Patients' charters and health responsibilities

We all have responsibility for our health, the health of others, and to the organisations that provide health care. But, as **Harald Schmidt** describes, specifying and formalising these duties can create ethical problems

Harald Schmidt assistant director Nuffield Council on Bioethics, London WC1B 3JS

Correspondence to: hschmidt@nuffieldbioethics.org

Accepted: 16 October 2007

The BMA recently called for a charter setting out the responsibilities patients have within the National Health Service and what patients can expect from the NHS.[1] The proposal raises questions about the scope, specificity, and status of such a charter. Should it be legally binding or simply set out aspirations? How many and what kind of responsibilities should be included? I examine how initiatives in Scotland, Germany, and the United States have dealt with these questions and look at the ethical tensions raised.

In sickness and health

The BMA's discussion paper refers to patient responsibilities and a patient charter. But at its annual representative meeting 2007 delegates also resolved with an overwhelming majority the need for a charter that "focuses on the individual's responsibility both in health and illness" (motion 25). The focus on patient responsibilities is too narrow, and in the following I will therefore use the term health responsibilities to cover the obligation of healthy and sick people to maintain, improve, or restore their health; to respect the health of others; and to contribute to the efficient operation of healthcare services.

I have chosen examples from three countries to illustrate the different ways that these responsibilities can be set out: the 2005 Scottish NHS' patients' charter *The NHS and You*,[2] which the BMA highlighted as a good model; book V of the 1988 German *Sozialgesetzbuch* (social security code), revised in 2007; and the Medicaid member agreement, implemented in West Virginia, United States, in 2007.[3] These documents all apply to publicly funded health programmes but set out responsibilities with varying degrees of specificity, legal status, and enforceability (box). Despite differences in social and cultural contexts, the core provisions overlap considerably. Although the analysis provides by no means a comprehensive or representative international overview, the examples highlight the principal issues raised by health responsibility charters.

Legal status of charters

The Scottish patients' charter is purely aspirational. It applies to users of the NHS in Scotland and general practitioners but there is no mechanism to ensure people's compliance; nor are there penalties for not abiding.

By contrast, the German code is hard law. Its provisions determine key elements of the policies of statutory sickness funds. These funds implement health responsibility through financial incentives and disincentives in the form of different levels of contributions and copayments and the option of reclaiming costs for treatment and awarded sick pay.[4]

The West Virginia Medicaid membership agreement is not a legal statute but its provisions are unambiguously binding for those enrolled. Medicaid recipients are assigned to a basic plan unless they accept the membership agreement, when they can access the "enhanced" plan. Members are reassigned to the basic plan if they fail to comply with the agreement (with the option of appealing and reapplying after 12 months if appeals fail). The enhanced plan is more comprehensive, including, for example, smoking cessation programmes, nutritional education, weight management programmes, and mental health and substance misuse services. The basic plan limits non-emergency medical transportation, and prescription drugs (a maximum of four prescriptions a month, compared with no limit on the enhanced plan).[5] West Virginia introduced the agreement in early spring 2007, and by the end of September 15% had signed up to the enhanced plan.[6]

Self directed health responsibilities

Health maintenance and promotion

The three documents all contain explicit health maintenance obligations: "Look after your own health and have a healthy lifestyle" (Scottish charter); "lead . . . a health conscious lifestyle . . . to avoid . . . illness and disability" (German code); and "I will do my best to stay healthy" (Medicaid agreement).

This article was published on bmj.com on 14 November 2007.

"We will do our best to stay healthy"

Key provisions of patient charters and similar documents*

Scottish NHS patients' charter[2]

Responsibilities of individuals are listed under the following headings:

- Look after yourself
- Treat healthcare staff considerately
- Keep your appointments
- Let us know if you have to cancel
- Make sure we can contact you
- Follow advice and treatment
- Ask about anything you don't understand
- Use health services appropriately
- Take care with medicines
- Help us stop the spread of infection
- Other ways you can help

West Virginia Medicaid Member Agreement[3]

The responsibilities for Medicaid recipients on the enhanced plan include:

- Follow the rules of the West Virginia Medicaid programme
- Make best efforts to stay healthy; attend special classes as ordered
- Read the booklets and papers given out and ask for help in case of questions
- Attend your medical home (or bring your children) for check-ups and when sick
- Take prescribed medicines
- Keep or cancel appointments for yourself or your children
- Use the hospital emergency room only for emergencies

German social security code

Under article 1 of the code, individuals have "co-responsibility" for their health and are expected to lead a health conscious lifestyle and play an active role in treatment and rehabilitation. Other provisions include:

- Services must only be used insofar as necessary
- Copayments are to be requested where treatment is required as a result of a criminal activity, deliberate self harm, or a "non-medically indicated measure such as cosmetic surgery, a tattoo, or a piercing"
- Financial incentives are to be provided to those taking part in preventive measures, screening, and check-up programmes, those taking part in managed care programmes, or those who do not use general practitioner or hospital services over prescribed periods
- Threshold for copayments of chronically ill and cancer patients are to depend on their compliance with screening and treatment regimens

