PERSONAL RESPONSIBILITY

Personal Responsibility: Introduction

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Individual health is determined by many factors, ranging from genetics through health services to housing. Among these, health-related behaviors such as smoking and exercising have an important place, which has become more prominent as the main causes of illness have shifted in recent decades from infectious to chronic diseases. Rising health care costs and demand for services combined with the recognition that health is, among other things, the product of individual behavior has given rise to the demand that individuals should share in the responsibility for their health. The implication of this for health policy and the organization of services is, however, not clear and still controversial.

Since people's illnesses place a burden on others, some see this responsibility as meaning that people have a duty to others to remain as healthy as possible and avoid disease, and if not, to pay the price by sharing the cost of treatment. Others see this view as tantamount to victim blaming, ignoring the fact that there are many complex reasons why individuals cannot always adhere to medical recommendations.

This track of the conference explored the issue of personal responsibility and the various ways in which it can be expressed in the context of health. One of the tract's strengths was that presenters came from different backgrounds with different perspectives. Legal, clinical, philosophical, and policy aspects were presented.

Mordechai Shani gives an introduction to the issue: many people behave in ways that jeopardize their health, and some health systems are trying to change this by using either rewards or punishments. However, these attempts raise serious questions of fairness.

Harald Schmidt, Daniel Wikler, and Gil Siegal frame the philosophic and legal aspects of the personal responsibility discussion. **Harald Schmidt** gives an overview of how the concept of personal responsibility features in three different health systems: in Germany, the United Kingdom, and the United States. The status of personal responsibility in these three countries varies: it is part of the law in Germany, aspirational in the United Kingdom, and dependent on insurers in the United States. He presents the two sides of the personal responsibility debate, a debate hindered by, among other things, the problem that different people mean different things when using the term "responsibility". He stresses that the fact that there is some causal connection between one's past behavior and one's present state of health does not mean that one should be penalized, and proposes an approach to the issue of personal responsibility that does not focus on blame and circumvents the polarization existing in this debate today.

Gil Siegal and **Neomi Siegal** discuss the issue of the determinants of human behavior, which, contrary to some economic theories, is not necessarily what an outside observer would call "rational". They make the point that it is possible to use behavioral sciences to design systems that will encourage people to make the right choices (in this case, health-promoting choices) while leaving them with freedom of choice.

One notable program in the United States mentioned by a number of presenters is that of the West Virginia Medicaid Program, which has recently become a leading but controversial example of efforts to reward personal responsibility. This program, which includes a two-tiered system with an enhanced package of benefits for "responsible" patients and a reduced one for others, was the impetus for **Gene Bishop**'s presentation. Bishop presented the perspective of a primary care doctor frustrated by programs of this kind for both ethical and practical reasons. As do others, she voices concerns that these programs end up punishing the most vulnerable in society, who find it most difficult to adhere to recommendations as well as to benefit from wellness schemes, and therefore enhance inequalities. Moreover, they are completely unhelpful and even detrimental to doctors in their efforts to give good treatment.

Leah Wapner and **Malke Borrow**, from the Israel Medical Association, discuss the issue of patient empowerment, as a way of sharing responsibility between patients and doctors. **Yael Applbaum** and **Orna Tal** propose a model of shared responsibility and shared rewards for doctor-patient teams achieving good health outcomes.

Joseph Betancourt and **Marina Cervantes** stress that addressing the root causes of chronic disease will require both personal responsibility and responsible options. Individuals cannot be expected to deal with these problems on their own. It is up to the community and the health system to make sure that people have the options that allow them to behave responsibly and in fact follow medical recommendations: safe places to exercise and stores in which healthy food is available and affordable, are two examples of this.

In addition to these papers addressing more general aspects of personal responsibility, there were papers focusing on how the issue of personal responsibility is reflected in specific contexts, like diabesity (**Elliot Berry** and **Sabina De Geest**), psychiatric patients (**Asaf Caspi**), or the Israeli Kibbutz (**Eitan Hay-Am** and **Yaniv Sherer**). **Baruch Velan** discusses responsibility in the context of vaccinations, a case in which each individual's behavior can have a direct effect on the health of others. This places great responsibility on the individual, but Velan stresses that this is not a unilateral responsibility: the state has a responsibility to make vaccinations as acceptable as possible to the public, so as to make it easier for the public to fulfill their part of the deal.

The next two papers consider various dimensions of the relationship between economic considerations and consumer/individual responsibility. **Regina Herzlinger** discusses how consumers could be given a greater role in controlling health care costs, while **Harald Schmidt** explores equity issues raised by individual-level health incentives. The section concludes with a paper by **Arnon Afek** and **Ari Shamiss**, which explores the ethics of personal responsibility in an historical context.

None of the presenters in this track took an extreme position in favor of placing all the responsibility on the individual; all are aware of both practical and ethical considerations. Similarly, none of the speakers took a stance at the other extreme and argued that the individual should have no responsibility. We should note, there are thinkers who do not view the term "personal responsibility" as a legitimate one and there are others who feel that most of the responsibility for health should be "personal responsibility". The consensus among the speakers at the conference was a more nuanced one. That consensus views participation of the individual as necessary in order to achieve good health, and holds that individuals should share responsibility, but this should be seen within the context of broader social responsibility.

Personal Responsibility: Preliminary Remarks

Mordechai Shani

Most of the discussions in bioethics and health policy concerning social responsibility for health have focused on society's obligation to provide access to health care.

As we know, simple lifestyle changes could do more than any number of new drugs or hospitalization. Yet, around 50 percent of patients do not comply with the advice of their physicians.

People often behave in ways that jeopardize their health. Examples are smoking, lack of exercise, excessive consumption of alcohol or food, poor dental hygiene, cycling without a helmet, and not taking preventive measures when traveling to areas with high risk of infectious diseases.

The concept of personal responsibility in health care is that if we follow healthy lifestyles (such as exercising, maintaining a healthy weight, and not smoking), and are good patients (as in keeping our appointments and heeding our physicians' advice), we might be rewarded. A different concept is to punish those who do not comply with a healthy lifestyle or are bad patients.

The German Federal Law of Health Insurance has stated since 1988 that citizens have co-responsibility for their health. 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.

Actually Germany is leading in innovative ideas about personal responsibility. I am sure that Dr. Schmidt will comment in detail about the German approach (Schmidt, Gerber, & Stock, 2009).

Several months ago, the leader of the German Medical Association called for a public debate about rationing of health care in Germany. Dr. Hoppe proposed that treatment for diseases caused by bad lifestyle should not be refunded. For example, in his opinion, cholesterol-lowering drugs belong to the category of luxury medicine ("German Doctors' Leader," 2009).

The West Virginia Medicaid Plan is asking patients who wish to receive enhanced benefits to sign a "Medicaid Member Agreement" that they agree, for example, to take their medications and keep their appointments. Patients who do not uphold their end of the bargain will have some enhanced benefits reduced or eliminated (Bishop & Brodkey, 2006).

In the U.K., the government is considering withdrawing benefits from people who are addicted to alcohol unless they consent to take part in a treatment program ("doctors Warn", 2009). A similar scheme is being piloted in England among people with drug addiction.

In Netherlands, the Council for Public Health and Health Care proposed several years ago a 10 percent variation in the premium rate in order to make it somewhat dependent on a subscriber's health status (Meulen & Maarse, 2008).

There is also a tendency of the population in Netherlands to be stricter toward risky and unhealthy lifestyles and to exclude persons from access to health services or let them pay higher premiums (Meulen & Maarse, 2008).

A fertility clinic in Central London is asking patients to sign a contract promising not to smoke or drink during treatment in return for a free cycle

of IVF if the first one fails. Eligible patients will be required to sign up to a health and lifestyle improvement program, which includes losing weight if necessary, before they embark on IVF treatment. In return, the clinic is offering a fixed-price package of treatment including optional acupuncture and a second free cycle of IVF if the first one fails (Daily Telegraph, 2009).

