should be recruited from each specific refugee population and could help to provide patient held records with an accurate and detailed medical history and support health promotion and screening.

Primary care groups are being introduced[25] and should be given the resources to address the distortions created by different practice policies towards the registration and care of refugees and other marginalised patients.

Conclusion

The refugee population is likely to remain large. High needs, especially psychological distress, combined with language barriers require a great deal of additional time in consultations. General practitioners in inner cities need adequate resources, especially interpreting services, and should be properly rewarded. We have outlined some ideas for dealing with this. A truly effective solution requires the political will to develop a comprehensive strategy at national level.

1   The state of the world's refugees: the challenge of protection. London: Penguin, 1993.
2   Turnberg L. Health services in London: a strategic review. London: Department of Health, 1997.
3   Promoting the health of refugees. London: Refugee Health Consortium, 1998.
4   Carey Wood J, Duke K, Karn V, Marshall T. The settlement of refugees in Britain. Home office research study 141. London: HMSO, 1995.
5   Joly D. Haven or hell: asylum policies and refugees in Europe. London: Macmillan, 1996:120-38.
6   Home Department. Fairer, firmer, faster—a modern approach to immigration and asylum. London: Stationery Office, 1998. (Cm 4018.)
7   Eisenbruch M. From post-traumatic stress disorder to cultural bereavement: diagnosis of Southeast Asian refugees. Soc Sci Med 1991;33:673-80.
8   Loizos P. The heart grown bitter: a chronicle of Cyprus war refugees. Cambridge: Cambridge University Press, 1981.
9   Dick B. Diseases of refugees—causes, effects, and control. Trans R Soc Trop Med Hyg 1984;78:734-41.
10 Karmi G. Refugees in North West and North East Thames Regional Health Authorities. London: NETRHA, NWTRHA, 1992.
11 Gorst-Unsworth C, Goldenburg E. Psychological sequelae of torture and organised violence suffered by refugees from Iraq: trauma-related factors compared with social factors in exile. Br J Psychiatry 1998;172:90-4.
12 Sinnerbrink T, Silove D, Field A, Steel Z, Manicavasagar V. Compounding of premigration trauma and postmigration stress in asylum seekers. J Psychol 1997;131:463-70.
13 Karmi G. Refugee health requires a comprehensive strategy. BMJ 1992;305:205-6.
14 Islington Refugee Working Party. Report on questionnaire survey. London: Islington Voluntary Action Council, 1992.
15 Grant C, Deane J. Stating the obvious—factors which influence the uptake and provision of primary care services to refugees. London: Brixton Challenge, Lambeth, Southwark and Lewisham Health Authority, 1995.
16 Ramsey R, Turner S. Refugees' health needs. Br J Gen Pract 1993;43:480-1.
17 Murphy A, Lynch M, Bury G. Caed Mile Failte: an assessment of the screening of 178 Bosnian refugees to Ireland. Ir Med J 1994;87(6):174-5.
18 Hicks C, Hayes L. Linkworkers in antenatal care: facilitators of equal opportunity in health provision or salves for the management conscience? Health Serv Manage Res 1991;4:89-93.
19 Jones D, Gill P. Breaking down language barriers. The NHS needs to provide accessible interpreting services for all. BMJ 1998;316:1476.
20 Stewart MA. Effective physician-patient communication and health outcomes: a review of the literature. Can Med Assoc J 1995;152:1423-33.
21 Meryn S. Improving doctor-patient communication. Not an option, but a necessity. BMJ 1998;316:1992.
22 Credit to the nation. A study of refugees in the United Kingdom. London: Refugee Council, 1997.
23 Gough CB. Review body on doctors' and dentists' remuneration pay: 27th report. London: Stationery Office, 1998.
24 Majeed FA, Martin D, Crayford T. Deprivation payments to general practitioners: limitations of census data. BMJ 1996;313:669-70.
25 Secretary of State for Health. The new NHS—modern dependable. London: Stationery Office, 1997. (Cm 3807.)