*More detail on the specific provisions of all three documents is available on bmj.com

Appeals to live (more) healthily are widely perceived as unwelcome forms of paternalism, infringing personal liberties or autonomy.[7] People often behave in ways that jeopardise their health. As well as smoking, lack of exercise, and excessive consumption of alcohol or food, other examples include poor dental hygiene, insufficient sleep, excessive salt intake, sunburn, unprotected sex, cycling without a helmet, or not taking preventive measures when travelling to areas with high risk of infectious disease. It is easy to make appeals not to risk health in such ways. But it is far more complicated to decide whether, or to what extent, people should be held responsible when things go wrong, especially when expensive treatment is required. Should perceived lack of responsibility be considered retrospectively or prospectively when patients seek treatment? Should patients have to repay benefits received (either in part or in full)? Clarity about such decisions is especially important for documents that have a binding status. They raise questions about equity and create a risk of victim blaming, where people in disadvantaged social positions are held responsible for factors that are largely beyond their control.[8-12]

Regaining health in the case of illness

The Medicaid agreement specifies: "I will go to my medical home when I am sick," and the German code urges patients to take "an active role in treatment and rehabilitation." These provisions may have several motivations. The most benevolent interpretation is that they seek to help people to pursue a good (and healthy) life, perhaps simply to enjoy it more or to be able to benefit fully from the arrangements in place in societies based on equality of opportunity.[13] In a more economy oriented vein, health appeals may be aimed at ensuring productive workforces. Or the motivation may be to reduce demands on the healthcare system.

Health responsibilities towards third parties

Several responsibilities towards third parties emerge from the documents. The first is not to harm the health of other people. The Scottish charter, for example, urges use of condoms, highlights other measures to control the spread of infections, and emphasises that medicines should be stored safely and not used past their expiry date. Secondly, it also includes clauses on preventing harm to healthcare workers and patients, stating that rudeness, violence, racial, sexual, or other harassment or abuse are unacceptable. Thirdly, the Medicaid agreement emphasises the vulnerability of children by including clauses agreeing to take children to medical services for check-ups and when they are sick. Lastly, the Scottish charter suggests donating blood, organs, tissues, or bone marrow under "Other ways you can help."

As with self directed responsibilities, responsibilities to third parties may have various motivations. However, they seem far less controversial. The prevention of harm to third parties ties in with legal instruments. Obligations to donate blood or organs may draw on notions of solidarity (asserting that it is reasonable to help—without expectation of return—when this is possible without undue sacrifice) or fair reciprocity (emphasising that in relying on a publicly funded healthcare system we benefit from resources and should contribute to their maintenance and development, wherever possible[14]).

Responsibilities to the healthcare system

All three documents emphasise obligations to contribute to fair and efficient use of healthcare resources. The German code is most specific. Article 2 urges people to respect "the clinical and cost effectiveness of services, which are only to be used insofar as necessary." An "appropriate copayment" may be requested if poor health is caused "deliberately" or results from criminal activity or from a non-medically indicated measure. People can also redeem no-claim bonuses if they do not require general practitioner appointments for prescription medicines or hospital admission.

The Scottish charter and Medicaid agreements are less specific but clearly state that emergency services should be used only in a real emergency and emphasise the need to keep (or cancel) appointments and

"follow advice and treatment." The German charter goes further, stating that chronically ill and cancer patients qualify for the lowest copayments only if they comply with screening and treatment regimens.

In principle, there is nothing wrong with appeals to use necessarily limited resources in a reasonable manner. But the initiatives may give rise to several problems. Firstly, people may take health responsibility too seriously. "Only use emergency services in a real emergency" is a relatively straightforward provision. But pride coupled with an exaggerated sense of obligation may lead people not to request treatment when they need it, or with delay, which may result in poorer overall health and higher costs for the healthcare system. Similar consequences may result from no claims incentives, where people refrain from using medical services because they wish to preserve a financial bonus.

Secondly, the German code appeals to a concept of social justice under which the entitlement to have your clinical needs met by public funds may be questioned if ill health results from an activity that substantially harms the community, such as a criminal offence. More problematically, it extends this principle to cases where the action is not directly harmful to society but the risks are viewed as freely chosen and unnecessary, giving examples of cosmetic surgery, piercing, and tattooing. The difficulty here is to offer robust and equitable criteria that help assess what kind of actions—and on what grounds and evidence—should fall under this category.

Thirdly, the capacities of those who are given the responsibilities require careful consideration. The example of keeping appointments illustrates this. At first sight, this requirement seems uncontroversial, and several key reports emphasised its importance for maximising efficiency and reducing costs within the NHS.[15 16] Not wasting appointments is also fair towards other people wishing to access services. However, the underlying assumption is that keeping appointments is equally easy for all. But patients with mental disorders, minor forms of depression,[17 18] or externally determined work schedules may have good reasons for missing appointments, creating a risk of victim blaming. Thus, even when the responsibility seems reasonable, implementing it can be more complicated.

