Patient organizations and public health

Introduction

In a stimulating paper in the British Medical Journal,1 Show and Baker described the turmoil produced 15 years ago in the medical profession by what has since then been coined the ‘expert patient’: a patient whose specific knowledge about his disease challenges the power of the medical profession to decide alone the nature and the way his care should be organized. Several alternative models of the clinical encounter have emerged, focusing on the ability of a patient to cope actively with his disease, and emphasizing the ‘patient empowerment’ which is facilitated by the specific knowledge which the patient draws from his experience.2

A ‘patient collective identity’ sometimes emerges from the experiences shared between members of the same disease group. Patient organizations (POs) have been a strong factor in shaping these identities. As a recent special issue of Social Science and Medicine shows, some of these POs have got involved in activities (e.g. medical research or health planning) previously considered a professional prerogative.3

The community of public health researchers has not yet fully appreciated the impact these developments may have on their activities. While a recent viewpoint in this Journal seems to reflect a certain awareness of this ‘blind spot’, when it acknowledges the fact that ‘a new partnership to involve the whole society in reorienting health policies’ is necessary,4 POs are not mentioned as potential stakeholders.

Dynamics of patient organizations

Sharing patients’ experiences with a specific disease has been the basis of the action of many POs. Until the 1980s, POs were frequently dominated by professionals in their boards or scientific councils, so they lacked the capacity to develop specific knowledge and shape their actions autonomously. Two sets of closely related factors can be considered as major drivers towards a better institutional recognition and autonomy.

The first, fuelled by various crises (Bovine Spongiform Encephalitis), scandals (contaminated blood; asbestos) and controversies (Genetically Modified Organisms), is linked to the perception by the public of growing health threats. These threats cast doubt on the capacity of scientists, health professionals and politicians to frame the political decision process. Building on the perception that voices from all stakeholders were necessary ingredients to fuel a more open and transparent decision process, POs claimed the recognition of their specific form of expertise.5

Their political ability to put patients’ expectations at a higher level in the political agenda was facilitated by a second factor linked to the evolution of democratic societies: a growing individualism which entitles each consumer to take responsibility for decisions impacting on his life. Long before POs began their fight for more autonomy, core health institutions had started to take these elements into account: Successive European regulations since 1948 have promoted patients as partners, raising them to the same (formal) level of responsibility as professionals and regulators, while setting out some principles and instruments to implement this new policy.6 In 2000, the fifth recommendation of the ministerial council of the European Union stipulated that ‘consumers and patients should participate in the process of defining goals for the health system’.

Patient association involvement in the fields of research and health care policy

POs’ involvement in biological and clinical research offers a first striking illustration of their expanded role. Not only have POs sometimes influenced the process of research, but also decision making on research. In France, in the context of the AIDS epidemic, by creating a new balance of power between patients and professionals, POs succeeded in redesigning the methodology of clinical trials in order to take into account patients’ disease experiences and rights. Considered as ‘new experts’, they were active partners in the selection of the population to be included in trials.7 In the United States, the ‘Women’s coalition for breast cancer’, in order to tackle the medical uses of oral contraceptives, had a critical role in the launching of randomized clinical trials, and continues to be active in the controversies related to their results. In the field of rare diseases, research design and orientation were directly tackled by POs: Rabeharisoa has shown how the French Association against Neuromuscular Diseases, boosted by their fund raising capacity, turned the research community in another direction. This was called a ‘distributed knowledge acquisition process’ in which each partner recognizes and gives equal value to the specific knowledge of the other.8

It is worth paying attention to two elements. First, while working with professionals, patients have demonstrated their ability in assessing, formalizing, staging and distributing knowledge drawn from their specific experiences. Also, in parallel with their fight for ‘patients’ rights’, they have challenged medical practices such as diagnostic processes, medical consultations and the side-effects of drugs. So today ‘lay expertise’ can be described as a ‘body of hybrid knowledge in-between patients’ experience and professionals’ expertise’.9 Secondly, in various institutions, we are witnessing the development of initiatives aimed at integrating patients’ experiences and knowledge into experts’ groups. In France, the non-governmental drug agency investigates and circulates patients’ experiences on drugs and therapeutics, while HAS (the French agency equivalent of the British NICE) involves PO representatives in groups working on clinical recommendations, hospital certification or clinical paths for chronic conditions.