A national survey conducted in 2006 estimated that 53% of Americans think it is "fair" to ask people with unhealthy lifestyles to pay higher insurance premiums and higher co-payments and/or deductibles than people with healthy lifestyles (Steinbrook, 2006).

The Province of Alberta is poised to become the first jurisdiction in the world that will try to make crime pay by suing convicted people for the cost of treating injuries they sustain committing crimes ("Alberta to Seek", 2009).

Alberta already has the power (under the Hospital Act) to pursue drunk drivers and other "wrongdoers" for the cost of treating their victims. If drunk drivers have liability insurance, their health care costs would be paid out of a fund created from mandatory contribution by the insurance industry.

Total health expenditures are very high in health care systems around the world, leading to rationing. Therefore the belief is that there should be no waste by "inefficient" behavior that can be prevented. Rationing of health care is a fact of life due to its high costs, and since resources must be preserved for other social needs such as education, welfare, and housing.

Citizens have rights but also duties. In this sense, one could argue that sensible care for oneself and one's health is a moral duty. It is part of what free and adult citizens with a sense of justice may expect of one another.

An argument in support of rationing by responsibility is grounded in the antisocial character of irresponsible health behavior. Just as a person can forfeit his or her right to liberty by criminal behavior, one could argue that a person can forfeit his or her right to health care by failing to act responsibly. It is unfair that those contributing to the insurance pool pay the extra costs of those who voluntarily engage in risky actions that increase their need for medical services, and it is fair to withhold societal funds from needy persons whose medical needs resulted from voluntary risk taking. This conclusion does not conflict with the rule of fair opportunity, because those who are voluntarily risking their health have had the opportunity to be healthy (Denier, 2005).

The idea of personal responsibility raises fundamental issues of fairness. It places responsibility on patients for factors that may be out of their control. Is there a linkage between poorer and less well-educated patients and low compliance with medical care? Here we are canceling some of our fundamental principles of patient autonomy and the principle of social justice (Walter, 2005).

There is the problem of causal responsibility. We want to be sure that we know exactly what actions or behaviors lead to a certain condition before holding patients responsible for the consequences. While this is easy in many cases, the causes of several of the conditions most often cited as being preventable through healthy behavior (diabetes, high blood pressure, some cancers) are multifactorial Some factors are related to individual health behavior or lifestyle, but others are environmental, societal, or genetic.

The benefits of vaccination to the child and the public have been demonstrated with scientific data. But parents weigh choices about vaccination using conceptions of risk, benefit, and trust. It is well established that people who are better off are more likely to participate in preventive measures than poor people. People with higher socio-economic status get more bonuses, since they know how to better utilize the system. Therefore, in practice we punish the poor and those with low education. Braun has shown in Germany that almost twice as many bonus users were in the fifth quintile of earning than in the first quintile (Denier, 2005).

The example of keeping appointments seems at first glance uncontroversial. Keeping appointments is important to reduce cost and is also fair towards other people wishing to access services. However, patients with mental disorders or depression may have good reasons for missing appointments, thus implementation is complicated.

Over-diagnosis is a widely recognized problem in prostate cancer screening, but it has been reported in other cancers. In mammography there is a delicate balance between benefit and harm, since it hurts some women (Heath, 2009; Welch, 2009).

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Personal Responsibility for Health: A Proposal for a Nuanced Approach[1]

Harald Schmidt

Introduction

The debate around responsibility for health, like many long-standing controversies, has become somewhat polarized. At one end of the spectrum, commentators make what might be called a "get-real" argument: they emphasize, for example, that lifestyle choices about physical exercise and the consumption of food and alcohol clearly do affect health outcomes; that successful treatment depends on patient compliance; and that peoples' individual actions have a significant effect on whether a healthcare system can be run efficiently. Since it can make sense to say that in all these areas people are responsible for their actions, proponents then often assert that people should also be held responsible. This may entail that they suffer a penaltyor disadvantage in cases where they behave irresponsibly. At the other end of the spectrum, commentators equally make a "get-real" argument. Here, it is stressed that the very concept of lifestyle choice can be cynical. It seems to assume that it is equally easy for all to be healthy, with some simply choosing an unhealthy as opposed to a healthy lifestyle. Even if the claim is not that it is equally easy for all, the assertion still seems to be that the options people have in their lives are generally such that all people could be healthy if only they decided to. But – leaving aside deeper philosophical debates about the freedom of the will – there is much reason to doubt that this is the case. For example, in presenting the final report of the World Health Organization's (WHO) Commission on Social Determinants of Health

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[1] Please note that major sections of the conference presentation were based on publications published prior to the conference (principally Schmidt, 2008, 2009a, 2009b). The author is grateful for the permission to reproduce the material in this form, and for the opportunity to make revisions in view of comments received since the publication, including in response to valuable feedback during the conference.

(CSDH), Director – General Margaret Chan noted: “The Commission’s main finding is straight forward: the conditions in which people are born, live, and work are the single most important determinant of good health, or ill health; of a long and productive life, or a short and miserable one,” (Chan, 2008). Hence, proponents of the social determinants of health view would argue that talking about a person’s responsibility to maintain a healthy weight is of relatively limited use in the case of a single unemployed teenage mother who grew up and lives in a deprived inner city borough with a high density of cheap fast food outlets, poorly maintained and unsafe parks, no affordable sports facilities, and so on. Holding her responsible for being overweight, by imposing some disadvantage or financial burden would amount to unacceptable victim-blaming, as not she, but the circumstances in which she lives, are responsible for her poor weight: as the CSDH report noted, instead of focusing on the causes of her poor health, more attention should be paid to the “causes of the causes” (CSDH, 2008).

In the following I argue that this often encountered polarization is misguided and unhelpful for making progress in the debate around responsibility for health. I suggest that, to some extent, it is due to confusions about the way we typically use the concept of responsibility, and I suggest a more nuanced approach that permits a debate about personal responsibility beyond the blame-game.

I begin with a review of how personal responsibility features in health policy in Germany, the UK, and the USA. I then draw out some common themes arising from these policies, and make a number of conceptual distinctions between different senses of personal responsibility. In the final section I set out a framework that, I hope, can help in planning, carrying out, and evaluating policies that seek to implement reasonable responsibility standards.

Personal Responsibility in Health Policy

Germany

Book V of the German Social Security Code (Sozialgesetzbuch [SGB V]) regulates the provision of statutory healthcare. Its norms are binding for some 200 sickness funds that provide care for approximately 90% of the

German population (the remainder being covered by private insurance). Article 1 of SGB V has overarching function and is entitled "Solidarity and personal responsibility". A characterization of both concepts is provided in the wording of Article 1 that reads:

> In the spirit of a mutually supportive community [Solidargemeinschaft] the task of the statutory health insurance is to maintain, restore or improve health of the insured. The insured have co-responsibility for their health; through a health-conscious way of living, taking part in appropriately timed preventative measures [and] playing an active role in treatment and rehabilitation, they should contribute to avoiding illness and disability, and to overcoming the respective consequences. The statutory sickness funds are to assist the insured persons through the provision of information, advice and services, and should encourage a health-conscious way of living [my translation].

The principal characterization of solidarity and personal responsibility is that the community as a collective, and people individually, are co-"producers" of health. The notion of co-responsibility has two important facets in this respect. First, it states that the "mutually supportive community" has a certain degree of responsibility for the health of each individual. In this sense, individuals are entitled to claims against the community for assistance. Second, it also implies that the community has certain claims against individuals. Leaving prudential benefits aside, the appeal to staying healthy has the aim of containing overall expenditure and opportunity costs. For all care needs to be financed by the solidaristic community, and cost can be reduced or at least contained if demands on the healthcare system are limited. Using services unnecessarily may also deprive another person in need of resources or medical attention, exacerbating resource allocation dilemmas. Article 2 SGB V on "necessity, cost-effectiveness, and personal responsibility" is unequivocal in stressing people's obligations in this respect:

> Services … are to be provided by the sickness funds with due respect to cost effectiveness [Wirtschaftlichkeitsgebot] … and insofar as the need for services is not attributable to the personal responsibility of the insured person. […] Sickness funds, service providers and insured persons must seek to ensure the clinical and cost-effectiveness of services, which are only to be used insofar as necessary [emphasis added, my translation].