Conclusion

The BMA's proposal for a health responsibility charter as part of an NHS constitution has focused attention on a highly complex issue, although it lacked detail on the scope, specificity, status and implementation of particular responsibilities. The government also seems to be considering the idea. Health secretary Alan Johnson alluded to an NHS constitution after the once in a lifetime review of the NHS.[19] And in the review's recent interim report, Lord Darzi confirmed that a working group would be set up to assess the case for a constitution and whether it should include "a stronger focus on rights and responsibilities for patients, the public and staff."[20] The working group's assessment must consider arrangements in other countries: not only the ethical arguments for and against different types of policies, but also the evidence about the effectiveness of different initiatives.

With rising healthcare costs, higher burdens of chronic diseases, and increasing evidence about the contribution of genetic and behavioural factors to disease, the issue of personal responsibility for health is here to stay. Moreover, the health responsibility debate is not only for the future. There have been concerns about the decision of some primary care trusts to require, for example, patients to lose weight or stop smoking before routine surgery.[21] A clear policy is needed that engages in detail with the highly complex issues raised by health responsibilities. A health responsibility charter within an NHS constitution would be a unique opportunity to clarify which types of responsibilities are compatible with the ethos of the NHS, and which ones are not.

SUMMARY POINTS

- The concept of patient responsibilities is inadequate and should be replaced with health responsibilities
- Health responsibilities can be directed towards oneself, others, or the efficient operation of a healthcare system
- Charters of health responsibilities raise ethical tensions
- Proposals for an English NHS charter should draw on experience of what works elsewhere

I thank Alena Buyx.

Contributors and sources: HS has an academic background in philosophy and bioethics. This article arose from general background research carried out for a part time PhD at the London School of Economics and Political Science. The views expressed here are his own and must not be attributed to the Nuffield Council.

Competing interests: None declared.

Provenance and peer review: Not commissioned; externally peer reviewed.

1 BMA. *A rational way forward for the NHS in England*. London: BMA, 2007.
2 NHS Scotland. *The NHS and you*. Version 1, 2006. www.scottishambulance.com/docs/NHS%20and%20You%20SCREEN.pdf.
3 West Virginia Department of Health and Human Resources. *West Virginia Medicaid member agreement*. www.wvdhhr.org/bms/oAdministration/Medicaid_Redesign/redesign_MemberAgreement20060420GW.pdf.
4 Schmidt H. Personal responsibility for health—developments under the German healthcare reform 2007. *Eur J Health Law* 2007;14(3):1-9.
5 West Virginia Department of Health and Human Resources. *Important notice about changes to your Medicaid benefits*. www.wvdhhr.org/bms/oAdministration/Medicaid_Redesign/redesign_NoticeMembers_MHC.pdf.
6 Eyre E. Reworked Medicaid program expanded: sluggish enrollment leaves some wondering about states move. *Charleston Gazette* 2007 Sept 21.
7 Waller BN. Responsibility and health. *Cambridge Q Healthcare Ethics* 2005;14:177-88.
8 Cappelen AW, Norheim OF. Responsibility in health care: a liberal egalitarian approach. *J Med Ethics* 2005;31:476-80.
9 Roemer J. *Equality of opportunity*. Cambridge, MA: Harvard University Press, 1998.
10 Minkler M. Personal responsibility for health: context and controversies. In: Callahan D, ed. *Promoting healthy behaviour: how much freedom? Whose responsibility*? Washington, DC: Georgetown University Press, 2000:1-22.
11 Wikler, D. Personal and social responsibility for health. In: Anand S, Peter F, Sen A. *Public health, ethics, and equity*. Oxford: Oxford University Press, 2005:109-34.
12 Buyx A. Eigenverantwortung als Verteilungskriterium im Gesundheitswesen, *Ethik Med* 2005;17:269-83.
13 Daniels N. *Just health—meeting health needs fairly*. Cambridge: Cambridge University Press, 2007.
14 Harris J. Scientific research is a moral duty. *J Med Ethics* 2005;31:242-8.
15 Wanless D. *Securing our future health: taking a long term view*. London: HM Treasury, 2002.
16 Halpern D, Bates C, Beales G, Heathfield A. *Personal responsibility and changing behaviour: the state of knowledge and its implications for public policy*. London: Cabinet Office, 2004.
17 Bishop G, Brodkey AC. Personal responsibility and physician responsibility—West Virginia's Medicaid plan. *N Engl J Med* 2006;355:756-8.
18 Steinbrook E. Imposing personal responsibility for health. *N Engl J Med* 2006;355:753-6.
19 Johnson seeks to soothe NHS anger. *BBC News Online* 2007 Jul 4. http://news.bbc.co.uk/1/hi/health/6269508.stm.
20 Darzi A. *Our NHS, our future:NHS next stage review—interim report*. London: Department of Health, 2007. www.dh.gov.uk (search for: 8857).
21 Chapman J. Millions too fat for NHS surgery. *Daily Mail* 2007 May 1. www.dailymail.co.uk/pages/live/articles/health/healthmain.html?in_article_id=451575&in_page_id=1774.