

Analysis of this problem is crucial for a genuine partnership with the volunteer sector in public health nursing. There should be clearer differentiation between participation (free participatory engagement) and recruitment of community volunteers asked to execute a particular health promotion action in a pre-established framework. The vertical relations of control place public health nurses in a bureaucratic grid of planning and evaluating, which is foreign to the lay people who are appointed to implement change in their community and causes misunderstanding of ends and means. This article offers a new way of viewing partnership and participation as set out in the Ottawa Charter, by calling for respect for the autonomy of community groups consisting of lay volunteers.

The Nature of Partnerships Between Civil Society and Public Health Institutions

Participatory rhetoric in the health-care system goes back to the 1960s (Albrecht, Fitzpatrick, Scrimshaw, & White, 2000). In 1978 the Alma Ata declaration pointed clearly to public participation: "The people have the right and duty to participate individually and collectively in the planning and implementation of their health care" (WHO, 1978). In 1986 the

Ottawa Charter underlined the strengthening and empowerment of communities through increased participation (WHO, 1986). Furthermore, a globalized world required public-private partnerships and the establishment of alliances (UNAIDS/UNDP/WB, 2006; WHO, 2006) — even though traditional approaches to public health programming and evaluation are often at odds with these aims (Gendron, 2001; Mantoura, Gendron, & Potvin, 2007; McQueen, 2001; McQueen & Anderson, 2000; Pluye, Potvin, & Denis, 2004). Glouberman (2001) stresses that hierarchical, top-down approaches still prevail in political decision-making in health planning, in a process that is heavily influenced by competition and the interaction of multiple interests. Official documents on health promotion are not clear on the nature of the partnerships that are expected to result. For example, the National Program of Public Health (Gouvernement du Québec, 2002) aims for collective empowerment but is unclear about actions to be encouraged or discouraged, such as militancy and political strategizing by social movements.

Ideological ambiguities increase the friction among partners; moreover, when public health decision-makers control the gathering of information civil society is often the loser in the hierarchical struggle (Hamel, 1993; International Council of AIDS Services Organizations, 2006; Potvin, Gendron, Bilodeau, & Chabot, 2005; Public Health Watch, 2006). Public health agencies call for pre-defined objectives, linearity, and predictability in their programs, while community development requires an ability to deal with uncertainty (Labonté, 1994). Boutilier, Cleverly, and Labonté (2000) underline the powerlessness of community actors and lay participants, in clear contradiction of the Ottawa Charter, since public health agencies have a tendency to subordinate civil society participation to demands for detailed technical forms.

Over the years, many health promotion researchers have supported a more active role for the community (Altman, 1995; Bracht & Gleason, 1990; Minkler, Wallerstein, & Hall, 2008; Novotny & Healton, 1995; Wallerstein & Bernstein, 1988). Nevertheless, the unilateral form of the protocol, the financing, and the lack of interest by planners in the local context weaken the avowed orientation (Burton, 2009; Cargo, Salsberg, Delormier, Desrosiers, & Macaulay, 2006; Israel, Eng, Schulz, Parker, & Satcher, 2005; Potvin, Bilodeau, & Gendron, 2008; Syme, 1997). Volunteering in Quebec is based on a model of collective responsibility that is quite different from the individual philanthropy prevalent in English Canada:

> In Quebec, the Church was the prototype for the organization of the community sector. . . . In the popular imagination in Quebec, what becomes historically salient is the collective responsibility of communi-

> ties, in contrast to an emphasis on altruistic acts by individuals [in positions of power]. The Quiet Revolution of the 1960s preserved this ethos in order to replace the Church with the modern state. In the famous words of [Premier] Lesage in 1961: "We do not have the luxury of underutilizing the state." (White, 2001, p. 2; author's translation)

Methodology

Field Research Approach

The field research approach adheres to non-linear, multi-method, flexible methodology (Becker, 1963; Quivy & Campenhoudt, 2006). In methodological pragmatism, the research process does not derive from a preconceived action model but evolves according to field events and retroaction by the participants. Questions evolve continually according to the fieldwork in an iterative process between theory and empirical inputs (Quivy & Campenhoudt, 2006). A purposive sample was made up of five diverse groups selected collectively by the 37 members of the coalition. Four sources of information were used on a continuum between direct action and intellectual organization: a critical review of the literature; collective discussions with actors from community organizations as a device for reflexive practice; direct participation in developing and testing evaluation tools; and volunteer work with the community organizations.