Theories in health care and research

Theories of disability in health practice and research

Michael Oliver

This is the fifth in a series of six articles on the importance of theories and values in health research

University of Greenwich, Eltham, London SE9 2UG
Michael Oliver, professor of disability studies
M J Oliver@ gre.ac.uk

Series editor: Priscilla Alderson

BMJ 1998;317:1446–9

All health care and research are influenced by theories. This paper considers the influence of implicit and explicit theories[1] on interventions and research on disabled people. Another important influence is the experience of disabled people, and their increasing insistence that their voices be heard at all stages of research about their lives.[2]

The experience of disability

Over the past 20 years, writings by disabled people have transformed our understanding of the real nature of disability. They move beyond the personal limitations that impaired individuals may face, to social restrictions imposed by an unthinking society. Disability is understood as a social and political issue rather than a medical one, and this leads to critical questioning of medical interventions: attempts to cure impairments or to restore "normal" bodily functioning. Instead, social and political solutions are sought, to challenge disabling discrimination.

Summary points

The health care that disabled people receive is influenced by theories

Positivist theory remains the dominant influence on health care given to disabled people

Other theories are beginning to have a significant influence

The rise of these theories is posing important questions for health care and research

This radically different view is called the social model of disability, or social oppression theory.[3] While respecting the value of scientifically based medical research, this approach calls for more research based on social theories of disability if research is to improve the quality of disabled people's lives. Definitions are

central to understanding theories of impairment and disability.[4] In 1986 Disabled Peoples International made a clear distinction: impairment is the functional limitation within the individual caused by physical, mental or sensory impairment; disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others because of physical and social barriers.

This schema accepts that some illnesses have disabling consequences and disabled people at times are ill; it may be entirely appropriate for doctors to treat illnesses of all kinds, such as bronchitis or ulcers. Yet it questions why, for example, doctors should decide about access to welfare services such as education or disability living allowance. Theories of impairment, disability, and illness influence which aspects of disabled people's lives require health treatment, or policy developments, or political action, as sometimes radical alternatives (see box).[5]

Positivism and disability research

Health research about impairment and disability is dominated by positivist theories. It focuses on searches for cures, means of reducing impairments, or assessments of clinical interventions and uses methods such as controlled trials, random statistical samples, and structured questionnaires. Even when researching disability (in the sense given above), positivist research tends to use the World Health Organisation's classification,[6] now being revised at the insistence of disabled people,[7] which is difficult if not impossible to apply in research terms and yields few useful data.

Disabled people are beginning to influence scientific research.[8] This influence poses difficulties for positivist research in questioning one of its bedrocks: the notion of objectivity. Although positivist researchers accept that subjectivity can be studied objectively, they resist involving subjects for fear of bias. However, scientific researchers often use the words "suffering" and "victim" as if they are accurate descriptions and not untested, biased assumptions which many disabled people do not experience. In contrast, social constructionism sees experience and subjectivity as central to the research process, and critical theory sees disabling barriers as a key research issue. Though these theories pose intellectual challenges, almost all funding goes to positivist research.

The influence of implicit and explicit positivism on the Department of Health which, it seems, has discovered the "user," is shown in a recent report: "The NHS is attaching increasing importance to seeking out and acting upon the views of its users on the coverage and delivery of the services it provides."[9] The programme has spent £3.9 million on 30 projects; all are located in universities or the health service. Despite consumer views being the second named priority for selecting research proposals, disabled people have not been involved. None of their organisations have received funding, and no projects could be said to be based on the social model of disability—they are all based on positivist theories.[10]

Social approaches within positivism

Positivist social medicine recognises the social context to impairment as well as disability, and it examines

Interventions to normalise impairments		
Impairment	**Intervention**	**Alternatives**
Deafness	Cochlear implants	Sign language teaching in schools
Cerebral palsy	Conductive education	Barrier removal
Achondroplasia	Limb lengthening	Barrier removal, awareness raising
Down's syndrome	Cosmetic surgery	Awareness raising
Congenital conditions	Genetic screening	Legislation for equal opportunities

environments as well as individuals. Hence public health measures concerned with sanitation, poverty, health education, and the like have proved extremely effective in preventing rather than curing a range of impairments such as tuberculosis, polio, rickets, and river blindness.

