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“It’s not a textbook thing, is it?”

The use of lay knowledge in promoting health and increasing equity in more economically developed countries

The phrase “economically developed countries” is deliberately used in the title of this essay to draw attention to the fact that many affluent societies are insufficiently developed with respect to other aspects of well-being. Persistent health inequalities are an example of the way in which developed countries are as likely as less-affluent countries to be less developed in terms of social justice. In the United Kingdom (UK), public health has improved considerably over the last century, yet the gap between those at opposite ends of the social spectrum continues to grow. Men in the central London borough of Kensington and Chelsea live on average 83.7 years, while the average life expectancy for their counterparts in the Carlton area of Glasgow is just 53.9 years (1), the lowest in Europe. How can it be that a community in a so-called “developed country” has a life expectancy that compares badly with almost anywhere in the world? What can and should the health service do to address this situation?

Over the past few generations, the diseases afflicting the developed world have undergone dramatic changes. Polio, diphtheria and many other infectious diseases are disappearing, while two thirds of all deaths in the UK can now be attributed to cancer, coronary heart disease and stroke (2). These shifts are generally equated with a decrease in suffering and attributed to more and/or better medical care, though there is no evidence that a direct relationship exists. For example, almost 90% of the decrease in scarlet fever, diphtheria, whooping cough and measles in children took place before the introduction of antibiotics and extensive immunization. The advances have largely been a result of economic growth, which has contributed to rising standards of living, improved education, better nutrition and better housing. However, some segments of the population have not benefited from the improvements to the same extent as others. At the same time, individuals from these groups are more likely to exhibit “unhealthy” behaviours such as smoking, consuming a poor diet and physical inactivity, which are known to be major determinants of morbidity and mortality.

Health-related behaviours are often referred to as preventable lifestyle factors that, when they are subject to an appropriate behavioural intervention, can be reversed, resulting in health improvement. Examples include smoking-cessation services and weight-management programmes, which have the potential to increase health inequality by being more attractive and accessible to the middle classes. Furthermore, the separation of lifestyles into different elements reinforces the biomedical model of health, wherein the biological is emphasized at the expense of the social, and the physical to the detriment of

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All professions are conspiracies
against the laity.”

—George Bernard Shaw, 1911

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the psychological. This results in the decontextualization of health behaviours by failing to consider how these factors interrelate and neglecting the real issues that people face in their lives. The resistance of disadvantaged groups to lifestyle advice often reflects a valid lay epidemiology whereby "unhealthy" behaviours can be deemed a rational response to everyday reality (3, 4). A common example is the use of smoking as a coping mechanism in stressful situations.

Lay knowledge represents a "privileged" form of expertise about health, which poses an epistemological and political challenge to the institutional power of expert knowledge (4, 5). Medicine rests upon the concept of disease as something that can be treated objectively, while lay knowledge is rooted in the subjective experience of illness. This tension is growing in importance with the inadequacy of medical explanations for many common lifestyle-related conditions and with explanations becoming so reductive they exclude what is significant to the individual. The anthropologist Cecil Helman suggested that modern medicine carries the risk of dehumanizing the patient by focusing on events within the body and creating "paper patients", i.e., emphasizing written records over patients' narratives (6). There have consequently been calls for new ways of humanizing medical practice to respond to changes in the financing, organization and delivery of health care, which have resulted in a fundamental shift in the relationship between patients and care providers.

Recent years have seen a reconceptualization of patients as clients or consumers, particularly with the individualistic ethos of the lifestyle approach and neoliberal resurgence in public policy. A key public health document entitled *Choosing health: making health choices easier* was published by the UK government in 2004 (2). This policy emphasized consumer choice and personal responsibility for health, while paradoxically acknowledging that socioeconomic disadvantage limits opportunity and restricts choices for many of those in the poorest health. Rather than aiming to improve their circumstances, the intention was to help these individuals cope better with their continuing disadvantage through a mix of education, advice and personal support to make informed lifestyle choices. Much of this work will be carried out by health trainers, who occupy a new non-professional workforce role in the National Health Service. Rather than having any sound empirical or theoretical basis, the introduction of this new role seems to imply a widespread recognition that health professionals have failed to meet the needs of people living in local communities.

