

physician in such circumstances? And of course, each consultation, scan, treatment, or whatever requires a follow up consultation at my general practice, where it is quite likely that the general practitioner who referred me is not the general practitioner who deals with the consequences of the referral.

Towle and Godolphin make much of the need for patients to formally take a measure of responsibility in planning their treatment, and this requires that they are well informed about their condition and possible treatment options. Excellent. In my case I can and do monitor the scientific and academic press, websites, and news groups to stay aware of any developments that may have a bearing on my future treatment. But this is only possible because I am 51 years old, literate, articulate and have access to and an understanding of the techniques of information gathering and evaluation. What chance is there for elderly, poorly educated, and socially disadvantaged patients with the same condition that I have? Must they rely on the posters on their general practitioner's surgery wall?

Furthermore, not all patients will see informed shared decision making as desirable. Many patients— young and old—much prefer to believe that “Doctor knows best,” and this cannot be lightly dismissed, even though it might be unacceptable to Towle and Godolphin, and perhaps to many other doctors. For such patients, informed shared decision making will be seen as doctors opting out of their responsibilities rather than an improvement in the doctor-patient relationship.

Finally, I wonder how such a tiny sample size of physicians, patients, and “patient educators” can be cited as valuable in making “a set of necessary and sufficient competencies.”

Desirable though it might be for some patients to be more closely involved in managing their condition, the authors' suggestion that informed shared decision making become standard working practice presumes too much about the role of patients.

Competing interests: None declared.

Acknowledging the expertise of patients and their organisations

Judy Wilson

The proportion of people living with a long term medical condition, both in the United Kingdom and throughout the world, is rising.^{1 2} By living with and learning to manage a long term illness many people develop a high degree of expertise and wisdom. This article suggests ways in which people with a long term medical condition and their organisations can help develop partnerships between healthcare professionals and patients and questions how much their potential contribution is appreciated and capitalised on.

The US Centers for Disease Control and Prevention defines chronic diseases as “illnesses that are prolonged, do not resolve spontaneously and are rarely cured completely.”³ The Long-term Medical Conditions Alliance is developing a much broader definition that emphasises the effect that this type of illness has on people's emotional and social wellbeing; on their social, community, and working lives; and on their relationships. The alliance's definition emphasises the opportunities available to improve a person's quality of life, even when there is no cure for a particular condition. All these issues must be taken into account in planning when assessing a person's needs and how best to meet them.

The Long-term Medical Conditions Alliance is the umbrella body in the United Kingdom for 96 national voluntary organisations. Formed initially because of concerns arising from the reforms to the NHS in 1990, during which market principles were adopted to increase the efficiency of the service, the alliance enables organisations to work together to gain mutual support, to identify common concerns, to develop solutions, and to influence policy and practice.

Summary points

People living with a long term illness develop expertise and wisdom about their condition and want to play a part making decisions about their own health care

Partnerships should be encouraged between individual patients and healthcare professionals and between patients' organisations and the healthcare system

Developing partnerships between patients and healthcare professionals is not good in itself but offers a chance to improve health care and to make better use of resources

Partnerships can only be developed if there is investment by governments, if patients' capacity for self care is increased, and if the role of patients' organisations is developed

Partnerships between individuals

The concept of patients working in partnership includes the idea of patients working with healthcare professionals. Research in the Netherlands has shown that people with a long term condition want their relationships with clinicians to be based on mutual trust and respect. Most want to be responsible consumers of health care if the providers of that care create an environment in which patients receive guidance when choosing between alter-

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BMJ 1999;319:771-4

natives.⁴ There are areas in medicine in the United Kingdom, such as diabetes care, in which it has long been accepted that a person with a particular condition can play an important, and sometimes a leading, part in their own care and in the management of their disease, but most patients' organisations believe that this ideal has not yet been generally accepted.⁵ The concept of patients forming partnerships with healthcare professionals does not exist universally no matter how easily the rhetoric embraces it.

Patients' organisations

Organisations of patients, service users, and carers, which are often led by users, have grown in number as has their impact. The College of Health (<http://homepages.which.net/~collegeohealth>), a national charity promoting patient centred care through research, training, and information, maintains a database of 2500 patients' organisations, compared with the 800 that it had 15 years ago.

Patients' organisations have many elements in common. They frequently develop as the result of a local or national need, and they are usually formed in response to a specific medical condition. Some are small, based in a member's home, and run voluntarily by committee members who have the condition themselves (box). Others have multimillion pound budgets and a large number of staff (box).

Patients' organisations in the United Kingdom

Depression Alliance

Depression Alliance describes itself as an alliance of people who have depression or who have recovered from depression; membership also includes their carers, families, and friends. Depression Alliance provides publications and runs workshops, seminars, and conferences and a network of self help groups across the United Kingdom. There are offices in England, Scotland, and Wales, and Depression Alliance has developed strong links with similar European organisations.