The Voluntary Fieldwork Experience of the Researcher

The researcher's participation as a regular volunteer for the community group became necessary in order to ensure proximity and relations of trust. It allowed for discussion of everyday topics in which participants wanted to be assured of confidentiality. The amount of work this required of the researcher was equal to that of an anthropological fieldworker (Borneman & Abdellah, 2009). A total of 427 hours spread over 20 months of fieldwork included 105 visits linked to volunteer activities and 29 visits linked to other activities, such as participation in four coalition general assemblies and attendance at collective and provincial network meetings and at a HIV/CBO conference. During the course of this work, the researcher spoke with people living with HIV, parents, friends, volunteers, interveners, CBO members, coordinators, representatives of funding agencies, federal public health agents, HIV/AIDS researchers, and coalition board members. The conversations took place in a variety of settings, such as bars, corridors, cafés, sidewalks, and CBO centres. In addition to those interviewed collectively as part of the more structured research process, approximately two hundred persons were contacted.

Data Collection and Analysis

The research process began with word-of-mouth among coalition members. Thirteen collective interviews were conducted in urban, semi-urban, urban-rural, and metropolitan regions (47 participants). The interviews focused on collective actions among people living with HIV/AIDS and possible ways of evaluating actions at the local level: How to bridge the distance between funding sources, the requirements of abstract models of evaluation, and the real operating conditions of community groups?

The coalition tool Strategic Analysis of Strengths and Weaknesses (Zúñiga & Luly, 2005) was used to explore the collective reconstruction of the community group's history (experiences, competencies, routines, fieldwork) in order to visualize the "project" as a realistic projection into the future. The original project constantly interacted with the concrete possibilities emerging in the action process. It looked at internal relationships (organizational dynamics, atmosphere of cooperation, administrative control, forms of participation, etc.) and external relationships (interpersonal dynamics, information, contacts, alliances, network, etc.).

The gathering and analysis of data from the collective interviews took place simultaneously during the fieldwork. Continued presence in the field allowed for early presentation of the results to coalition participants (first within member groups and then at general assemblies). The meanings that emerged from the data were tested for plausibility and factual grounding.

All results were analyzed and summarized by the researcher and then presented in draft form to the participants in all five groups. Discussion followed and the participants were asked to read the notes, comment on the analysis, and suggest further interpretations. Their opinions were added, so that the analysis included the viewpoints of all participants. The participants decided which results should be made available externally. The final conclusions were presented at a coalition general assembly.

Reflexive Analysis

A number of factors emerged from the collective interviews. These included: (a) the relative autonomy of the decision-making process, (b) recognition of different levels of participation in negotiating objectives and conditions of success, (c) the impact of inequalities on evaluation outcomes, (d) the cultural diversity of inter-organizational partnership settings, and (e) the presence of internal colonization. These specific conclusions are reported elsewhere (Laperrière, 2009a, 2009b).

Data from collective interviews cannot be treated outside the political and social contexts of the communication (Markova, 2003). The settings of HIV/AIDS prevention interventions reflect the structural realities of the local CBO organizational culture. Given the physical proximity of identifiable individuals living with HIV/AIDS and the political militancy of CBOs, the issue of privacy was of paramount concern. Threatening topics required a fine balance between ensuring trust and incorporating the opinions and viewpoints of all participants. It was mutually agreed that private information shared between the researcher and the participants would be kept private; this created a space for unguarded mutual trust within the formal collective interviews.

Schön and Rein's (1994) strategy of "reflecting in action" was crucial in order to analyze conflicts underlying controversies about policies, programs, and government projects. Schön and Rein see policy positions as "underlying structures of belief, perception, and appreciation," which they call "frames" (p. 23) and which must become explicit in order to lead to better understanding and cooperation of all actors involved. As the field research evolved, insights gave rise to questions relevant for public health nursing, such as: To what extent do the health promotion strategies contained in the Ottawa Charter promote control and autonomy by local communities? Do these strategies concern those members of community organizations who are volunteers engaged in transformative action? How can volunteer organizations, as autonomous actors, fulfil the mission that the Ottawa Charter has expressly assigned to them, a mission that considers the need to have their input as a reality-check, one that will make the planning strategy one in which the original plan is understood, enriched, and modified in order to meet the realistic criterion of turning the affected population into willing partners?

Findings

The findings concern the thematic insights derived from the collective reflexive analysis developed throughout the research process. They emerge between the fieldwork and the theoretical background.

Evaluation Conflict Between the Coalition and Public Health Agencies as a Collision of Frames of Understanding

Historically, the coalition has negotiated the space to adopt its own perspective on evaluation and produce its own evaluation tools (Jalbert, Pinault, Renaud, & Zúñiga, 1997). Between 2003 and 2005, interveners representing the coalition's HIV/AIDS CBO members developed 19 tools. The evaluation guide was aimed at increasing mutual understanding in terms of efforts both to better communicate and to better understand the issues under evaluation in such a way that partners would be aware of the differences in perspectives and the strategies in order to better understand and respect those of their partners. Financed by the AIDS community action program of Canada Health, the work was negotiated and supervised by five representatives of public health funding agencies.