Prevention of impairments is complicated, however, by prenatal screening to prevent conditions such as Down's syndrome, cystic fibrosis, or Huntington's chorea, and by research into genetic engineering. Leaving aside the efficacy of such interventions, they pose profound ethical, social, and cultural issues for us all. "Life and death decisions are vested in the hands of people who have very little understanding of the reality of disabled people's lives."[11] With the lack of systematic evidence, why should doctors assume, for example, that life with Down's syndrome is not worth living?

Social approaches to disability[12] within positivism classify and count disabled people. Although some support this work,[13] others question the accuracy of the data[14] and say that they yield few significant changes for disabled people.[8]

Recent research, attempting to combine theories, and scientific measures of the extent of disabling barriers with disabled people's own experiences of the extent and nature of those barriers, involves disabled people in designing, collecting and analysing the data.[15] Its success remains to be seen.

The Candoco dance company includes members with missing limbs—but these "disabilities" do not keep them from participating in what they want to do

Functionalist theory and disability

Influential functionalists emphasise medicine's role to cure and to maintain the "normal" functioning of individuals and of society. In this model, the "sick role" involves being compliant and wanting to get well.[16] This can make people with incurable conditions, including disabled people who are classified as sick, seem to be deviant. The link between disability and social deviance that functionalists make influences health care and research and supports the continued dominance of professionally controlled health and welfare services for disabled people.[17] Thus, under current welfare arrangements, more than 70% of spending goes on the salaries of professionals working with disabled people. Only recently has this been reduced through the funding of independent living schemes controlled by disabled people. A variant of functionalism, normalisation theory, underlies some programmes that claim to enable devalued people to lead culturally valued lives. An example of this controversial approach is cosmetic surgery for people with Down's syndrome.[18]

Functionalism confuses impairment and disability with the sick role. By failing to recognise that disabled people do not necessarily have "something wrong with them," it simply reproduces discriminatory norms and values—instead of addressing the cultural and economic forces that precipitate them. The crucial problem is that disabled people, regardless of the type or severity of their impairment, are not a homogeneous group that can be accommodated easily within a society that takes little account of their individual or collective needs. As with the whole population, disabled people differ widely in terms of ethnic background, sexual orientation, age, abilities, religious beliefs, wealth, access to work, and so on. Clearly, their situation cannot be understood or, indeed, transformed by any policy based on narrow theories of conventional normality or uniformity.

Social constructionism

This theoretical approach is centrally concerned with meaning. It shows the crucial importance of learning from disabled people's experience to understand meanings of disability. For example, blindness differs according to the economic and cultural contexts. A classic study showed that in the United States blindness was experienced as loss requiring counselling, in Sweden as a problem requiring support services, in Britain as a technical issue requiring aids and equipment, and in Italy as the need to seek consolation or even salvation through the Catholic church.[19]

Anthropologists and historians show how different societies produce certain types of disease, impairment, and disability.[20] Disability can be produced by "the disability business." In modern America, industrialisation, the subsequent growth of the human service sector, and the more recent politicisation of "disability rights" by the American disabled people's movement have transformed "disability" and "rehabilitation" into a multimillion dollar enterprise. Disability becomes a commodity and a source of income for doctors, lawyers, rehabilitation professionals, and disability activists.

These examples treat disability as a shared experience, in contrast with conventional individualistic interpretations. Yet each fails to address key structural factors. Consequently, disabled people tend to be treated as an abstract, somehow distinct from the rest of the human race, and the crucial question of the causes of disability is fudged rather than clarified. For example, how is disability physically based but socially constructed by the disabling environment?[20]

Postmodernism

Postmodernism sees society in terms of fragmented and complex social structures in which social class has less importance, and other sources of social difference (including sex, ethnicity, sexuality, and disability) have more importance. Postmodernists call into question many of the certainties of earlier eras, creating multiple meanings for practically everything.

This theory has, as yet, had little impact on health research about disability. However, a study on concepts of a healthy body, so central to government health promotion, is beginning to show how these concepts can, in themselves, be disabling, unrealistic, and oppressive. "Health promotion is working against popular culture, attempting to construct a view of health that is not privately held."[21] In other words, to have an impairment is not necessarily unhealthy; disabled people are not actually ill, and confusion between impairment and illness fails to deal with complex meanings in the postmodern world.

