Chronic illness: beyond the expert patient

Coping with a long term illness requires much more than medical management. **Trisha Greenhalgh** looks at different models of patient involvement and argues that we need a wider approach

It is a truth universally acknowledged that patients with chronic illness should be involved in their care. It is also increasingly accepted that the public (as individuals, communities, and the voluntary sector) should be involved in designing, delivering, and evaluating services for chronic illness and in creating the conditions to support healthy living. In this article I examine these truths about patient and public involvement from four different perspectives: self management (drawing on biomedical and cognitive psychology), coping (sociology and narrative traditions), whole systems approaches (social ecology), and critical public health (table). The article is based on my own reflections and analysis, but draws on several systematic reviews and meta-analyses on self management, patient empowerment, and community empowerment, as well as literature on illness narrative.[1-3 w1-w16]

Why involve patients and the public?

Involving patients and the public in preventing and managing chronic illness is advocated for many reasons. In a qualitative review of 73 publications in the German literature, Dietrich identified four framings of the "modern" patient in the clinical encounter[4]: law and ethics (patients have a legal or moral right to autonomy and self determination); knowledge and information (patients can

access information and should be supported to do so); quality improvement (patients can drive improvements in the healthcare system through informed choice), and health economics (patients could reduce healthcare costs—for example, by taking on tasks previously done by professionals or spending their healthcare budget more judiciously). Three additional framings, which focus on the citizen or person at risk rather than the patient, are evident in the wider literature: engagement (informed, engaged, empowered individuals look after themselves better); citizenship (socially aware individuals contribute to community action because the health of all is a public good); and activism (oppressed people and their allies challenge social injustice).[5-9] The first four of these framings map broadly to the top two rows of the table (self management and coping); the next two map to whole systems approaches, and the last to critical public health.
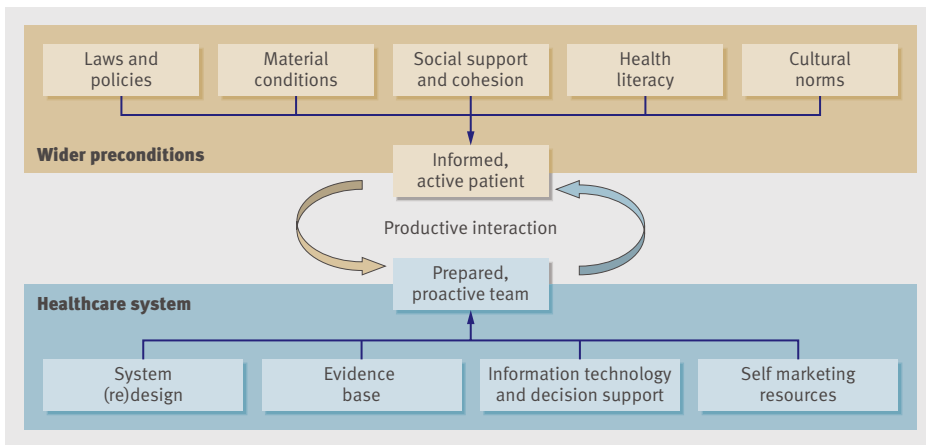
Self management

For many medical readers, patient involvement in managing chronic disease will be synonymous with the work of Kate Lorig in the United States. Originally a nurse working with arthritis patients, Lorig developed a structured programme of self management training focusing on building patients' self efficacy. She conducted and inspired numerous randomised

trials that (overall) showed benefits in arthritis and other chronic diseases.[10 w17-w20] In these trials, self management training was delivered either by health professionals or by trained lay people.[w19]

This gave rise to the concept of the expert patient, hailed by England's chief medical officer in 2003 as "ushering in a new era of opportunity for the NHS,"[11] and featuring prominently in national health policies across the Western world.[w21-w23] Practitioners have been encouraged to eschew paternalistic management and instead to involve people in their own care and "teach them the skills necessary to adjust their behavior to control their own health outcomes."[w24] The clinician's role shifts from professional expert (instructing and deciding) to guide (supporting, advising, and navigating).[w25] Self management is seen as the foundation for a pyramid of care that has low cost, lay led interventions at the bottom and increasingly specialist care towards the top, and hence is offering potential cost savings to healthcare systems.[w26] Publicly funded primary care organisations in the United Kingdom, Australia, and US are currently implementing expert patient education programmes. However, these policies are based on several misconceptions about Lorig's work, including:
Self management training leads to significantly improved disease outcomes—In fact, in most

Different perspectives on patient and public involvement in preventing and managing chronic illness

