Lessons from community participation in health programmes: a review of the post Alma-Ata experience

Susan B. Rifkin

Department of Social Policy, London School of Economics, Houghton Street, London WC2A 2AE, UK

Received 2 February 2009; accepted 20 February 2009

KEYWORDS
Community participation; Primary healthcare; Community health workers; Community-based healthcare; Process indicators

Summary The year 2008 marked the 30 year anniversary of Primary Health Care, the health policy of all member nations of the WHO. Community participation was one of the key principles of this policy. This article reviews the experiences of and lessons learned by policy makers, planners and programme managers in attempting to integrate community participation into their health programmes. The lessons, identified in an earlier article by the author, are still relevant today. They help to identify three reasons why integrating community participation into health programmes is so difficult. These reasons are: (1) the dominance of the bio-medical paradigm as the main planning tool for programmes, leading to the view of community participation as an intervention; (2) the lack of in-depth analysis of the perceptions of community members regarding the use of community health workers; and (3) the propensity to use a framework that limits investigation into what works, why and how in community participation in health programmes. Despite these challenges, evidence suggests that community participation has contributed to health improvements at the local level, particularly in poor communities, and will continue to be relevant to programme professionals.

© 2009 Royal Society of Tropical Medicine and Hygiene. Published by Elsevier Ltd. All rights reserved.

1. Introduction

Last year, 2008, marked the 30th anniversary of Primary Health Care (PHC), the health policy accepted by all member nations of the WHO at Alma-Ata in 1978.¹ The celebrations have provided opportunities throughout the world to reflect upon the lessons and experiences of PHC policy in various settings and nations. A number of organizations, both with the support of WHO and independently, have held meetings to review PHC.² These meetings mostly reached a consensus that PHC is critical to health improvements and should be revitalized and pursued.

Community participation was one of the founding principles of PHC. This principle reflected the underlying value of social justice, confirming the view that all people have the right to be involved in decisions that affect their lives. It also reflected the value of participation in improving health, often among the poor, particularly in rural areas, based on health programmes mainly in the non-governmental
organization (NGO) sector. Community participation became a defining characteristic of the PHC approach to health. Why is community participation important for health improvements? Distilling the arguments of WHO, the United Nations Children’s Fund (UNICEF) and the Christian Medical Commission, all of which played influential roles in the formulation of PHC, the following reasons may be cited:

1. People are more likely to use and respond positively to health services if they have been involved in decisions about how these services are delivered, thus helping to make the services sustainable;
2. People have individual and collective resources (time, money, materials and energy) to contribute to activities for health improvements in the community;
3. People are more likely to change risky health behaviours when they have been involved in deciding how that change might take place;
4. People gain information, skills and experience in community involvement that help them take control over their own lives and challenge social systems that have sustained their deprivation.

The WHO is now calling for PHC to be renewed. The World Health Report 2008 is entitled *Primary health care: now more than ever.* For this reason, if no other, it is timely to review the principle of community participation and seek, from experience, insights to help assess its contributions and the challenges it presents to health programmes.

The purpose of this paper is to review experiences of community participation in health programmes in the years following Alma-Ata and to identify key reasons why the theory behind this principle has been so difficult to put into practice. To do this I shall use lessons about programme implementation defined in a paper I wrote in 1986, review their relevance in the post-Alma-Ata period and suggest three reasons, based on these experiences, why community participation is so challenging for policy makers, planners and health programme managers.

2. Methods

The analysis in this paper is based on an examination of the data from the experience of community participation, in the context of lessons defined in an earlier paper. The data are drawn, for the most part, from reviews of experience of community participation in health, rather than individual case studies. It also draws upon major policy documents, particularly those from the WHO.

In the period leading up to and immediately following the promulgation of the PHC policy, a number of efforts, mainly in the NGO sector, focused on introducing community participation as a component of their health programmes. In the early 1980s, at the request of WHO, a review study was undertaken examining over 200 case studies in the area of maternal and child care. The purpose of the review was to ‘single out the factors and conditions that encourage effective community participation’ to help programme managers integrate participation into their programme planning and implementation. One spin-off of the study was the publication, in a separate article, of lessons about community participation that would be useful to planners. The following four lessons were identified:

1. It was neither useful nor possible to have a standard definition of the term ‘community participation’. The literature showed that ‘community’ and ‘participation’ meant different things to different people in different circumstances. Programme planners set up their own working definitions and proceeded with activities, despite lack of agreed definitions.
2. Studies showed that it was not possible to consider participation outside a political context. Effective participation encounters issues of power and control over decisions, particularly those related to resource utilization.
3. The literature review suggested that it was not possible to create broad, self-sustaining community participation through health services alone. People and communities had other priorities, such as food, shelter, education and income. Health was rarely a priority unless people were sick.
4. It was not realistic to define or pursue a standard model for creating community participation in health programmes. History and culture were strong defining elements of the value, structure and sustainability of any community health programme, with or without community participation.