Article 2 raises the question of what exactly, in practice, the respective scope and limitation of solidaristic and personal responsibility should be. Is there a worst-case scenario in which solidaristic coverage would be refused? Article 52 SGB V sets out conditions under which statutory sickness funds may limit funding for services, and the most recent healthcare reforms of 2007 included a noteworthy specification in this respect. In its pre-2007 version, Article 52 stated that insurers may demand a reasonable contribution to the costs of treatment if a person's need for healthcare is the result of engaging in a criminal activity. Solidarity and personal responsibility are interpreted in such a way that whoever harms the solidaristic community has lost the claim to having healthcare needs met at their exclusive expense. In such cases, financing healthcare can become a matter of personal responsibility. However, this responsibility extends to the costs only: for solidarity still clearly requires the criminal person to be treated by the healthcare services. Under the 2007 amendments, this principle has been extended to state that insurers may ask for equivalent contributions where people request treatment for complications arising from "cosmetic surgery, tattoos … piercings," or another "non-medically indicated" measures, and I will return below the some of the issues this raises.

In addition to these provisions, there are a number of initiatives that are framed as incentives for people to behave responsibly, as summarized in Figure 1. The common theme here is that a certain advantage, usually a financial one, such as lower insurance contributions, co-payments, or a lump-sum payment, can be obtained where people minimize their healthcare usage, regularly attend dental care check-ups, take part in preventive or wellness activities, or comply with treatment. All major sickness funds offer incentive programs and, typically, a single person can obtain an annual reimbursement of around EUR 50-100 for participation in different prevention measures (Schmidt, Stock, & Gerber, 2009). The different schemes have different rationales that may overlap. In the most benevolent interpretation, they are simply intended to improve people's health. Additionally, as the provisions of SGB V Art 65a set out, there is also the assumption that healthier people will require less healthcare expenditure. Lastly, in a somewhat more indirect way, incentive programs function similarly to schemes such as air miles or store loyalty cards. If programs are designed in such a way that they appeal in particular to the better off and healthy, incentives can help sickness funds attract "good risk" customers, who are likely to require less care, and contribute disproportionately more, as insurance contributions are income-tested. In this way incentive programs may help insurers secure a competitive advantage, and it is noteworthy that schemes such as the no-claims-bonuses (SGB V Art 53) were introduced under the 2007 Act to improve competition among statutory sickness funds.

Figure 1. Summary of provisions on personal responsibility for health in the German Sozialgesetzbuch V – SGB V (Social Security Code), 1988, last revised Jan 2007.

Incentives to limit use of healthcare services

Article 53 – "Personalised healthcare plans" [Wahltarife]

This Article provides that sickness funds may offer reduced contributions (or lower co-payments, where required) to those agreeing to take part in schemes thought to reduce the burden of morbidity and costs for the sickness funds, such as managed care programs. Sickness funds may offer what amounts to no-claim bonuses: Reductions of up to 20% of the annual contributions may be granted, capped however at 600€ maximum (or 900€, where several different bonus plans are combined) if the insured requires no primary care consultation leading to a prescription, or hospitalization over a year.

Incentives for compliance with dental check ups

Articles 55 and 56 – "Entitlement to services"

These Articles stipulate that statutory sickness funds must cover 50% of the costs for required dental replacements, with the other half falling to the insured person. The law also requires insurance providers to up their contribution by 20% of their initial payment, if, over a period of 5 years, adults have taken part in annual check-up programs (and under 18-year-olds in biannual ones). If there are no gaps over the past 10 years this is increased to 30%. However, if there are gaps, the insured persons have to pay their full 50%.

Incentives for 'looking after oneself'

Article 65a – "Bonus for health-conscious behaviour"

This Article provides that sickness funds may offer bonuses to insured persons who regularly participate in preventive health-promotion, screening, and check-up programs. In practice, bonuses are provided in cash, reductions of insurance contributions, or goods, such as sports equipment. The law also specifies that bonus payments may only be made if savings for the sickness funds result from participation in the activities that are rewarded.

Incentives for compliance: chronically ill and cancer patients

Article 62 – “Thresholds for co-payments”

This article and subsequent interpretation by the Gemeinsame Bundesausschuss (G-BA) states that patients who suffer breast, colon, or cervical cancer will have to pay a maximum of 1% of their gross annual income as co-payments for treatments and medicines if they have attended counseling sessions on the advantages and disadvantages of the respective screens, and do not refuse treatment. In case of non-compliance, the cap is 2%. All other chronically ill are, at present, eligible for the 1% threshold.

*Note that this is an excerpt of the most relevant provisions. Note also that there is no official translation of the SGB V [all translations mine, HS].

United Kingdom

The UK, like Germany, has a long history of providing healthcare universally, even if the largely tax-funded single payer system differs in many ways from Germany’s social health insurance system. While personal responsibility featured explicitly and prominently in Germany’s health law for at least two decades, there is no similar longstanding acknowledgement of the concept in the UK, even if major Government reports and discussion papers explored different aspects of it (Halpern, Beales, & Heathfield, 2004; Wanless, 2004). However, in 2008, the 60th anniversary year of the NHS, the UK Department of Health (DH) held a consultation on a draft NHS Constitution, publishing a final version in January 2009. The document aims to set out the NHS’ fundamental values and principles, and includes a range of individual rights of NHS users and details their responsibilities (see Figure 2).

Figure 2. Excerpt from NHS draft Constitution – Section 2b on “Patients and the public – your responsibilities” (DH, 2009).

The NHS belongs to all of us. There are things that we can all do to help it work effectively and to ensure resources are used responsibly:

You should recognise that you can make a significant contribution to your own, and your family’s, good health, and take some personal responsibility for it.

You should register with a GP practice – the main point of access to NHS care.

You should treat NHS staff and other patients with respect and recognise that causing a nuisance or disturbance on NHS premises could result in prosecution.

You should provide relevant and accurate information about your health, condition and status.

You should keep appointments, or cancel within reasonable time. Receiving treatment within the maximum waiting times may be compromised unless you do.

You should follow the course of treatment which you have agreed with y our clinician.

You should participate in important public health programs such as vaccination.

You should ensure that those closest to you are aware of your wishes about organ donation.

You should give feedback – both positive and negative – about the treatment and care you have received, including any adverse reactions you may have had.

The first paragraph differs from the following in that it is somewhat more general than the remaining provisions. Presumably what is meant here is something like “lead a healthy life, take part in preventative and health maintenance activities, attend check-ups if you are in the relevant age and risk group, and play an active role in treatment and rehabilitation”.

The remaining items are then very specific, focusing on obligations that would help ensure efficient operation of the NHS and generally also benefit the person concerned. During the consultation phase, the Constitutional Advisory Forum to the Secretary of State for Health (CAF) noted in its summary of the consultation exercise that the section on responsibilities was generally supported, but that there had been "anxieties about enforcement". While some respondents took the view that "only those responsibilities with clear sanctions for individuals would have an impact", others worried that "excessive or inappropriate enforcement might deter people from the services they need" (CAF, 2008).

The overall status of the responsibilities is – apart from one regarding interactions with NHS staff and other patients, which may entail legal sanctions – non-binding and merely aspirational. There is no mention of positive or negative conditions, be these financial or other incentives or disincentives, or other forms of rewards or penalties. Apart from pilot programs, the UK has so far not yet considered a broader rollout of incentive programs, although such options have been considered by different parts of the Government's health policy advisory bodies, such as Health England (Le Grand & Srivastava, 2008).