During the research with the coalition, the federal agency hired a private firm to set operational criteria for the distribution of federal funding under ACAP. The external evaluator stated explicitly that the aim was to achieve a high degree of comparability among all volunteer organizations in Canada (PHAC, 2006). It recommended concentrating on evidence-based indicators to determine the distribution of funds among AIDS community action programs. The federal funding agencies accepted this comparison model.

The operational premise of ACAP and the chosen evaluation model test the logic of equal partnership. The federal program has adopted an integrative approach among different partners at the local, national, and global levels, aimed at "coherent action" by "peoples, organizations and systems involved with HIV/AIDS" (PHAC, 2009). Little space is left for exploration of the characteristics of a particular setting; no space is left for different peoples and organizations to better understand their inevitable partners.

Changes in the Perspectives of Participants

An "internal colonization" interpretation gradually emerged from the critical discourse. Some participants saw the HIV/AIDS CBO organizational culture as one of internal self-censorship. Self-censorship begins when community organizations surrender their autonomy for the sake of assured funding. In meetings among group members and in coalition meetings, participants said they felt they silenced themselves even before the federal agent asked them to omit certain details from the evaluative annual report. Such omissions obliterated from the text significant local knowledge that did not fit the objectives of the federal program.

After the "honeymoon" stage of sharing what was significant for the community participants, one group expressed discomfort with the "community manner of evaluating." The threatened accountability criteria were stifling the free expression of opinion. The participants spoke of an underlying ethical dilemma: "Should we respond to requests for information by federal agents on their terms or according to the needs expressed by community members?" "Why are our volunteers, some of whom are living with AIDS, expected to work with these programs?" "Should we be asking volunteers to put the aims of the program before their own needs?" Some members had drifted away from their original mission to help people living with AIDS to fit in projects that emerged sporadically from new national health policies. For others, the benefits of secure funding led to unquestioning acceptance of the imposed criteria and thereby threatened the very survival of the group.

Using the Results to Reframe Health Promotion Concepts

The literature on international relations uses the terms "colonization" and "internal colonization" to illustrate the dynamics involved in subordinating peoples and countries to a dominant nation and having local elites act as willing local multipliers of the values and practices of that nation. Colonization is "the relation of dependence — economic, political and cultural — imposed by one society on another" (Akoun & Ansart, 1999, p. 87). "Internal colonization" refers to the changes in perspectives and attitudes of sectors of the dependent society that are closest to the external influences (for example, cultural brokers, community leaders, intermediaries). Convinced of the benefits of the new model of national development, they gradually distance themselves from local values and practices.

The notion of internal colonization as described by Casanova (2002) suggests a merging of the values disseminated through socialization and the power differential implicit in this dissemination. The notion of internal colonization suggests a calm, peaceful movement towards "something better," with no apparent aim other than progress and the increased well-being of the population.

In the dynamics of internal colonization, popular organizations are not physically forced to change. This was particularly clear at one point in the research with HIV/AIDS CBOs. In group discussions, the questions that were developed collectively evolved in a way that the participants called "realistic," "down to earth," from "What do we think of our actions?" to "What do they want to hear from us? We'd better think before we sign a contract with the Queen!" (Laperrière, 2009a) (all Canadian government publications, including those setting out public health policies and programs, are the copyright of Her Majesty the Queen).

Attitudes were transformed through a complex process of "seeing the light," as per the program's stated objectives. In the process of internal colonization, members of CBOs might suddenly envisage the benefits of the socio-economic resources offered, or devise a personal strategy to profit from the connection with the "powerful" public health agency.

As a volunteer with HIV/AIDS CBOs, the researcher uncovered a complex typology of unpaid activities such as conviviality, care, social support, accompaniment of complex-care HIV/AIDS patients, what was called "festive networking" (to differentiate it from social networking), political militancy, fundraising, and participation in evaluation (Laperrière, 2009a). These activities were not included in formal evaluations and were actively discouraged in official evaluation grids. The question arises: Must one choose between answering to federal health authorities and answering to community members?