The concept of lay, indigenous or paraprofessional health workers is not a new one. It is born out of the belief that every community has people to whom others turn naturally for help and advice, and is supported by theoretical arguments from anthropology positing the existence of folk and popular (lay) health systems alongside the formal system. These theories suggest that, whereas health professionals may be the most effective at treating disease, indigenous folk healers may be better suited to dealing with illness (7). The evidence for the effectiveness of lay-led programmes has so far been mixed, but there are good arguments for identifying and training people who share the language, beliefs and cultural characteristics of the communities they support to act as 'cultural

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brokers' between the various health systems. Programmes that rely on lay workers have proliferated in the United States since the 1960s, when the role was implemented to provide mandated outreach services in poor neighbourhoods and migrant labour camps. In addition, developing countries frequently rely on lay workers where professional providers are scarce.

The UK model is situated towards the primary prevention end of the health-care continuum, rather than playing a significant role in diagnosis, treatment or disease management. This is due to universal health system coverage and the high quality of primary care in this country. However, the inverse care law continues to operate, such that individuals from poorer areas tend to experience further disadvantage in terms of their access to, uptake of and outcomes from a range of health services and interventions. The aim of the health trainer is to facilitate the uptake of preventative services, as well as encouraging healthier behaviour and engaging groups that are typically hard to reach. Roughly 1-2% of the population is not registered with a general practitioner, yet this figure is 8% among the clients of health trainers, indicating that they have achieved some success in engaging marginalized or excluded groups (8). A possible explanation is that a shared cultural identity between health trainers and service users makes it easier for them to access these individuals and understand their health needs. In my research, clients frequently make comments such as "they're on my wavelength" and "she's just one of us", bringing benefits in terms of "experience of the community", rather than textbook knowledge.

The health trainer role is relatively new and, in many areas, still being integrated into local health systems. There has been mild resistance, reportedly due to some professionals perceiving it as a "cheap way of ousting existing staff" and expressing concerns about the quality of the service. Lay or paraprofessional workers are likely to play an increasingly important role in health-care environments that are challenged by limited financial and human resources and expanding populations with chronic illness. There is some concern that these developments, combined with increasing lay knowledge of health, have undermined the cultural authority of doctors and weakened the monopoly of medicine. Hence, moves towards greater control and choice for patients and the public have naturally been met with scepticism and anxiety by some health professionals.

Despite the provocative quote at the start of this essay, the intention has not been to suggest that health professionals have no role to play in promoting health or enhancing equity. Instead, I would like to see greater pluralism in health systems and more openness to lay participation, with rejection of expert-dominated relationships in favour of more egalitarian models of client-provider partnership. The UK health trainer role is beginning to generate evidence to suggest that lay workers can be effective in terms of reaching populations that are unlikely to access formal health-care services. If the role is to be successful, the value accorded to different types of knowledge needs to be much more equal than at present. Lay expertise should be seen as a valuable source of experiential knowledge to be used in contextualizing and delivering all services seeking to improve health equity.

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Biography

Shelina Visram graduated from Oxford University, United Kingdom, in 2003 with a Bachelor of Arts in human sciences with honours. She began working for Northumbria University, Newcastle-upon-Tyne, United Kingdom, as a research assistant in 2004, where she developed a keen interest in health promotion. After completing a part-time Master of Public Health at Northumbria University in 2007, Shelina was awarded a doctoral research fellowship by the National Institute of Health Research in 2008. This fellowship has enabled her to design and conduct a project exploring the use of lay health trainers in the National Health Service. Her thesis is due for submission in September 2011.



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