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The experiential knowledge of patients: a new resource for biomedical research?

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Abstract

Both governments and patients' movements are increasingly making a plea in favour of the active participation of patients in biomedical research processes. One of the arguments concerns the contribution that patients could make to the relevance and quality of biomedical research based on their 'experiential knowledge'. This article reflects on the validity of patients' experiential knowledge in the context of biomedical research processes. Since a conclusive argument on the validity of patients' experiential knowledge could not be reached on the basis of theoretical reflection alone, a pragmatic approach was chosen that assessed the validity of patients' experiential knowledge in terms of its practical usefulness for biomedical research. Examples of patient participation in biomedical research were sought through literature research and more than 60 interviews with (bio)medical scientists, patients, representatives from patients' organisations, and health professionals in the Netherlands and the United Kingdom. These examples were analysed for a concrete contribution by patients to the research process. Twenty-one cases of patient participation in biomedical research were identified. After further analysis, concrete use of patients' experiential knowledge could be traced for nine of these cases. These findings suggest that patients' experiential knowledge, when translated into explicit demands, ideas, or judgements, can contribute to the relevance and quality of biomedical research. However, its deliberate use would require a more structural and interactive approach to patient participation. Since the implementation of such an approach could face various obstacles in current biomedical research practices, further research will be needed to investigate its feasibility.

Keywords: Patient participation; Experiential knowledge; Consumer involvement; Biomedical research; The Netherlands; United Kingdom

Introduction

During the last two decades, the role of patients[1] in health research has changed considerably from being passive objects of research to increasingly becoming active partners. For example, they take part in advisory panels on ethical issues, in prioritisation panels or

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[1] In this article we use the term 'patients' to indicate everyone who has personally experienced diseases or illnesses. In participation literature, many authors use terms like 'consumers' or 'users', referring to all (potential) users of health care services. Since we are specifically interested in the knowledge people acquire as a result of repeated personal experiences with having an acute or long-term health condition, we think the term 'patients' is more appropriate.

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steering committees, and review research proposals and draft reports (Oliver & Buchanan, 1997; Funnell, 2001; Hanley, Truesdale, King, Elbourne, & Chalmers, 2001; Koops & Lindley, 2002; Telford, Beverley, Cooper, & Boote, 2002).

Several reasons for this change have been identified. Firstly, patient participation increases the legitimacy of health research. Health research is largely a public good and therefore decision making about the direction and execution of health research should be a democratic political process involving all relevant actors, including patients. Moreover, patients have a moral right to participate in decisions that may substantially affect their lives and bodies. Secondly, patients can contribute to an improved quality and relevance of health research, especially through the specific kind of knowledge and expertise that patients gain as a result of experiences with their illness. This knowledge can complement the knowledge of researchers by providing wider perspectives and options (Popay & Williams, 1996; Entwistle, Renfrew, Yearley, Forrester, & Lamont, 1998; Goodare & Lockwood, 1999).

Most examples of patient participation described in the literature turn out to concern public health research, health care research, or clinical research. Biomedical research,[2] which can be considered the scientific foundation of Western medicine, rarely involves patient participation. Given its technical character, it is generally considered to require highly specialist knowledge, which makes biomedical research a less obvious option for patient participation. Biomedical researchers have often argued that patients lack the objective knowledge that would enable them to make any relevant substantive contribution to biomedical research processes (Oliver et al., 2001; Boote, Telford, & Cooper, 2002). This is clearly illustrated by the remark of a biomedical researcher we interviewed:

> Patients should not interfere in processes of which they know nothing about.

However, others argue that the specific knowledge of patients is a rich source of information that could improve the relevance and legitimacy of biomedical research, as is already the case in other types of health research (Entwistle et al., 1998; Flinterman, Teclemariam-Mesbah, Broerse, & Bunders, 2001). The fact that it may be difficult and complex to realise is in the opinion of these scholars a poor excuse for not pursuing the integration of patient knowledge into biomedical research processes. Some patients share this view as well. One patient whom we interviewed, also a member of several consumer-oriented and patient-oriented organisations, remarked:

> The problem with biomedical research is that research questions are often relevant from a scientific perspective, but this does not imply that they are also relevant from the perspective of patients. Biomedical science is very reductionist. This leads to useful knowledge and innovation, but the broader context—the overarching 'system'—is ignored. Patients have specific knowledge about what it is like to live with one or more ailments. By not involving patients, biomedical research is overlooking an important source of knowledge.

These contrasting views call for closer scrutiny.

This article therefore focuses on the added value of patient participation for biomedical research: what knowledge can patients contribute to the biomedical research process? After a theoretical reflection we investigate the validity of patients' knowledge by analysing its potential value for biomedical research in practical examples. To this end, interviews were conducted with more than 60 (bio)medical scientists, patients, representatives from patients' organisations, and professionals from intermediate organisations, such as research councils, research financiers, research institutes focusing on patient empowerment or patient participation, research knowledge agencies for patients and patients' organisations, etc. The practical feasibility of structurally including patients in biomedical innovation processes is discussed in the final reflection.

A theoretical reflection

Expert knowledge is usually considered more general and objective and therefore more accurate than the subjective knowledge of lay persons—which some authors call 'lay' or 'non-expert' knowledge (Popay & Williams, 1996; Entwistle et al., 1998; Nordin, 2000). To avoid any suggestion of inferiority, we use the term *'experiential knowledge'* which directly refers to the ultimate source of patient-specific knowledge—the often implicit, lived experiences of individual patients with their bodies and their illnesses as well as with care and cure. Experiential knowledge arises when these experiences are converted, consciously or unconsciously, into a personal insight that enables a patient to cope with individual illness and disability. When patients share

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[2] We define biomedical research as bringing together fundamental and applied aspects of biology and medicine with the ultimate aim of contributing to the improvement of human health, e.g. by searching for causes and working mechanisms of, and/or therapies for, pathological disorders. In contradiction to others, we explicitly exclude clinical trials from our definition since this type of research more or less concerns test stages in development processes whereas biomedical research concerns early stages in research and development processes, which are far less accessible for patients.