To examine the relevance of these lessons and to analyse what new insights, useful to planners, have emerged over the past 30 years, reviews and analysis were examined. The reviews were those from 2004, as they assimilate previous experiences and focus on programmes that target the poor and underprivileged. Policy documents, mainly from WHO, were also used to review programmes and to put in context some of the findings.

3. Findings

The lack of a standard definition for community participation continues to plague and provoke both academics and planners. In the field of health, where epidemiology has had a particularly strong influence on identifying and seeking solutions to the health of populations, the term community is often used to denote a population living within a specific geographic area. In the PHC discussions, community-based health care (geographically defined) is the concept often used to translate community participation into policy and programmes. As a result, there is a tendency in both theory and practice to see a community as a target group for a health intervention, and participation as the response of the group to take up advice and activities that have been proven to deliver better health. A recent issue of *The Lancet* devoted to examining the contribution of PHC, especially to the poor in low-income countries, gives many examples of this type of contextualization of community participation.

This view of community participation, however, has been challenged by health professionals, social scientists and, in recent years, by community activists, highlighting the second lesson — community participation must be considered in a political context. The report of the Commission
on the Social Determinants of Health focuses attention on factors going beyond service delivery that are crucial to health improvements. In addition to the obvious, such as water, sanitation, housing, income and education, the report clearly addresses the role of power — who has it and who does not.4 The discussion consolidates a long discourse about how community participation links with and becomes re-defined by addressing issues around power and control.10,11 Among many in the health field, and particularly in the area of health promotion, the term empowerment replaces community participation12 to acknowledge both the need for action and, more importantly for those who are poor and powerless, the need to transform their thinking about their own abilities and capacities.

Examining the contribution that empowerment has made to health improvements, Wallerstein,13 in her review of health and empowerment, concludes that empowerment helps people to act collectively, challenge power inequities and gain outcomes in a range of domains, including greater access to resources and transforming institutions. In the conceptual realm, the work of the Nobel Prize-winning economist Amartya Sen has led cutting-edge thinking about how the capabilities and choices of the poor must be expanded to ensure a greater opportunity to improve life chances.14

The empowerment discourse has been greatly influenced by advocates for health as a human right. The People’s Health Movement is based, according to its charter,15 on health as a human right. Since that time it has mobilized groups throughout low-, middle- and high-income countries to take up causes such as the closure of pollution-causing businesses, access to healthcare, food sovereignty and the rights of political prisoners.16 Its emphasis has been to develop the decision-making capacities of the underprivileged in order that they may exercise their power to gain specific demands, and to give people confidence to act for their own improvement. The activities of such civil society groups has influenced policy promulgation at the international level, particularly in the Pan American Health Organization. Its document on renewing PHC, published in 2007,17 highlighted human rights and community participation in terms of solidarity, an emphasis that was not mirrored by the WHO World Health Report.3 All these experiences substantiate the lesson that there is no standard definition for community participation and that the political context is critical. They also illustrate that the definition of the term remains flexible and fluid, reflecting changes in both local and global dialogues.

Review data suggest that community participation in health cannot be sustained by participation in health services alone; the literature examines health as part of wider community development programmes. A review by Hossain and colleagues18 of community participation and its impact on health in South Asia brings together evidence that community development programmes have made an important contribution to health improvements. It details case-study programmes that have involved communities in the planning and implementation of programmes and have given training and skills that enable poor people to take some control over their own lives. They conclude that it is possible to show the impact of some community development programmes at the community level, but not at the national level. The factors that improve health and the links between those factors and the process of implementation have yet to be identified.