It is noteworthy that the explanatory text of the Constitution's consultation document stated unambiguously: "We have firmly ruled out linking access to NHS services to any sort of sanction for people not looking after their own health." (DH, 2008). Perhaps some of the anxieties that the CAF reported might have been avoided if this, or a similar phrase clarifying the primarily aspirational nature of the responsibilities, had been included in the opening paragraph of the actual text of the responsibility section elsewhere in the Constitution, or in one of the accompanying guidance documents. In any case, the CAF's report concluded that "The responsibilities in the Constitution as currently drafted do not need strengthening. The [DH] will, however, need to argue for an understanding of 'responsibility' that reaches beyond duties and sanctions to a concept linked to 'mutuality' – as taking responsibility with consequences for all rather than sanctions for individuals" for, "responsibility to the NHS is, at bottom, a responsibility to each other" (CAF, 2008).

USA

In contrast to Germany and the UK, the provision of healthcare in the USA is organized in a far less centralized fashion, and there is no universal coverage. Instead there is a mix of private and public provision of healthcare. Large employers offer their own health insurance, while others purchase coverage for their employees from private providers. Federal programs such as Medicaid provide services for the least well off, and people older than 65, and some who meet special criteria, are eligible for Medicare coverage. The Veterans Health Administration provides services for former military personnel. There are also significant differences in the way in which the different states provide services under Medicaid or Medicare, and while some view this diversity as an excellent opportunity to learn from different approaches, many view it as inequitable and problematic. Not least because of the diversity in providers of healthcare, there is currently no explicit single set of norms that would specify responsibilities of healthcare users in different areas. However, similar to the German initiatives on health promotion and incentives, there is federal guidance on the conditions under which wellness incentives may be offered.

The 1996 Health Insurance Portability and Accountability Act (HIPAA) sought to improve continuity of health insurance when individuals moved between providers. The Act established that a group health plan may not discriminate among insurance holders based on health factors such as disability or medical history, for example, by varying premiums. But HIPAA clarified that this did not prevent insurers from offering reimbursements for certain wellness programs, distinguishing between two types. First, in the case of what can be called "participation-incentives", a premium discount, rebate, or reward may be given simply for participating in a scheme, such as a weight-loss or smoking cessation program. Second, in the case of what can be called "attainment-incentives", a reimbursement may be given for meeting certain health status targets, relating to risk factors such as Body Mass Index (BMI) or blood pressure. A subsequent joint decision by the Departments of Labor (DoL), Treasury (DoT), and Health and Human Services (DHHS) in 2006 clarified that the reimbursement for attainment-incentives must not exceed 20% of the total cost of an employee's coverage (i.e., the employee's premium plus the employer's contribution). Health reform bills before Congress at the time of writing propose to increase the level of reimbursements for attainment-incentives to 30%, with the option of 50% for particular initiatives, subject to approval by the DoL, DoT, and DHHS. Both under current and proposed initiatives, for individuals for whom it is unreasonably difficult due to a medical condition, or medically inadvisable to take part in the programs, a reasonable alternative standard must be provided so that they can access reimbursements, although such exceptions are dependent on a certification from the employee's physician that plans may request. The Health Education, Labor and Pension (HELP) Committee's health reform bill "Affordable Health Choices Act" of 2009 required that a 10 state demonstration project would assess in particular: "changes in the health status of employees, the absenteeism of employees, the productivity of employees, the rate of workplace injury, and the medical costs incurred by employees", illustrating the range of motivations behind the scheme.

A controversial initiative at the state level regarding personal responsibility beyond wellness incentives was introduced in 2007 in West Virginia, where changes were made to the way in which Medicare would be accessed. The Medicaid Member Agreement, initially published in April 2006, and introduced under special provisions of the Deficit Reduction Act of 2005, is not a legal statute but its provisions are unambiguously binding for those enrolled. Prior to the Agreement, all Medicaid patients were able to access the same services. The new initiative changed this by creating two different plans. By default, eligible Medicaid recipients are assigned to the "basic" plan. Accepting the conditions of the Agreement, they may access the "enhanced" plan (see Figure 3). Those failing to comply with the Agreement will be reassigned into the basic plan, with the option of appealing and re-applying after 12 months where appeals failed. The "enhanced" plan is more comprehensive and includes, for example, smoking cessation programs, nutritional education, weight management programs, and mental health and substance abuse services. The "basic" plan limits non-emergency medical transportation and prescription drugs (a maximum of four prescriptions per month, although, by contrast, there is no limit in the "enhanced" plan). The Agreement has been phased in since early Spring 2007, and the first evaluations are expected to be published shortly after the time of writing.

Figure 3. West Virginia Department of Health and Human Resources: Medicaid Member Agreement, April 2006.

1. I will follow the rules of the West Virginia Medicaid program.
2. I will do my best to stay healthy. I will go to special classes as ordered by my medical home.
3. I will read the booklets and papers my medical home gives me. If I have questions about them, I will ask for help.
4. I will pick a medical home within 30 days or one will be picked for me.
    - I will go to my medical home when I am sick.
    - I will take my children to their medical home when they are sick.
    - I will go to my medical home for check-ups.
    - I will take my children to their medical home for check-ups.
    - I will take the medicines my healthcare provider prescribes for me.
    - I will show up on time when I have my appointments.
    - I will bring my children to their appointments on time.
    - I will call the medical home to let them know if I cannot keep my appointments or those for my children.
    - I will let my medical home know when there has been a change in my address or phone number for myself or my children.
5. I will use the hospital emergency room only for emergencies.

*Note that only the first part of the agreement has been reproduced here, concerning the responsibilities of Medicaid members. The full agreement, which lists member's rights in the second section is available from: http://www.wvdhhr.org/bms/oAdministration/Medicaid_Redesign/redesign_MemberAgreement20060420GW.pdf

Summary

Personal responsibilities set out in policy and law in Germany, the UK, and the USA specify obligations with three different directionalities. First, there are responsibilities directed at oneself, to stay healthy, or to regain health where it was poor. Second, there are responsibilities where the object is the health of others, for example those under one's stewardship (children or the elderly), or otherwise people whose health may be better or worse, depending on how we act (for others' benefitf we ensure that we do not spread infectious diseases, donate blood, etc.). Third, there are obligations towards the healthcare system, to ensure its efficient operation. Closely connected to the question of to whom one is supposed to have some obligation is the question of on what grounds. An at best implicit rationale is that health in itself is a good that should be realized, or, in a more instrumental sense, that good health is something that is necessary for accomplishing things that matter in life. More explicit rationales are that we have obligations not to harm others, and that behaving responsibly and being healthy will contain or reduce healthcare expenditure, or enhance fairness, as more people are able to access healthcare. Insurers or self-insured employers are also likely to consider the potential of incentive schemes to help them attract "good-risk" enrollees, who are likely to have lower morbidity, fewer sick days, less absenteeism, and greater productivity.

Responsibilities are set out with different status. In the German case, they form part of hard law (even if the sickness funds have some discretion in implementation), in the UK case they are purely aspirational, and the incentive policies set out in the USA depend on whether insurers make use of the provisions for wellness programs. However, in the case of West Virginia's Medicaid Membership Agreement, implications for healthcare users are, in principle, as direct as in the German situation. While some schemes are framed explicitly as "sticks" or penalties that are imposed where people do not comply with their responsibilities, the majority is presented as incentives (or "carrots").