What remains a partly open question is why POs sometimes succeed in establishing patients’ authority and legitimacy vis-à-vis the medical and political arena, and sometimes not. Why were they able to strongly impact the organization of health care for neuromuscular diseases and cystic fibrosis, as it happened in France, and has their influence tended to be weaker in the field of cancer?

Patient associations, collective interest and equity

Alongside their traditional role, POs also act as ‘mediators’ between the various
actors involved in the ‘war against disease’, endorsing new social responsibilities and gaining political leverage for negotiations with decision makers.

European coalitions of POs represent a powerful instrument not only in sharing collective knowledge between national POs, but also in their effective voicing of citizens’ claims at a European level. By mobilizing public opinion in favour of research, EURORDIS, the patients’ coalition for rare diseases, succeeded in passing the European Orphan Drug Act. It was also a key player in the development of an effective market approach, gaining the support of pharmaceutical firms for setting up medical trials involving patients and their representatives.

Coalition formation among different patient groups also offers a pragmatic answer to the following ethical issue: how can a specific organization, which captures resources to the detriment of others, act in order to represent common interests? Other examples are the mobilization of NGOs leading to AIDS treatment access in developing countries in which POs had an important role, and the ‘European patient forum’ acting as a powerful lobby in Brussels. In France, a coalition (CISS) brought together organizations of patients, disabled, consumers and the elderly in a joint fight for a ‘consumer and patient oriented health information system’, the creation of a specific indemnity process for people having experienced adverse health events, and the development of a more effective hospitals risks management process.

So one of the more robust results is that POs are not only to be considered as powerful resources in shaping patients’ strategies to face the consequences of their illness, but also as major instrument to help them organize their life as citizen or consumer.

What can public health learn from these facts?

Some public health researchers, facing issues involving competing sources of evidence and heterogeneous public expectations, may be willing to move toward new methods allowing ‘lay people’ more power in the research process or in designing public health programmes. But others may be reluctant to do so for two reasons.

First, the institutions informing and framing the decision-making process were always professionally led and staffed by experts. So it seemed inappropriate to involve the wider community of citizens, as public judgement was considered to be influenced by misunderstandings, prejudices, emotions or self-interests. The fact that the decision-making process requires the weighing up of information of a specialized and technical nature, and often leads to potentially contentious priority choices, reinforced the opposition to lay involvement. Even in cases where the decision process incorporated the opinion of lay persons, it usually relied on methodological assumptions defined solely by health care professionals with no real direct lay input, thus potentially misrepresenting public opinion.

Secondly, experts may be reluctant because they do not know how to work with groups of patients in a problem solving perspective. The answer lies in the application of existing methodologies which have been built in order to help lay persons participate in a transparent, accountable and inclusive decision-making process, even if the latter involves complex and multifaceted issues, and competing pressures and interests. Examples of such methodologies include citizen’s jury, Danish consensus conferences, deliberative conferences, and scenario framing. As they require a complex approach that goes far beyond the provision of information or the solicitation of public opinion, they are not straightforward to set up, and success is not guaranteed.

They share the capacity to allow participants to take a broader view of the issues at stake, because participants are provided with elements underpinning the trade-offs inherent in potential responses and solutions. So participants are brought in a position to engage collectively around the issues, to reflect on what they have been provided with, to weigh up information and data, to reason with the issues, and to refine their opinion through discussion with peers and experts. This is what transforms ‘public opinion’ into ‘public judgement’, and what fosters a genuine dialogue between professionals and lay people.