Critical theory

Critical theory covers similar ground to the other theories discussed here, but it sees disabled people's problems explicitly as the product of an unequal society. It ties the solutions to social action and change. Notions of disability as social oppression mean that prejudice and discrimination disable and restrict people's lives much more than impairments do.[22] So, for example, the problem with public transport is not the inability of some people to walk but that buses are not designed to take wheelchairs. Such a problem can be "cured" by spending money, not by surgical intervention, assistive computer technology, or rehabilitation.

Ideologies perpetuate practical barriers and exclusions.[23] As long as disability is assumed to be an individual matter of personal tragedy or heroic triumph over difficulty, disabled people are excluded from society. Ordinary education, employment, buildings, public transport, and other things which most people can take for granted remain largely closed to disabled people, or at least they present obstacles which each person has to tackle individually. By emphasising deficiency and dependency, doctors tend to reinforce these ideologies.[24]

The impact of this critical theorising on health care and research has tended to be indirect. It has raised political awareness, helped with the collective empowerment of disabled people,[25] and publicised disabled people's critical views on health care. It has criticised the medical control exerted over many disabled people's lives, such as repeated and unnecessary visits to clinics for impairments that do not change and are

not illnesses in need of treatment. Finally, it suggests a more appropriate societal framework for providing health services for disabled people.[26]

Conclusion

Implicit and explicit social theorising, coupled with disabled people's insistence that their voices be heard, have begun to change understandings of the nature of impairment and disability. The new understandings pose key questions for health care and research if they are going to provide an appropriate knowledge base for both medical and social progress:

- What is the proper balance for investment between research into bodily impairment and into social disability?
- Who should be setting the research agenda?
- Who should be in control of the research process?
- What are the most appropriate methods for undertaking disability research?
- How should disability research be disseminated and evaluated?

Such questions help us to identify both the common ground and fundamental differences between researchers.[27–29]

1 Alderson P. The importance of theories in health care. *BMJ* 1998;316:000-0.
2 Barnes C, Mercer G, eds. *Doing disability research*. Leeds: Disability Press, 1997.
3 Oliver M. The social model in context. In: *Understanding disability: from theory to practice*. Basingstoke: Macmillan, 1996:30-42.
4 Oliver M. Defining impairment and disability: issues at stake. In: Barnes C, Mercer G, eds. *Exploring the divide: illness and disability*. Leeds: Disability Press, 1996:39-54.
5 Shakespeare T. Re-defining the disability problem. *Critical Public Health* 1995; 6(2):4-9.
6 Wood P. *International classification of impairments, diseases and handicaps.* Geneva: World Health Organisation, 1980.
7 Tennant A. Models of disability: a critical perspective. *Disability and Rehabilitation* 1997;19:478-9.
8 Oliver M. Changing the social relations of research production. *Disability, Handicap and Society* 1977;7:101-15.
9 Peckham M. Foreword. In: *Consumers and research in the NHS*. Leeds: Department of Health, 1995.
10 Oliver M. Emancipatory research: realistic goal or impossible dream. In: Barnes C, Mercer G, eds. *Doing disability research*. Leeds: Disability Press, 1997:15-31.
11 Begum N. Rock-a-bye baby, or the treatment might stop: a discussion of the selective treatment of disabled babies. *Critical Public Health* 1995; 6(2):30-7.
12 Martin J, Meltzer H, Elliot D. *OPCS Surveys of disability in Great Britain: report 1—the prevalence of disability among adults.* London: HMSO, 1988.
13 Bury M. Defining and research disability: challenges and responses. In: Barnes C, Mercer G, eds. *Exploring the divide: illness and disability*. Leeds: Disability Press, 1996:17-38.
14 Abberley P. Disabled by numbers. In: Levitas R, Guy W. Eds. *Interpreting official statistics.* London: Routledge, 1996:166-84.
15 Zarb G. Researching disabling barriers. In: Barnes C, Mercer G, eds. *Doing disability research.* Leeds: Disability Press, 1997:49-66.
16 Parsons T. *The social system.* Glencoe, IL: Free Press, 1951.
17 Oliver M. A sociology of disability or a disablist sociology. In: Barton L, ed. *Disability and society: emerging issues and insights.* London: Longman, 1996:18-42.
18 Chappell A. Towards a sociological critique of the normalization principle. *Disability, Handicap and Society* 1992;7:1.
19 Scott RA. *The making of blind men.* London: Sage, 1969.
20 Albrecht G. *The disability business.* London: Sage, 1992.
21 Watson N. Health promotion and physically disabled people: implications of the national health policy. *Critical Public Health* 1995;6(2):38-43.
22 Sutherland A. *Disabled we stand.* London: Souvenir Press, 1981.
23 Abberley P. The concept of oppression and the development of a social theory of disability. *Disability, Handicap and Society* 1987;2:5-21.
24 Oliver M. *The politics of disablement* Basingstoke: Macmillan, 1990.
25 Campbell J, Oliver M. *Disability politics: understanding our past, changing our future.* London: Routledge, 1996.
26 Barnes C. *Disabled people in Britain and discrimination: a case for anti-discrimination legislation.* London: Hurst, 1991.
27 Barnes C. Disability and the myth of the independent researcher. *Disability and Society* 1996;11:107-10.
28 Bury M. Disability and the myth of the independent researcher: a reply. *Disability and Society* 1996;11:111-3.
29 Shakespeare T. Rules of engagement: doing disability research. *Disability and Society* 1996;11:114-9.