Conceptual Distinctions

The concept of personal responsibility, both as implied by policies such as the above, and as reflected in the broader academic debate warrants a closer inspection. For many, the ascribing of responsibility is intrinsically linked to holding someone responsible, and proponents argue that responsibilities without sanctions appear pointless, while opponents caution that imposing sanctions often entails the risk of penalizing people unduly. But this dichotomy is inadequate, for there are a range of different things people may mean when they say that "person X is responsible for p". Sometimes, distinct notions are made explicit, but other times, several meanings may be in use simultaneously, whether explicitly or implicitly. Much confusion arises from not distinguishing clearly between these different meanings, or from not being explicit about which sense is intended in endorsements or criticisms of particular responsibility-related policies (see also Figure 4).

Figure 4. Personal responsibility in philosophy and ethics.

A range of different characterizations can be found in the literature. The following examples have been set out to be applied in the context of healthcare, or are otherwise directly applicable:

- "causal … responsib[ility vs.] responsib[ility] … [as] being at fault and accountable" (Wikler, 1987)
- "role responsibility…, causal responsibility …, responsibility based on liability" (Dworkin, 1981)
- "responsib[ility] for … choices … [vs.] responsib[ility] for the consequences of … choices" (Cappelen & Norheim, 2005)
- "prospective … [vs.] retrospective responsibility", (Werner, 2002) "forward-looking … responsibility [vs.] backward-looking … responsibility" (Feiring, 2008)
- "substantive responsibility ... [vs.] responsibility as attributability" (Scanlon, 1998)
- "agent responsibility [vs.] consequential responsibility" (Stemplowska, 2008)
- "individual responsibility for reasons of … fairness, … utility … self-respect … autonomy … human flourishing" (Brown, 2005)

At the most basic level, it is important to distinguish whether we are ascribing responsibility in a backward-looking sense (where, for example, we assess someone's past behavior that is correlated to some health outcome) or in a forward looking one (where we may want to specify what people should do in the future). In a backward-looking sense, the phrase "person X is responsible for p" may mean:

1. X has played a certain causal role in having brought about p.
2. X has played a certain causal role in having brought about p, and should recognize this.
3. X has played a certain causal role in having brought about p, should recognize this, and try to avoid doing so in the future.
4. X has played a certain causal role in having brought about p, should recognize this, try to avoid doing so in the future, and make good any costs (with or without being blamed) for reasons of distributive justice.
5. X has played a certain causal role in having brought about p, should recognize this, try to avoid doing so in the future, make good any costs, and, in cases where X requires treatment, may be given a lower priority than patients whose behavior played none or a lesser role in contributing to their healthcare needs (typically with attribution of blame).

It is not uncommon for commentators to focus on the last type only, and/or to jump straight from the first to the last type, assuming that having established some degree of causal or role responsibility, a person must also be held responsible (see Cappelen & Norheim, 2005; Daniels, 2007; Heath, 2008). But this is far from necessary. For example, the concept of solidarity as featuring in the German SGB V – featuring in a less value-laden sense also in most risk-pooling arrangements underlying both public and private health insurance – may mean that we are quite clear that a person's action played a causal role in producing a bad health outcome, but that this does not reduce the person's claims on the community (Segall, 2007).

Nonetheless we may find it useful to draw on some notions of responsibility, whether in abstract policy, specific prevention campaigns, or consultations with healthcare professionals. For example, in a given case where a person is responsible in one of the first three senses there may remain some degree of freedom for personal action and behavior change even if environmental constraints have played a role, perhaps even a major one. Realizing the scope for action in this area is important for avoiding fatalism and resignation, which may have a powerful grip on people struggling to maintain or improve their health. While it is difficult to disagree with the strong emphasis that proponents of the social determinants of health approach put on the general need for improving environmental conditions, an exclusive or overly strong focus on the environment can overlook the degrees of freedom that people have, even in constrained conditions. For people to take action, then, it is necessary for them to realize the extent to which they contributed to, say, a bad health outcome, and, in this merely functional sense, to realize that they are, and can be, responsible. An important qualification is of course Kant's old adage of "ought implies can", which has particular relevance in this context. For it would be pointless, if not cynical, to specify responsibilities where, due to strong environmental constraints, it is impossible for people to act accordingly.

It is also important to recognize that talk of responsibility in a forward looking sense is in many ways quite different from the more common backward-looking perspective. Hence, what we may mean here when we say that "person X is responsible for p" may be:

1. X should do p as no-one else can, in principle (or will, practically) do p for X (e.g., exercise more, eat less).
2. X should do p, as this will be good for the health of X.
3. X should do p, as this will be good for the health of others, or the operation of the healthcare system, even though X won't be penalized if p is not done.
4. X should do p, as this will be good for the health of others, or the operation of the healthcare system, and X knows that a penalty will be imposed if p is not done.

Again, it is far from necessary that the first or second type of responsibility, which may be called prudential responsibilities, automatically lead to the last type, which, together with the third, may be called responsibilities of justice. For example, paragraphs one, two, four, and seven of the responsibility section of the NHS Constitution helpfully emphasize the value of prudential responsibilities. Some health-related behaviors simply require that people individually do them, as no-one else will do them for them, and not even the most optimal environmental conditions will make them do them, in some sort of mechanistic way. It is in this somewhat banal, but nonetheless crucially important sense, that a range of health-related behaviors are personal responsibilities. Noting them and appealing to them in health promotion activities is relevant since – environmental constraints permitting – in a significant sense it is up to us to decide on whether we wash our hands regularly, brush our teeth, exercise, see our GP when we are sick, are honest about our health-relevant information, take part in public health programs, and so on. Advocating such responsibilities can result in clear personal benefits and is also likely to complement the social determinants of health approach as it can help identify those social or other structural constraints that make it difficult for people to live healthily.

Equally, the NHS Constitution's responsibilities one, four, six, and seven, and the general characterization in Article 1 of the German SGB V clarify that achieving good health is necessarily a co-production process, requiring both individual and social action. Forde and Raine (2008) have characterized co-production as the idea that: "Responsibility for better health should be shared between society and the individual, … society's efforts for health improvement should be dovetailed with individuals' and families' efforts." Central to their discussion is that polices are required that "support … people to engage with decisions about their own health". This includes health-literacy campaigns and may, in principle, also speak in favor of financial incentive schemes that feature prominently in the German and US initiatives.

Even if the reader is persuaded that it does make sense to accept a more nuanced picture of what should be understood by the concept of personal responsibility for health, and that a focus on blame and punishment detracts from preserving an important core of the concept that can be independent of sanctions, at this stage a question that clearly remains is how such an approach should be put into practice. To this I turn next.

A Proceduralist Account for Ensuring Fairness in Personal Responsibility Policies

In one sense, the question of health responsibilities might simply be a matter of choosing “the right” normative framework. Various political perspectives have different ways or explaining which of the above notions of responsibility should be central, and which ones should be more peripheral. Equally, there are different accentuations of personal responsibility in philosophical contributions, such as luck, egalitarian ones (Arneson, 1997; Dworkin, 2000; Roemer, 1994, 1995), or communitarian (Callahan, 1998), or libertarian accounts (Engelhardt, 1981). However, there are two principal problems with this approach. First, in value pluralistic societies, agreement about what constitutes the right framework remains generally elusive. Second, even if we suppose that we are able to find a country in which all residents (or just citizens) can agree on a single monolithic theoretical account, whether political or philosophical, such value systems are typically of a very general nature, and do not tell us ad more geometrico how to decide in designing and evaluating concrete policies.