Most visible and concrete is the example of the community health worker (CHW). Alma-Ata was influenced by NGO programmes’ medical doctors with visionayr leadership, who had come to poor communities to bring medical care but, realizing their need for food, shelter and income, responded by extending their work beyond the clinic.19 The work of Raj and Maybelle Arole in Jamkhed in India became the symbol of community health and development at its best. Here, the doctor team went beyond medical care to train local people to work with them in the clinic and in community health, but also gave support to the priority need of agricultural improvement and built community solidarity to become a model of what might be achieved through community participation.20

CHWs became, in many cases, synonymous with PHC. They were initially inspired by the Chinese barefoot doctor who, in the new Communist regime, was a local person providing both basic healthcare and guidance to embrace the radical changes brought about by the new government.21 In the wake of Alma-Ata, CHW programmes expanded rapidly. They were perceived as a magic bullet to meet the difficulties of lack of health providers and lack of community acceptance of basic health interventions. There is evidence that CHWs have made strong contributions to health improvements at the local level.22 In specific case-studies, they have, in particular, contributed to maternal and child health and reducing mortality in these areas. They have also made contributions to the control of communicable diseases, such as malaria and TB, and to work in the area of HIV/AIDS.23

However, in programmes where CHWs are seen as essentially service providers, difficulties concerning their contribution have arisen. With particular reference to scaling up programmes in the national context, many programmes, especially those instituted by governments, proved not to be sustainable. Problems arose around integrating these local health providers into the national workforce. Questions of training, supervision, payment and clear roles became focus for indecision and the eventual denouement of many large-scale programmes.24

Where programmes have been sustained and accepted is where they have been integrated into other community development programmes. These situations are those in which the programmes are less vulnerable because they are ‘driven, owned by and firmly embedded in communities themselves’.25 Programmes that mobilize communities around health issues alone have proved to have short lives.

The discussions around the first three lessons attest to the lack of an existing model upon which to base community participation in health. It is not because of lack of interest. Reviews, such as that published by the US Population Reference Bureau (PRB),26 are examples of the continuing attempt to seek a formula by which to replicate both the perceived and documented benefits of community participation in health programmes. The PRB study examines five case studies in low-income areas seeking to identify factors that produce health benefits. Its data support the views that community participation facilitates better health status; often improves equity of access to resources and services; makes
demands on service providers as well as community members; demands that providers see health as holistic, not just service provision; and identifies trust as both a precursor to and outcome of participation. However, it cannot identify the critical factors, let alone prove their replicability and predictability to ensure specific outcomes.

Similarly, in The Lancet special issue on Alma-Ata, a paper on community participation that seeks to define a replicable strategy, can only find questions rather than answers. It also identifies factors that lead to scaling up small-scale programmes based on community participation, including building partnerships with government, the use of mass media, and spreading success stories by word of mouth. However, the article shows that success is determined by the situation, rather than ensuring that these factors are always present in programmes. They conclude, as does the PRB study, that more research is needed.

4. Discussion

The above findings confirm that the lessons identified in 1986 are still valid today. They also provide data and information that suggest why community participation in health programmes is so challenging. Three simple reasons can be identified that focus the experiences and lessons into points of reflection for tackling the challenges of community participation in health. These reasons are:

1. People hear what they want to hear
2. People hear better that in which they have experience
3. People do not behave in the way we think they should

These three adages reflect the general experience of most people about life. It is perhaps even more evident today, with the high speed and globalization of transfer of information and communications. However, in the context of health and community participation, substituting ‘health professionals’ for ‘people’ for the first two adages and ‘community members’ for the third adage can bring us insights for carrying out health programmes.

4.1. Health professionals hear what they want to hear

The majority of health professionals have been trained in schools that teach their discipline in the biomedical paradigm. This paradigm is essential for curing and controlling disease by addressing physiological factors. However, it has limitations when addressing health improvements, as the WHO World Health Report 2008 highlights. This paper presents evidence that the major limitation in assessing community participation for health improvements is to view it as an intervention. Using the same parameters as case-control studies to evaluate participation limits the type of information that is collected and the way in which it is interpreted. The PRB recognises the constraints, highlighting in its studies that community participation is a process rather than an intervention and thus concluding that interpreting the impact of community participation is not possible.

The inability of the biomedical paradigm to accommodate process evaluation has two other spin-offs. Firstly, community participation is often embedded in the concept of community-based interventions. The concept here is that community members support and contribute to health interventions defined, managed and evaluated by health professionals. Outcomes are measured by quantitative assessments, ultimately reflecting changes in health status. Indicators of process, such as ownership by community members that will lead to sustainability of the intervention programme, arguably the most important part of the intervention, are ignored.