Depression Alliance became involved in commissioning health care while working with the Wiltshire Health Authority to produce a service specification for depression. Conducting focus groups of service users proved to be an effective way of using patients' expertise. A Depression Alliance member now serves on the healthcare commissioning team in Wiltshire and close cooperation between the health authority and the alliance has resulted. Services for people with depression are now seen by both the authority and Depression Alliance as far more appropriate and more effective. Additional information is available from its website at www.depressionalliance.org.

Arthritis Care

Arthritis Care describes itself as a large national charity in the United Kingdom and a member of the European League Against Rheumatism; it aims to empower people to take control of their arthritis, their lives, and their organisation. It has been led by its users since its founding 52 years ago by a man who had arthritis.

The charity, with 59 000 members and 622 branches and groups, has produced best practice guidelines and increasingly frequently is able to influence policy. Its helpline responded to over 12 500 inquiries last year, and 1740 people took the organisation's self management course, "Challenging Arthritis."

This training course is run by lay people and lasts for six weeks. Leaders, who are trained volunteers, have arthritis and act as mentors and role models as well as trainers. Research has shown that as a result of completing the course people feel that they are substantially better able to manage their arthritis, reduce their pain, and that they have improved psychological wellbeing.⁶ Additional information is available from www.arthritiscare.org.uk.

Their common goals are to provide information and support to their members and to provide information to the public, raise awareness, and influence professionals and policymakers. Many organisations focus on highlighting deficiencies in services; some aim to promote the use of particular treatments or drugs. Most want to work with health professionals while retaining their autonomy. All of these groups face problems with funding and potential conflicts of interest.

Increasingly, organisations that receive part of their funding from pharmaceutical companies choose to address this potential conflict of interest by having their trustees adopt clear guidelines to ensure transparency in the organisation's operations and to ensure that the organisation maintains control of its activities.⁷ Some organisations have yet to address this potential conflict.

However, such organisations are often the source of innovation in health care and they often provide information to patients and health professionals and promote self management and the development of best practice. Their potential has yet to be fully developed, recognised, and used.

Benefits of user involvement

There is growing agreement that involvement by individual patients in making decisions about their care increases the effectiveness of their treatment. Service users are increasingly involved in planning and providing services and in monitoring and evaluating their outcomes, and their input is increasingly valued by healthcare providers and politicians.^{8,9}

Successful methods of involving service users have been developed by many healthcare organisations, including the health authorities that became partners with the Long-term Medical Conditions Alliance on its project, "Patients Influencing Purchasers." Nottingham Health Authority, for example, worked with people with breast cancer, kidney disease, and back pain to develop a model of involvement by holding a series of focus groups; 200 users worked with six health authorities to decide how best to commission services for people with specific conditions. The project also identified broad principles which should underpin services for people with long term conditions such as ensuring that there are people for patients to talk to, particularly soon after a diagnosis has been made.¹⁰

Constraints and difficulties

What are some of the constraints on these two interrelated activities: individuals' involvement in their own care and organisations' involvement in improving services? What techniques might overcome some of the difficulties?

Complexity of healthcare systems

A Canadian author, in describing the complexity of having a chronic illness, argues that the exhausting nature of the experience of finding one's way through a healthcare system needs to be acknowledged.¹⁰ Member organisations of the Long-term Medical Conditions Alliance often find that health and social care is provided by separate teams and agencies, each



The United Patients' Organisations of the Chronically Ill in the Netherlands receives substantial government funding

operating in its own way and to its own timetables.¹¹ There is no evidence of consistent, universal attempts to provide services which emphasise the patient's needs and social contexts. If service providers cannot work together effectively, then developing a partnership with patients is made even more difficult.

Professional attitudes

Member organisations of the alliance have also reported that patriarchal attitudes continue to exist among healthcare professionals. Although there have been changes, and these are welcome, the powerful position of many doctors and the lack of appropriate training in how to work in partnership with patients still prevents the appropriate use of patients' expertise and wisdom.¹¹

Lack of political commitment

Government policy documents which outline the framework for the new NHS set out principles for the involvement of service users and their carers. For example, the consultation document on quality in the NHS, *A First Class Service*, stated that "We need the active participation and partnership of clinical professionals and patients throughout the NHS."¹² In practice, the position of service users has been weakened because the involvement of users has been confused with public participation and health professionals have been given the authority to define users' needs for them.¹³ At a conference for primary care groups, the prime minister referred to "grateful patients" not to the potential contribution of patients to their care (Birmingham, 13 April 1999).¹⁴

Professional pressures

A substantial constraint arises from the lack of time available to clinicians to invest in forming partnerships with patients. The limited time scheduled for individual consultations by general practitioners, for example, does not allow for the discussion and debate implicit in the idea of a partnership. The heavy case load, which includes a substantial amount of non-medical matters such as housing, especially for general practitioners in urban areas, means that for some the concept of build-

ing partnerships is almost impossible to consider (personal communication).