Of course, this situation is not unique to the health responsibility debate. For example, regarding the central question of resource allocation, which, with Norman Daniels, is: “How can we meet health needs fairly when we can’t meet them all?” we are equally faced with a range of substantive positions that offer different perspectives. To make progress in practice, in a proceduralist approach Daniels suggested supplementing general principles of justice with fair processes for limit-setting, and draws on the framework of Accountability for Reasonableness, initially developed with Jim Sabin (Daniels & Sabin, 1999). This approach requires that policies meet four conditions concerning publicity, relevance, revision and appeals, and regulation. The relevance condition is specified in its briefest form as follows:

> The rationales for limit-setting decisions should aim to provide a reasonable explanation of how the organization seeks to provide “value for money” in meeting the varied health needs of a defined population under reasonable resource constraints. Specifically, a rationale will be “reasonable” if it appeals to evidence, reasons and principles that are accepted as relevant by [fair minded] people who

> are disposed to finding mutually justifiable terms of cooperation. Where possible, the relevance of reasons should be vetted by stakeholders in these decisions … (Daniels, 2007)

Below, I adopt the Accountability for Reasonableness approach to make progress with the debate around personal responsibility for health in a value-pluralist society. In order to specify the areas in which justification is owed under the relevance condition, I set out a number of "tests" that concern the impact of a policy in the planning, monitoring, or evaluation phase on key normative and structural values and components that are integral to practically all healthcare systems. These tests concern evidence, rationale, and feasibility; intrusiveness; equity; solidarity; attributability and opportunity of choice; affected third parties; and coherence (see Figure 5). I illustrate their relevance by focusing on financial incentive systems to promote health responsibility. This illustration is somewhat general, as the framework is not applied to a single specific policy, but comments on specific features of programs noted above. Nonetheless the discussion should help illustrate how the approach can be used in practice.

Evidence, Rationale, and Feasibility

Above, several different rationales were shown to underlie the policy initiatives in Germany, the UK, and the USA. The first step in planning personal responsibility measures is hence to justify these publicly, and to enable those affected by them to contribute their views, which includes possible arguments they would make to reasonably reject them, or request modifications. Insofar as incentive programs are offered on a voluntary basis, people might not be concerned about the rationale of using them to improve health. However, in practice, the implementation of incentives typically means not just that some people are offered an additional "carrot", but that those not taking part are denied one, and, in effect incur higher healthcare costs. For example, based on the average cost of healthcare coverage, the 20% reimbursement cap that is permissible under current US regulation can allow

Figure 5. Seven tests to evaluate the appropriateness of health responsibility policies.

Evidence, rationale, and feasibility

What are the policy's principal rationales and goals? Have they been justified in an open and transparent manner, with opportunity for comment by all those affected by the policy? How sure can we be that the policy will achieve its aim, in principle and in practice? Are the required efforts and cost proportionate

in view of the goals?

Intrusiveness and coerciveness

Are there ways in which the goal of the policy could be achieved in less intrusive ways? If not, is the extent of intrusiveness justifiable in view of the expected benefits?

Equity

Are there some groups (such as particular socio-economic, ethnic, or regional subgroups) who are likely to experience disproportionate benefits or burdens as a result of the policy? At what point would it be reasonable to reject a policy because of inequitable impact?

Solidarity/risk-pooling

Insofar as the healthcare system has an implicit or explicit principle of solidarity or risk-pooling: how does the policy affect it? If it should undermine solidarity or risk-pooling: are all affected clear about this, and can the effect be justified?

Attributability/opportunity of choice

To what extent are penalties or rewards based on actions that can be attributed to people's free and voluntary choices? Where peoples' opportunity of choice is limited: can waivers or alternative standards be implemented? Should rewards be given, even if people have not changed their behavior, but just happen to satisfy the policy's criteria?

Affected third parties

Does the policy have an effect on the relationship people have with, for example, their physicians or employer? Insofar as physicians are involved in assessing whether or not someone has complied with their responsibilities: is their involvement justifiable and accepted by them and their patients? What information should employers have (or not) about people's compliance with responsibilities?

Coherence

How does the policy compare with standards of responsibility, attributability, and blame in other areas of social policy and the law? Since tensions can be resolved in more than one way: in which way should they be addressed?

for a variation of as much as 965$ per year for a single employee; if the employee's family is also covered, the differential could be 2675. The German programs generally operate on lower levels, but in principle the same issues are raised. In both cases, what is offered as a "carrot" will seem to many far more like a "stick". In view of this situation it is desirable to justify implementations such as the above as reasonable, and it is especially important to provide evidence that the programs have a reasonable chance of success, both in terms of helping people change their behavior, and in terms of achieving goals such as cost reduction, that, as noted, also feature prominently. A major initiative that attracted much recent attention by US policy makers was the Healthy Measures program established by Safeway, whose CEO frequently claimed that it had helped reduce expenditure. However, robust evidence to support these claims has not been provided to date, and recent investigative journalism raises substantial questions about their veracity (Hilzenrath, 2010).

More fundamentally, it is also not clear that longer, healthier lives will lead to reduction in healthcare cost. Pieter van Baal and colleagues used a dynamic population model to analyze healthcare data from The Netherlands in order to estimate lifetime healthcare cost conditional on the presence of risk factors. They found that expenditure was highest for the healthy (defined as: non-smoking, BMI between 18.5 and 25: healthcare cost from age 20 was estimated to be €281,000) and lowest for smokers (€220,000), with obese people in an intermediate position (€250,000), largely due to differences in the longer life expectancy of healthy people, and associated cost for care (van Baal et al., 2008). However, there is also an as yet unresolved dispute about whether increasingly longer life expectancy will in fact lead to higher levels of morbidity and care needs (known as the “medicalization thesis”) or whether longer life will mean that the period in which care is needed is simply condensed over a shorter time than previously (the “compression thesis”) with some arguing that this will not lead to overall increases in healthcare expenditure and others less convinced about possible savings. These and further questions, such as those around the impact on productivity in the workplace, all require extensive study of empirical and modeling data and, clearly, not even an attempt at a conclusion can be offered here. However, it is noteworthy that some of the hard questions of distributive justice around people’s responsibilities may actually turn to a significant extent on an empirical analysis of the effectiveness of incentive programs in practice, and the actual costs associated with particular risk factors and ageing populations, which are often simply assumed. Of course, the mere fact that prevention programs may not lead to cost savings in the longer term does not mean that they should not be carried out. But it would seem that other reasons would need to be given in their support. Evidence on the total cost of poor health might also lead to a wider recognition that assessments of people who fail to behave responsibly (in the senses implied by incentive programs that seek to encourage a healthy way of living) would need to be re-adjusted, as, to some extent, the argument can be made that rather than costing society more, smokers and obese people have in fact “paid their way”, largely by dying earlier. Equally, such programs would need to be advertised in a way that avoided some form of unwarranted health paternalism or risk of stigmatization of already vulnerable groups, such as obese people.

Intrusiveness and Coerciveness

Incentive systems are generally framed as not being particularly intrusive or coercive, as it is commonly suggested that people are free to use them or not. However, high levels of reimbursement, as illustrated above, raise doubts about the extent to which people are free not to make use of the offers. Providers also differ in the way they advertise their programs, and it is not uncommon for insurance holders to receive frequent reminders by mail or other means. Such initiatives may be perceived as “nannying” of forms of “healthism” and may have a counterproductive effect on health responsibility attitudes.

Programs that reward participation in presymptomatic check-ups, such as cancer screens, may also be intrusive in the sense that they bring uncertain and unwelcome knowledge about disease susceptibility, possibly leading to anxiety or confusion, even if the degree of intrusiveness can be mitigated by focusing on providing information with suitable confidence intervals and the option for people to discuss any questions they may have. The level of intrusiveness or coerciveness therefore needs to be considered carefully, and is closely linked to the questions regarding evidence and rationale: poor evidence and rationales combined with highly coercive or intrusive measures would make for rather bad policy.