Researchers working on the quoted cases confirmed that it was precisely this kind of dynamic that made these experiments successful: in fields where professional expertise seemed previously unquestionable, when patient-specific knowledge was carefully embedded in the process of knowledge acquisition, they did contribute, together with the scientific expertise, creating a common knowledge and tracking new pathways for problem solving. This happened also in the field of environmental health. The contamination of air by particles and the way it affects the population at large, with differentiated impacts across space and social groups, is a concern for public health experts. In parallel, a number of ‘air crises’ have shown the inadequacy of current conceptions of knowledge and of public action to provide adequate responses in terms of decision-making processes. In a recent paper, Brown et al. give an example of how minority activist groups, in their struggle to reduce pollution, tried to influence the decision-making process by creating a coalition with asthmatic patients. Building on the controversy about the role of external environmental factors in causing or triggering asthma and using as a ‘moral argument’ the socially unequal health impact of the distribution of particles, they set up a strong partnership with academic researchers and then succeeded in enforcing more stringent local but also national regulations. The research showed how their work on environmental factors lead to a collective form of illness experience in which minority people with asthma were able to make direct links with social determinants of their health.

I am not saying here that all public health researchers should transform themselves into health activists, but only that the experiences cited may convey new understandings on how to build better research and design more efficient public health programmes by considering the unexplored creative capabilities of patients, consumers and citizens. While I am aware of the difficulties for many public health researchers in moving towards this kind of partnership with POs and community groups, as it represents a ‘cultural shock’, I believe they nevertheless should engage themselves in this direction, which has been efficient in other closely connected fields.

References
Patient organizations and prevention in the Netherlands

The paper ‘Patient Organizations and Public health by M. Naiditch’ highlights the importance of patients’ experiences and knowledge for health research and policy. The analysis also applies to developments in the Netherlands of the past 20 years, in which individual patients and consumers have founded hundreds of patients’ organizations. Some of these are organized around a specific disease or illness; others focus on broader issues related to the position of patients and consumers, like information and quality of care. In the early nineties the need was felt for an umbrella organization. The Netherlands Patient and Consumer Federation (NPCF) was founded in 1992 to represent common interests at a national level, creating one voice on subjects such as patients’ rights and access to care and public health programmes. The NPCF represents more than 3 million people: 3 million health care consumers. Jointly with its member organizations it promotes common interests towards influential parties in the field of healthcare, policy makers, healthcare providers, insurance companies as well as in the field of research. It develops and implements programmes to strengthen the position of the patient. Like other European countries, the Netherlands is confronted by a number of autonomous trends and developments that affect and challenge the health care system such as: increasingly demanding citizens, rising public expectations, an ageing population and rapid technological changes. Furthermore, the Netherlands is facing increasing pressures in terms of cost containment and financing, access to services and the quality and sustainability of health care.

A sustainable society calls for a sustainable health care system. Therefore, it is necessary to innovate the health care system based on the needs and demands of citizens. It is those needs that the NPCF tries to identify and promote. The main question is: do citizens receive the care that meets their needs and demands? In every ‘normal’ market it is said that the customer is always right. This means that he receives a good product that meets his needs, and that he is being serviced to his satisfaction. The NPCF works on a long-term strategy on the position of consumers, in order for them to become the so-called third party in our health care system, or better still, the first party in the long run! This strategy does not only apply to the patients’ position in negotiating the cure and care packages of healthcare. The NPCF encourages investments in national preventive programmes and makes an appeal for including prevention in health insurance packages. It promotes patient participation in research and in the development of intervention strategies. Today, patient and consumer organizations are in a position to negotiate collective contracts with healthcare insurers not only to get a lower premium, but also to have preventive programmes included in the contracts.

The NPCF critically follows the political process and the health care research programmes from a patients perspective. Today, ‘the patient’ has become a respected and honoured participant in the political discussion and decision-making process in the Netherlands. This strong position can and will be used to promote improved treatment services as well as improved prevention services.

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