A book that changed me
Many patients are struggling too

All practising clinicians are being exhorted to the dual imperatives of evidence based medicine and respect for patient autonomy. Indeed these are twin strands of the government's white papers on the NHS. Yet, these two virtuous objectives may be incompatible, and the attempted pursuit of both too often leaves the pursuer exhausted, frustrated and, above all, guilt ridden. How is the clinician to hold them in constructive tension and so interpret the evidence of medical science in the light of the individual patient's own values and priorities? Which good should prevail when there is irresolvable conflict?

The author of *The Reader* was born in Germany in 1944 and he writes of his generation's struggle to come to terms with the unspeakable horror of the Holocaust.[1] In the book, an adolescent boy begins an affair with a woman who rescues him when he falls ill in the street. After a while, he loses touch with her, but some years later, while he is training to be a lawyer, he is sent to observe a war crimes trial and recognises her as one of the defendants. She is accused of crimes committed while she was working as a concentration camp guard. During the trial, he is surprised by her apparent unwillingness to defend herself, and then realises, quite suddenly, that she is unable to read. She could only have committed the principal crime of which she is accused had she been literate. Yet she seems to prefer the probability of being found guilty to the shame of openly admitting her illiteracy.

The young man feels that he should go to the judge and explain the impossibility of her guilt, but to do this he must betray her secret. He seeks advice from his philosopher father: "He

instructed me about the individual, about freedom and dignity, about the human being as subject, and the fact that one may not turn him into an object." He comes to understand that: "She was not pursuing her own interests, but fighting for her own truth, her own justice. Because she always had to dissimulate somewhat, and could never be completely candid, it was a pitiful truth and a pitiful justice, but it was hers, and the struggle for it was her struggle."

Reading this, I understood that many of my patients are struggling for their own health in a similar way, in the face of the science of medicine which, so often, turns individuals into objects in the pursuit of truth. It is crucial that we find ways of understanding why our patients do not act in what, to us, seems so clearly to be their best interests. Why, despite all our efforts, do our patients continue to smoke, why do they refuse hearing aids, why do they not take prescribed medication, why do they kill themselves? Perhaps because part of the meaning of health is that it should be defined, understood, and achieved on the patient's own terms.

This renewed understanding does nothing to relieve the fundamental responsibility that we, as clinicians, hold for making available to our patients the very best evidence based medical science. But it does make me at least feel less guilty about my frequent failure to meld conflicting goods into a coherent whole.

Iona Heath, *general practitioner, London*

1 Schlink B, *The reader.* London: Phoenix House, 1997.