Equity

The fairest way of providing health interventions is often simply to make them available universally for all: this avoids stigmatization and leaves uptake to people who are suitably motivated. On the other hand, such approaches can be prone to problematic self-selection biases. Here, not only the penalizing effect resulting from cost-shifting that has been noted above needs to be considered (which is likely to disadvantage most those who are generally poorer in health and income), but also the question of whether unequal reaping of benefits should be acceptable. For example, it is not implausible to assume that a sizable proportion of those who are eligible for incentives would have behaved in the way that “earned” them the reimbursement anyway, simply because they follow a healthy way of living. In the “post-incentive” phase, they therefore act no different than in the “pre-incentive” phase. Where reimbursements are offered for meeting certain health standards, such as BMI or blood value levels, or for activities such as an active gym membership or attending yoga classes, there are questions about whether the better-off benefit more than the worst-off. Certainly, initial data from Germany suggests that this is the case: 19%, or almost twice as many people belonging to the fifth (least poor) quintile, used incentive programs in 2004-2005 as opposed to 11% of the first (poorest) quintile (Braun, Reiners, Rosenwirth, & Schlette, 2006). Trends since then have pointed in the same direction (Schmidt & Doran, forthcoming).

Wellness or prevention incentives aside, programs that offer reimbursements for not utilizing primary care consultations or hospitalizations over a year (see Figure 1, Art 53) raise some very similar issues, and moreover may lead to a problematic form of “health gambling”: if the insured persons stay healthy, they may make a gain. However, if they banked on redeeming the incentive and end up requiring treatment, they may either be faced with a financial “loss” of varying degrees or, alternatively, may seek to avoid or delay necessary prescriptions or even a necessary hospitalization. The effect is likely to have more impact on those who are worse off financially, who may, nonetheless, be more tempted to try their luck. On the whole though, such initiatives will be of more interest to the young and healthy, and less to the frail or elderly – unless they are very lucky gamblers. Here, again, inequitable distribution of both benefits and burdens needs to be assessed.

Solidarity

Solidarity, as noted above, is a value that explicitly underlies the German statutory health insurance system, and in practice it means that the healthy support the sick; the young support the old; the employed the unemployed; and the better off the worse off, as contributions are income tested. To a significant extent, key aspects of the principle can be found in other insurance systems that rely on risk-pooling, even if the value would be more implicit in such cases. In one view, it could be argued that incentive schemes have nothing but a positive effect on solidarity, as they reward those who behave in ways that are assumed to make the healthcare system more efficient. As noted above, the truth of the economic element of this assumption depends to some extent on empirical evidence. However, there is also a more conceptual point to be made. For where inequitable uptake as described above should occur, and the worse off face a higher financial burden than the better off, key aspects of the principle of solidarity risk being undermined.

In a lesser sense, solidarity might also be undermined in that the meritocratic element behind incentive programs might not be appreciated equally by all insurance holders. Those who are not able to mobilize themselves to actions for which reimbursements are provided might envy those who do and find any competitiveness at odds with a conception of solidarity that relates to a union of people who have come together to offer mutual support rather than join in a race for incentives. Alternatively, finding that they are not able to perform rewarded behavior may result in a feeling of disappointment and may lessen their sense of belonging to the solidaristic community, or feeling that their needs are being cared for appropriately.

Attributability and Opportunity of Choice

As highlighted above, there are a number of ways in which it can make sense to attribute a good or bad health outcome to a person without linking this assessment to questions of praise or blame, or reward and punishment. Often, causal attributability will only be partial, as a number of other factors, typically arising from the environment within which a person lives or works also need to be considered. Where negative sanctions are contemplated – whether framed as incentives or disincentives – there needs to be good evidence that the people concerned had a reasonable range of opportunities to avoid what is regarded as a poor health outcome. In this regard the requirement in the U.S. regulations that an alternative standard must be provided for those who feel unable to meet the standards required by particular attainment incentives programs are a useful way of acknowledging that peoples' circumstances differ, and that some programs will simply be incompatible with the range of choices people have in their daily lives. However, the provision is also very narrow in focusing on medical conditions only, and hence ignores much of the data that come from the social determinants of health literature, which demonstrates that the socio-economic situation of a person can imply equally powerful, and often directly linked, constraints. Care is hence required in devising policies that offer fair chances to all.

The question of attributability also raises another issue that is related to the difference between forward- and backward-looking responsibilities. Above it was noted that the most recent German health reforms had introduced provisions that would require people requesting treatment for a non-medically indicated measure such as cosmetic surgery, tattoos, or piercings to share some of the cost of treatment. I leave aside here an exploration of the arguments around whether such actions should be seen analogous to requiring treatment that may arise from engaging in a criminal action; that was initially addressed in Art 52 SGB V – in my view they simply are not. However, beyond this question the policy raises other relevant issues, as it is introduced retrospectively and without a cut-off date, and hence people concerned could not have been aware at the time they received their tattoo, piercing, or beautification, that doing so would also mean they could be faced with a greater financial burden when things go wrong. This illustrates that the relationship of forward- and backward-looking responsibilities is such that the former are required to be put in place first, in order for the latter to have strong legitimacy and acceptance.

Affected Third Parties

Depending on implementation, incentive systems may not involve any third parties; for example, in the case of the German incentives for regular dental check-ups, reception staff may log a visit electronically, and the patient then receives the rebate for any work that needs to be done. However, the determination of other types of incentive-qualifying behavior may involve healthcare staff; for example, they are required where rewards are made if key health data, such as blood pressure, stay within a certain range over a year. Those on no-claim plans may wish that healthcare staff was not involved if they require treatment before completion of the qualifying period, and issues may arise where patients appeal to staff not to record their appointment. Equally, the US requirement that a physician needs to attest that a person is unable to meet a standard for an attainment incentive can lead to similar situations. Most of these situations are likely to lead to awkward situations, but depending on the size of the incentive at stake, more serious tensions may arise, and healthcare professionals may not be pleased with being put in an actual, or perceived, policing position, which may have a detrimental effect on the doctor-patient relationship (Bishop & Brodkey, 2006).

Another relationship that needs to be considered is that between incentive program participants and their employers, in particular in cases where incentive programs are offered in the work place. For obvious reasons, employers are likely to be interested in their employees' health status, and while most countries have in place data protection legislation that regulates access, the implementation of wellness programs provides opportunity to review compliance and adequacy.

Coherence

The coherence test asks how benefits or disadvantages that result from a personal responsibility policy fit in with the wider context of social policy and law. It is probably more relevant for cases where explicitly penalizing sanctions for contributions to a bad health outcome are envisaged, and, for example, the concept of contributory negligence as applied in jurisprudence regarding road traffic accidents offers an approach where similar questions are addressed on a day to day basis. However, while coherence across different areas of social policy and the justice system more widely is clearly desirable, possible conflicts can be resolved either by aligning a particular health responsibility policy with the wider context, or, alternatively, it may be that the health context shows the relevance of significant constraints that require us to re-assess the justification of other policies, provided they are similar in all relevant aspects. In any case, an evaluation of the basic principles of incentive systems in the context of reward cards in shops, or car insurance standards emphasizes again the consumerist, market-driven element of such initiatives, and it needs to be assessed whether or not the differing goals of these initiatives are compatible with goals such as improving population health or fairness in healthcare.

Conclusion

It must be admitted that the approach set out here is somewhat less clear-cut than one of the for-or-against personal responsibility stances often encountered in the literature and especially in political debates. With a number of different types of forward- and backward-looking responsibilities; a procedural justice account supplemented with seven tests to specify the areas in which justification is owed, without a single test whose outcome would necessarily “trump” all others, the situation seems to be messy. But I contend that this situation is still preferable to any of the alternative options, if we want to avoid the victim blaming potential that personal responsibility police typically have, and equally the potentially fatalistic implications of the social determinants of health approach, and instead seek to preserve a meaningful concept of health responsibility that is appropriate in descriptive, epidemiological, and moral terms. Particular policies that seek to implement personal responsibility standards hence depend on a holistic justification in a number of different areas. These areas, as circumscribed by the seven tests outlined above, concern central values that are integral to the provision of healthcare, and I believe that much progress can be made in policy and practice if, in a transparent and open process, valid and explicit reasons, and sound evidence to support them, are given in the design and evaluation of personal responsibility policies.

