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Commentary: The people know best

Michael Calnan

One trend which has characterized health policy in the western world over the last decade or so is an attempt to shift away from expert dominated, 'top-down' policy towards 'bottom-up' policies which aim to articulate and mobilize the interests of individuals and/or populations. One example of this is in public health where traditional legislative, regulatory, or educational policies, prescribed by government and increasingly linked to expert 'evidence', have lost popularity. Policies aimed at community empowerment where policy development involves a 'negotiation' between scientific and lay groups are now in favour. There are a variety of reasons for such a shift in emphasis such as the need for policy to be more accountable and legitimate, to counteract the democratic deficit, or to increase the likelihood of social change by ensuring initiatives have more meaning and relevance to the population or to the local community. Such bottom-up policies are sometimes 'mobilized' through provision of resources to help facilitate community involvement or occur 'spontaneously' as a result of the development of social movements or self-help groups.

A similar trend has occurred in health-related research where there has been an increasing call for users (defined in a broad way from individuals to consumer agencies) to be involved in research.[1,2] Once again a number of reasons might explain such a development but the popular one is that research needs to be increasingly salient and relevant to users' needs. Commentators vary in the extent to which they advocate users' involvement, ranging from the initial phase of shaping the research agenda or priority setting through being fully involved in different stages of the research process, such as research design, data collection, and analysis and interpretation.

Epidemiological research has also been encouraged to adopt an approach to involve community representatives in the research process. This is well illustrated in the article by Leung, Yen and Winkler,[3] which advocates a community-based participatory research (CBPR) as the way forward for epidemiology. CBPR is defined, according to these authors, as a systematic inquiry, with the participation of those affected by the issue being studied for the purposes of education and taking action or affecting social change. More specifically CBPR is characterized by participation and engaging community members and researchers in a joint process to which each contribute equally; it is a co-learning process; it involves systems development and local capacity building; it is an empowering process through which participants can increase control over their lives, and it achieves a balance between research and action.

The motive behind such a call for a shift in paradigms is the perceived failure of epidemiological research to influence policy. This is accounted for, at least in part, by the inherently apolitical

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stance of epidemiology with its positivistic approach which emphasizes the superiority of objective, scientific knowledge, and the need to remain independent of policy agendas, decisions, or actions. CBPR takes a more 'social constructionist' approach emphasizing the relationship between knowledge and power and the value of taking into account the experiential knowledge of the 'lay' public or at least sections of it. These authors argue that CBPR will democratize knowledge through the participation process so that 'it is accessible both intellectually and practically, as well as being locally relevant to participants'.[3]

CBPR is claimed also to overcome the individualistic approach in traditional epidemiology with its concern with screening, lifestyle, and risk factor change. However, such an argument appears to neglect the social susceptibility approach in epidemiology which shows how clusters of diseases are associated with social and economic status, gender, ethnicity etc,[4] and also the social capital model which highlights the contribution of the 'community' to an individuals health.[5]

Popular epidemiology, according to Leung, Yen, and Winkler,[3] is one of the better illustrations of CBPR as it recognizes social factors as part of the disease causal chain through the participatory process. It differs from social epidemiology which examines the social patterning of health and disease primarily through quantitative methods in that it relies on or takes into account lay observations and reports of health hazards, effects, and possible causes. Such an approach requires the use of a broader and more flexible range of methodologies, such as qualitative methods to elicit these perspectives and experiences. Popular epidemiology is claimed to differ from traditional epidemiology also in its approach to advocacy and activism. While social epidemiology may shape the agenda in social inequalities in health, popular epidemiology is seen to be more radical in that it is rooted in political action and social movements and is more aggressive in campaigning for major structural changes.

Science and scientists are under threat[6] and epidemiology is no exception. Eliciting the support of the public might be seen as crucial to its continued legitimation. However, CBPR appears to be more than 'tokenism' in that it represents a genuine attempt to make epidemiology more policy relevant by looking into the needs and interests of the community. In principle then, an approach that is promising and should be supported, although relying solely on the perspectives of the community may not always be appropriate, and while scientists' perspectives may be clouded by their professional position the same argument might also apply to a community whose interests and concerns may overshadow those in more disadvantaged positions.[7] This raises the question of how much weight should be given to the interests and views of the community. There are also the questions as to what extent communities or their representatives want to be involved or participate in research, whether those who are involved in research adequately represent the community interests, and what the most appropriate and effective mechanisms are for articulating the communities' views. There is also the fundamental issue of how power will be shared. Recent research in healthcare in the UK[8] suggests that the incentives for the public and users to be involved in decision-making need to be great, even where structures and mechanisms exist for them to do so. The evidence indicates that although lay people wish to be informed and consulted about the planning and provision of services, few wish to participate in health-related decision-making: they prefer to leave this to managers and professionals. The same may be said of participation in research, although the level of motivation will depend on the extent to which the problem poses a direct hazard to the community.

CBPR offers a promising way forward for epidemiology although its theoretical position of shifting from a positivistic paradigm to a more social constructionist position is fraught with problems—not least the relationship between structure and agency or in this context the relationship between social structural position and beliefs and practice. To bridge these two paradigms CBPR maybe needs to look to other promising approaches such as critical realism.[9] The critical realist perspective is interested in seeking to understand the fundamental structures that affect the empirical world, examining how in a given context actors may be constrained by wider social forces.

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