Overcoming hindrances

Progress is being made in some areas of building partnerships but not enough to make the most of them. Investment is necessary in different forms of capacity building: time, training, and cash.

Equipping the NHS for partnership

Capacity must be developed within the NHS to put new policies into place.¹⁵ Building capacity requires investment in training and development and in structuring organisations so that employees have the relevant skills and competencies. This is as true of building partnerships with patients as it is for any other development in the NHS.

Developing self management skills

Self management programmes led by lay people, which combine teaching techniques for managing a chronic disease with inspiration from role models and the offer of mutual support, can develop the capacity of individual patients to contribute to a partnership. Studies in the United States have shown that these programmes can improve the health of the individual and reduce both the incidence and number of days of hospitalisation.¹⁶ The UK government's new consultation paper on public health recommends the development of an "expert patients" programme.¹⁷ When initiatives like this are taken together with new programmes developed by the Long-term Medical Conditions Alliance through the "Living with Long-term Illness" project, there are real opportunities to develop patients' self efficacy—that is, an enhanced sense by an individual of how much they can cope with and achieve.

Making patients' organisations more effective

The third form of investment needed is to develop the contribution made by patients' organisations. Greater government support, professional endorsement, and their own efforts are needed to allow these organisations to strengthen their role and effectiveness in the healthcare system. Constructive alliances

Patients' organisations in the Netherlands

United Patients' Organisations of the Chronically Ill

The United Patients' Organisations of the Chronically Ill in the Netherlands (WOCCZ) was established in 1991 by seven patients' organisations whose members were angry at being regularly presented with government plans, without consultation, which had adverse effects on their members. The organisation works to ensure that the voice of the patient is heard; it is now a welcome third partner in the healthcare system along with healthcare providers and insurance companies. The organisation receives substantial government funding through the Patients' Fund.

With its 50 member organisations and 10 staff members, it has put people with long term medical conditions on the political agenda. As a result, there have been changes in taxation, payments for drug treatment, and in employment practices; the health care provided has become more attuned to the needs of people with long term conditions; and training by patients for health professionals has been instituted (EG Venselaar, personal communication). Additional information is available at www.spin.nl/wocz0101.htm; the email address is wocz@wocz.spin.nl.

formed through umbrella organisations, both generalist and specific, have a particular part to play. Although funding for patients' organisations has increased in the United Kingdom, there is still no long term commitment to support the work of these organisations or to use their potential to the full, as is happening in the Netherlands, for example (box).¹⁷

Conclusion

Partnerships with patients should not be seen as good in themselves. They are rather one route to a better life for people living with long term medical conditions, especially when these partnerships allow patients to have a greater degree of control over their lives and access to services that are of better quality. Partnerships between patients and clinicians can also help make better use of health professionals' time. Partnerships are not a panacea, nor is partnership a simple term to be used unthinkingly. If constraints hindering the development of partnerships are tackled, they could make a real difference to patients and clinicians.

Competing interests: None declared.

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Participatory research maximises community and lay involvement

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BMJ 1999;319:774-8

Participatory research attempts to negotiate a balance between developing valid generalisable knowledge and benefiting the community that is being researched and to improve research protocols by incorporating the knowledge and expertise of community members. For many types of research in specific communities, these goals can best be met by the community and researcher collaborating in the research as equals.

Methods

This integrative review is based on a search of medical, nursing, and social science databases and ethical research codes. The material selected had to be significant theoretical works, source documents, or concrete examples of participatory research. We assessed the texts on the basis of our own experiences as members of Native communities (LEC, MLMcC, CMR) and researchers (WLF, NG, ACM, MLMcC, PLT) in participatory research projects. The preliminary draft was reviewed by a wide range of researchers and community members. The members of the North American Primary Care Research Group reviewed and accepted the final draft as a policy statement for participatory research. This article summarises that document (the full document can be found at <http://views.vcu.edu/views/fap/napcrg98/exec.html>).

Summary points

The knowledge, expertise, and resources of the involved community are often key to successful research

Three primary features of participatory research include collaboration, mutual education, and acting on results developed from research questions that are relevant to the community

Participatory research is based on a mutually respectful partnership between researchers and communities

Partnerships are strengthened by joint development of research agreements for the design, implementation, analysis, and dissemination of results

Results of participatory research both have local applicability and are transferable to other communities

Why participatory research?

Participatory research began as a movement for social justice in international development settings.¹ It was