Approach	Framing of patient's involvement	Framing of lay involvement	Framing of health professionals' role	Assumed model of change	Preferred research design	Definition of success
Self management (conventional medicine and nursing, drawing on cognitive psychology)	Following a self management plan, which requires psychological resources (eg, self efficacy) and skills (eg, injecting)	Lay trainer (expert patient)	Trainer, adviser	Cognitive development (gain in knowledge, skills, and motivation)	Randomised trial, psychometric questionnaire	Compliance with management plan; change in disease or risk markers and psychometric attributes
Coping with illness (sociology of health and illness, drawing on narrative theory)	Constructing a coherent self; getting on with life despite chronic illness	Peer supporter (witness, role model, conveyor of experience of coping)	Witness, supporter	Emplotment (life unfolds unpredictably; response must be pragmatic, adaptive, coherent)	Naturalistic (eg, ethnography, narrative interview)	Patient copes with life. Professional comes to understand, value, and seek to enhance the lived experience of illness
Whole systems approaches (drawing on social ecology)	Developing and achieving a holistic, personalised care plan, drawing on available resources in the community	Engaged citizen, aligned with prevailing norms and values, seeking to develop health and community services	Coach or guide; partner in social learning and participatory change	Organic (multilevel, whole system change)	Participatory action research, usually linked to mainstream services	Emergence of new structures and opportunities for supporting healthy living and managing illness
Critical public health (drawing on critical sociology)	Recognising and challenging structural barriers to good health (eg, poverty, discrimination, social exclusion)	Engaged citizen, opposed to prevailing norms and values, seeking social justice (eg, resistance, revolution)	Potential oppressor (perhaps agent of the state), or radical ally	Dialectic (social change)	Political action research, outside mainstream services, and driven by clear values framework eg, equity, democracy	Fundamental change in the social and political structures that constrain individual action and underpin health inequalities

Ecological model for supported self management of chronic illness (adapted from various sources)[6 19 w39 w40]

trials, only certain psychological outcomes, most usually self efficacy, improved[w1 w16 w20 w27 w28]; although modest improvements have been shown in diabetes and asthma control, a meta-analysis found evidence of publication bias[1]

Lay trainers have greater effect than professional trainers—In fact, a meta-analysis showed no difference between lay and professional trainers[2]

Increased self management is directly related to reduced use of professional health services—In fact, greater engagement in health may lead to increased access to formal care[12 13]

Self management reduces the overall costs of health care—There is no evidence that this is the case

Lay led self management training is effective across range of social and ethnic groups— In fact, most of Lorig's trials were in carefully selected patients from stable, insured clinic populations, most of whom were white. Although two small studies have shown a modest benefit from lay led self management training in minority ethnic groups,[w29 w30] it has proved difficult to recruit people from such groups outside the research setting, especially in socioeconomically deprived areas[10 14 w31-w33] and those with low health literacy.[w34 w35]

Critics have argued that the model underpinning self management training is simplistic and politically naive. This is perhaps harsh criticism of Lorig, who was working in clinical care and never claimed to have tackled the underlying social and political context.[3 w12 w36 w37] However, the decision by the UK Department of Health to extend the expert patient programme by encouraging commercial companies to recruit lay trainers in the community[15] chimes well with prevailing ideologies on inclusiveness, choice, and shared decision making but is built on a weak evidence base.[16]

Evidence is growing that conventional clinic based self management programmes often fail because of lack of awareness and engagement among patients and staff; failure to consider low health literacy or cultural norms; lack of attention to the need for family and social support; and a fragmented approach to the provision of health and social care.[w9 w38]

Coping with chronic illness

Most conventional chronic disease self management programmes and policies take a biomedical view of the self, characterised by capacity and motivation to perform certain goal oriented tasks expected by doctors and nurses. An alternative framing is of a sociological self focused on coping with illness rather than managing it. Kralik et al, for example, found that people with arthritis identified self management as a process initiated to bring about order in their lives, including recognising and monitoring their personal boundaries, mobilising resources, managing the shift in self identity, and achieving balance and pace.[17]

In a detailed ethnographic study of diabetes care in the Netherlands, which covered both self care and clinical care, Mol found that both patient and clinician had to work hard to achieve the goal of getting on with life despite diabetes.[18] She argues that health care should be seen not as a series of decisions made by the patient or clinician at particular times (as in shared decision making) but as never ending, full of surprises, and having continuously to adapt to the messy reality of life. The clinician's role in this process is necessarily flexible, since it depends on understanding and helping patients respond to the challenges and constraints of their lives.

Aligned with the coping approach is peer support, often provided by self help organisations such as Weight Watchers, Alcoholics Anonymous, or parenting support groups. These groups typically use narrative methods (a person telling a story) to inspire confidence and ignite action among fellow participants. Although such initiatives are widespread,

and provide an increasingly important contribution to the health economy in many settings, research into their effect is limited. One example from our own work began as a research study to develop an education and support programme for patients from minority ethnic groups with diabetes, based on sharing personal stories of living with the condition.[12] A subsequent randomised controlled trial of the programme showed that unstructured story telling leads to a highly significant improvement in patient enablement compared with that achieved by conventional nurse led diabetes education, with comparable changes in biomedical markers of diabetic control (Current Controlled Trials ISRCTN68516177, unpublished data).