Secondly, where attempts to accommodate process have been undertaken, they are often constrained by the framework in which they are analysed. For example, an article on the contribution of women’s groups to improving mother and child care in Nepal presents findings that view mothers’ groups as an intervention, ignoring the process of what happens within the groups. It presents its findings in a framework that has no way of examining and analysing the process as a contribution to the outcome. Using a paradigm that seeks to evaluate community participation as an intervention restricts the understanding of and expectations about its contribution to health. It has been previously argued that both process and impact are important to comprehend how health improves. Increasing evidence suggests that a serious dialogue should be undertaken to incorporate both approaches.

4.2. Health professionals hear that in which they have experience

Health professionals know about service provision and a great many are aware of the problems of lack of human resources, especially in low-income countries. The obvious solution is to expand the number of health providers, and CHWs appear to be a fairly easy answer to this problem. The Joint Learning Initiative, in its report entitled Human resources for health: overcoming the crises, highlighted the contribution of CHWs to healthcare with evidence from the field. There are, at present once again, attempts to promote them as a fairly rapid and easy solution to a critical health problem.

As has been noted, community participation in PHC has been closely identified with CHWs. Although CHWs found great support in the period just after Alma-Ata, it has been noted their history has not been consistent. Lack of support, in terms of money and government commitment, has not been the only problem. Others include inappropriate training, lack of supervision, lack of incentives for their contribution, including payment and recognition, and lack of integration into existing community health services. With the push to recruit more local workers to fill existing gaps, there is little evidence to suggest that these problems are being addressed. Critical factors such as trust, respect and partnership with community members and service providers are easily overlooked when seeking to deliver known remedies for cure and prevention. The result is often a rapid turnover of personnel as well as drain of patients to the private sector, which very few can afford. The tendency is to overlook personal interactions to gain coverage in numbers.
4.3. People (in this case, intended beneficiaries) do not behave in the way we (professionals) think they should

With the provision of healthcare at the local level, with planning and implementation done in conjunction with the intended beneficiaries, taking account of their needs and problems and attempting to address issues around empowerment, health professionals expect a positive response to their help and advice. When this is not forthcoming, as has been the case in many attempts to develop community-based health programmes, planners and managers seek reasons for their failures. They ask: why hasn’t health status improved through community participation?

As this article has intimated, perhaps it is the wrong question. The articulation of a question that assumes a direct relationship between participation and outcome in a linear, causal paradigm ignores critical factors that influence the relationship. In the case of health improvements, these factors include leadership, compassion, bonding relationships and building of partnerships. All these factors are difficult to quantify and are heavily influenced by community history, culture and social development. All these factors also give insight as to why people don’t behave in the way we think they should.

It is possible that the questions we ask should be framed as ‘what works, for whom and why?’ rather than ‘is it reliable and representative of the phenomenon that we are investigating?’ Rather than looking for direct causal relationships we should be looking at the views, experiences and perceptions of those involved in community health programmes and describe these findings without trying to fit them into our preconceived view of how the world should operate because of assumptions of patterns of behaviour. Community participation is essentially about people. Perhaps we need to listen to them rather than to shape their contributions into a universe that we understand.

5. Conclusion

Evidence has been forthcoming to show that community participation has made significant contributions to health improvements, particularly among the poorer members of the population. However, the term itself has a number of meanings and experience suggests that standardization of the concept is neither possible nor desirable. Communities are composed of different people at different times, and depending on the needs and capacities of its members, participation runs along a continuum from merely responding to professional advice to empowerment. It therefore appears that the success of community participation is situational, and attempts to replicate it on a massive scale are futile. Leadership, trust, building partnerships and solidarity are critical and are a result of history, culture and tradition. Replication is neither necessary nor urgent to attain sustainable improvements.

In conclusion, community participation as a critical factor in health improvements was identified 30 years ago in the Alma-Ata declaration. Like the entire declaration, it has continued to be relevant over this period and is, once again, being highlighted as an essential element for improving health, particularly among the poor, in all countries. Over these years, experience, analysis and insight have identified ways in which we can better understand and support this concept. We need to grasp these ideas, break barriers that limit new applications and take the challenges they bring to improving health, rather than confining our attention to curing and controlling diseases.

Author’s contribution: SBR has undertaken all the duties of authorship.

Acknowledgements: The author wishes to thank M.R. Bhatia, N. Gerein and M. Rosato for their comments and suggestions.

Funding: None.

Conflicts of interest: None declared.

Ethical approval: Not required.

References