Sharock and Iedema (2004) argue that most health promotion theorists, notwithstanding their modernization aims, engage in an "evolutionary transcendent discourse." This discourse makes it impossible to question the official historical vision of health. In the view of Sharock and Iedema, development is conceptualized as rational, progressive, cumulative, and functional. Societal values can nevertheless influence choices regarding knowledge production and dissemination methods, which become instruments for instituting local health practices (Laperrière, 2008). This dissemination opens the way for new paradigms that are unfamiliar to local volunteers. It presents the volunteers with new dilemmas in adhering to health promotion guidelines.

Health promoters do this in the name of developing national public health policies. CBOs are expected to adapt to modern society, conscious of the principles of social justice, equality, and democracy. These values derive from the historical context out of which the Ottawa Charter emerged (Kickbusch, 2003). According to Petersen and Lupton (1996), modernizing conceptions of health promotion are reinforced through the use of terms such as participation and empowerment. This does not alter the political desire to orient community action towards the objectives of health authorities — in the hope of creating a better future society.

The Participation of CBOs in Representative Democracy

In political systems such as Canada's, to participate means only to be consulted or to be free to express one's opinion. This kind of participation does not include sharing in a project's design, administration, or evaluation. Hamel and Jouve (2006) distinguish between representative and participative democracy in terms of individual preferences and aspirations; in representative democracy, the collective choice is expressed in one representative voice, whereas in participative democracy each citizen can express his preferences and make his voice heard, free of frameworks, procedures, and institutions.

As a generic concept, participation encompasses three different meanings. One speaks of *communicative participation* when people participate in an activity or social event that they value and identify with (e.g., a concert, a patriotic act, a celebration). It creates a feeling of "we," of sharing and belonging. *Deliberative participation* includes the right to express a point of view or make a proposal (House & Howe, 1999). The vast majority of self-described democratic governments provide mechanisms by which members of the public can express their views, such as opinion polls and opportunities to give feedback by telephone or via electronic media. Finally, in the much more demanding *decisional participation,* individuals or groups assume the right to be considered an integral part of a decision-making collective. This conflation of meanings leads to ambiguities — for example, any contact between the researcher and the targeted subjects, including presentation of the project in order to obtain the consent of targeted subjects, can come under the participation label.

Decisional participation is a major challenge for representative democracies and public health systems (including public health nursing). "Participation is an ethical and political term that amounts to . . . conferring individuals with the power to concretely influence, and therefore change, the conditions that affect them" (Zask, 2003, p. 23; author's translation). Only the more restrictive decisional participation encompasses the full political and democratic act of participation. This was the meaning agreed upon by the participants in the present study.

Building a Participatory Action Model for Public Health Nursing

The culture of public health nursing generally seeks to involve volunteer organizations in order to achieve optimal *efficiency* (economic factor measurement) with respect to federal programs. The use of the volunteer sector in government programs limits the definition of "efficacy" to explicit, predetermined objectives defined in the absence of those who are meant to implement them and those who are meant to benefit from them (Potvin et al., 2008). In addition, efficacy is reduced to its definition by public agencies, marginalizing its meaning to the concrete interests of local communities.

Public health nurses are often encouraged to introduce programmed activities in CBOs as an obvious benefit. Unquestioning implementation by the volunteer sector nevertheless implies the subtle replacement of the local community (civil society) mission with a societal (government) mission. The spirit of support among CBOs will gradually be replaced by "networking" linked to a government agency. This mechanism promotes the consolidation of undifferentiated national public health programs in a form of internal colonization, by federal institutions, of local community groups (volunteer sector). There are built-in inequalities between those who define the programs (public health agencies) and those who are expected to implement them — the volunteer sector (civil society). Those inequalities will widen if health promoters, including public health nurses, do not take into account the harmful effects of prescribed or forcefully suggested actions on the lives of volunteers.

Conclusion

Public health philosophy has historically been directly related to the expansionist dissemination of concepts such as change and development, which prevailed in the 1960s and 1970s. In political decision-making structures and the planning of national agencies, volunteer activities are seen primarily as means to implement public health policies. The process of strengthening community actions (WHO, 1986), which is significantly influenced by the social movements of the 1980s (Kickbusch, 2003), paradoxically entails the rejection of engagements that are considered outdated such as militancy and the favouring of new beliefs in programmatic practices.

A vertical conception of the scientific dissemination of imported change through the participation of volunteers carries costs for public health programs, such as limited acceptance by the population and limited effectiveness. The verticality of public health programs can increase domination and minimize peer exchange and voices emerging from the grassroots. The volunteer activities that are permitted (financed) are controlled and measured according to supposedly universal dynamics and equally universal indicators — at the cost of prolonging or even obstructing the emergence of context-specific projects. The challenge of attaining convergence of public programming and popular participation is still unclear. Shedding light on it will certainly increase the likelihood of achieving the cooperation that is both desirable and necessary.

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