Patients and citizens as partners

Whole systems (also known as social ecology) models see chronic illness as arising from the interplay of influences within a complex system (from the genome to the macro-environment), and acting dynamically through time (figure).[19 20] Responsibility for preventing and managing illness lies at many levels—with individuals (who should, as far as possible, choose healthy lifestyles and take care of themselves), with health professions (who should provide accessible surveillance, care, and multidisciplinary support), and with wider society (which should create healthy environments and remove structural and cultural barriers to individual lifestyle choices).[6 19] In this approach, interventions must go beyond the clinic and into the community.

Social ecology approaches generally reject standard protocols in favour of diversity of provision and adaptation of local programmes to meet the individual and cultural needs of different audiences.[21 w41] The patient is a vital member of the team, since the process of planning and implementing care for anyone is essentially one of negotiating personalised goals in the family, social, and cultural context.

Because of their multilevel nature, whole systems approaches tend to be large scale programmes involving people from several organisations. In the US, for example, Fischer et al worked with the Robert Wood Johnson Foundation to develop a programme of resources and supports for self management in diabetes, comprising individualised assessment, collaborative goal setting, skills enhancement, follow-up and support, access to resources, and continuity of good clinical care[21]; their website (www.diabetesinitiative.org) offers a wealth of resources and models.

In Australia, Osborne's team used a whole systems model to extend self management

training towards broader, socially oriented goals including the development of social networks and social capital.[14] [w44] Being both poor and ill can bring shame and insecurity that can generate a vicious circle of insecurity, depression, and social isolation. For this reason, a suite of programmes with varied content and delivery modes (individual consultation, group sessions, email, television) and settings (clinic, workplace, community) should be developed and tailored to the needs of different groups. Osborne's team have developed some promising new instruments for measuring clinical, psychological, and social outcomes of these broad based programmes.[22]

In whole systems approaches, citizens have an important role in negotiating and building the environmental preconditions for healthy living. The box shows examples of contextual conditions which, while not determining individual behaviour, create the preconditions for adverse lifestyle choices. The means by which citizens might change these conditions is controversial (box 2 on bmj.com).

Critical public health

The ecological model implies that building a healthy society is essentially an organic, collaborative, and apolitical process in which different stakeholders contribute to an agenda that benefits everyone. A more radical viewpoint sees the struggle to improve health for disadvantaged people as essentially political and characterised by conflict rather than collaboration, since many of the structural preconditions listed in the box involve powerful vested interests and entrenched social inequalities.[9]

To some extent, the question of whether change should be ecological or political depends on whether the issue is (for example) deciding on the location of a new jogging route in Sweden or challenging policy on HIV and AIDS in South Africa.[23] Levy and Storeng studied the challenge of "living positively" with HIV in South Africa by collecting stories from 12 women and visiting support groups, activist events, and public health meetings.[24] They found that a positive approach was shaped by practical and structural constraints (particularly the availability of basic health care and antiretroviral drugs) and by prevailing political campaigns. Their findings showed the distinction between the conventional medicalised illness narrative (which often reflects the "morally correct way of being ill") and the same person's narrative told in an activist setting, where it can come to embody (and so expose) questions about social injustice. In such a setting, the focus

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Examples of contextual influences on development and outcome of chronic illness (adapted from Glass and McAtee[19])

Material conditions
Availability of fresh healthy food
Presence of fast food outlets
Availability of sports and leisure facilities
Built environment (eg, walkability, connectivity)

Laws, policies, and regulations
National (taxes on cigarettes, restrictions on advertising junk food)
Local (traffic calming measures, healthy school meals)
Direct to consumer advertising

Area deprivation
Poverty
Unemployment
Overcrowding
Poor housing
Low social cohesion

Cultural norms and expectations
Diet
Exercise
Smoking and alcohol
Religious observance
Media influences and role models (eg, sport, fashion)

Community ethos
Crime and fear of crime
Neighbourhood solidarity
Local support networks
Xenophobia

Conditions of work
Control over nature and pace of job
Discrimination or oppression at work
Gender issues (eg, pay differentials, maternity leave)

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for living positively shifts from individual self management to challenging political preconditions for poverty and health inequalities.

Conclusion

I have deliberately challenged the accepted view of patient and public involvement in preventing and managing chronic illness. Self management programmes based on the expert patient model remain the preferred policy in many countries, but the evidence base for their efficacy is weak. It is time to move beyond them and embrace richer, more holistic models which consider a person's family, social, and political context. We need to support clinicians to engage with the unique challenges that every patient faces in getting on with life despite chronic illness. We need more whole systems programmes of change, especially where social determinants of health inequalities loom large. And we need to understand the place of activism and critical consciousness in settings where poor health outcomes for oppressed groups are politically rooted.

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