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Leadership and the Road to Personal Responsibility to Healthy Behavior – Between Autonomy and Paternalistic Interventions

Gil Siegal, Neomi Siegal

Introduction

Governments seem to be positioned in a most appropriate spot to lead, influence, and improve the health of the populace. Yet designing appropriate policies aimed at improving the public's health is a daunting mission. While the endpoints seem rather clear – for example, to improve individuals' health status, to assure access to needed health services, or guarantee an acceptable cost-benefit ratio for invested resources – the road there is rather bumpy, to say the least. Indeed, health policy leaders are facing growing pressures from numerous and sometimes conflicting sources. Such demands include, among others:

a. Consumers' expectations for up-to-date, innovative, faultless, and accountable performances;

b. Budgetary constrains in face of escalating costs due to the growing burden of chronic diseases, higher life expectancy, and expensive new technologies;

c. A challenging undertaking in equipping today's workforce for contemporary and the prospective needs of complex healthcare systems.

In addition, policymaking is subject to tightened scrutiny on part of the media, the public, and legal institutions – by both the legislature and the courts. Clearly, society's tenets (for example, in Western liberal societies – liberalism and autonomy, democracy and egalitarianism, solidarity, or fairness) are expected to frame the issues and reflect in policymaking in every field, and health is no exception. Therefore, merely identifying an acceptable end (such as eradicating an infection, or averting obesity) could face great resistance if the means are objectionable (such as mass quarantine or compelled treatment).

The result of such powerful and non-converging influences can explain inadequate, inefficient, or conflicting resolutions with respect to policy design and missed opportunities to improve individuals' and overall society's health.

In this essay we focus on one such confrontation – the need to balance individuals' *right* to govern their life-decisions as they pertain to their health on the one hand and the *right* of society, via its representatives in public health agencies or the legislature, to attempt to promote healthier behavior on the other hand. Does an individual's right to be left alone dictate no interventions on the part of the government, even in the face of self-destructive or harmful behaviors? How far can the argument against imposing externalities on society ("Your behavior is costing us too much") vindicate curtailment of individual's liberty?

Our goal here is to add to the discourse on *rights* a sound reference to the duties and obligations of these respective stakeholders. What are the obligations of individuals to their own health, and how and who should monitor them? What is the duty of the government to assist individuals in their quest for a healthier life and what can be regarded as accepted means? These queries require determination of the scope and limits on such interventions, and juggling/balancing colliding principles and interests such as autonomy, beneficence, and other-regarding behavior, and overarching social interest and social welfare. Our premise is rather simple – in too many instances no real clash exists, but rather an unfortunate amalgam of inhibitory influences on people's clear desire to advance their well-being.

Our discussion draws heavily on the paternalistic debate (Childress, 2007; Dwarkin, 1988; Glaeser, 2006). We aim at incorporating insights from cognitive psychology and behavioral economics to ascertain the permissibility of certain state-driven interventions, which will make most people better off from a utilitarian perspective, but also from an autonomy-driven stance. This assertion is an evolution and adaptation of the *Libertarian Paternalism* (Thaler & Sunstein, 2003) concept in health policy design. In a nut-shell – many people fall prey to their inherent bounded rationality, and systematic appreciation of these limitations can positively promote individual as well as society's interest, while remaining faithful to liberal ideas and individuals' autonomy.

Automy and Self-Governance

Contemporary discourse on citizenry's rights in liberal societies was strongly shaped by the powerful concept of autonomy. The most prevailing notion grasps and portrays this right in its negative formulation, also known as *"negative liberty"* – the right to be *free from* unwanted intervention by the government or other source of civil powers. Under this construction, if only left alone, individuals are capable and will actively pursue their pre-determined objectives. This in turn implies that people can identify what is important to them, and the avenues to reach their goals, and what is required in order to achieve these objectives. The limits on one's actions are usually framed by the harm principle – your liberty ends where the nose of your fellow begins (Feinberg, 1984). Recognized harms to peers and to society are reasons to prohibit an activity (e.g., smoking in public). Harm to self is a far more problematic justification (we still allow tobacco commerce, and we recall the failure of the alcohol prohibition). However, the underlying assertion of the sufficiency and constructive role of negative liberty is being challenged on several fronts, two of which we tackle here: (1) a philosophical critique and (2) an empirical dissonance.

A Closer Look at Autonomy

From a philosophical stance, negative freedom is really only a means to a more important end, which is self-determination, also termed *"positive freedom"* – the right to engage in meaningful self-rule, the positive right to realize one's life plans (Berlin, 1969). How are we to balance between the two? Hanoch Dagan's words are instructive:

> Rather, *negative freedom* serves a more fundamental purpose: *personal development and autonomy*, in other words, self-determination. In many cases, promoting the means (negative freedom) does not clash with achieving the end (self-determination).

> In some cases, however, promoting the means does threaten to undermine the end. In such cases the legal norms that best promote negative freedom must retreat and give way to those norms that best promote the individual's more essential interest to act on her goals and aspirations. (Dagan, 1999).

It is important to our discussion to note that acknowledging such a positive right on the part of individuals can create a reciprocal/parallel active obligation on the part of the government to provide the needed elements to make self-rule possible. We return to this point shortly.

Notably, since people have the capacity to reflect on their wishes and to revise their own preferences, negative freedom, being left alone (which also means the possibility to err undisturbed), carries the risk of inadequate probing into one's predilections or harmful omissions. Indeed, liberty should entail a process of (moral) deliberation in which we assess the value of what we want. For example, if we are to target people's diet, negative freedom would constitute the right to choose the foods we will consume, at our sole discretion. Positive freedom may incorporate a process in which one has the opportunity to answer the question: Why are you choosing these items? Do you think consuming them is aligned with your own goals?[1]

This having been said, the obvious fear is that in the name of positive freedom, paternalistic interventions, truly or supposedly aimed at one's own good, will end up abusing individuals and their rights. As a result, and backed by unfortunate and notorious historical precedents, liberal societies reject paternalism. Therefore, the leadership challenge of policy-design in these circumstances is to navigate and sometimes mitigate between the negative and positive aspects of our liberty. Promoting healthy behavior in a society that adheres strongly to negative freedom will generally be limited to educational campaigns in the hope that individuals will eventually make the "right" decision. In communities that

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[1] A more specified probing, such as "What would you like your HDL level to be?" and as a result informing this individual of the dietary content of his choices is a result of our behavioral insights and positive "nudging", as we discuss infra.

might prefer a greater certainty of people making the right choice (e.g., food consumption, vaccinations), additional tools can be employed to bring people to the position they themselves favor.

Finally, negative liberty has very little to offer with respect to individuals' obligations. Unless one is harming others, her obligations toward herself are not clearly demarcated. On the other hand, acknowledging the importance of positive liberty brings about more powerfully the need to ascertain that an individual's choices and actions are in accordance with her ambitions, including some obligations to herself and to others. In other words, self-rule implies the expectation that people would choose correctly in so far as reaching their own goals. In the sphere of health, it is easy to assume most people are interested in decreasing morbidity, or increasing their quality of life (notwithstanding other conflicting and valid objectives such as wanting to enjoy a good meal or hanging out with friends who smoke). If we accept the notion of meaningful self-rule – what obligations can we expect from an individual to promote their own health? The following section deals with such an example, as it has received legal interpretation that defies some of the above-mentioned assertions.

Negative Freedom and Personal Responsibility – One Legal Precedent in Israel

Health law in Israel was re-shaped in 1996, the year in which the Patient Rights Act was enacted (Siegal, 2005). The crux of contemporary health law and medical ethics is patient sovereignty: the right to informed consent prior to any medical treatment, the right to confidentiality, and more. However, patients' responsibilities are not enumerated. This discrepancy was illuminated by the Israeli Supreme Court ruling in 6023/97 Taig v. Glazer (1999). Ms. Taig suspected she might suffer from breast cancer, a fear driven solely by her family history. After consulting with her physician, she was referred to and performed two tests: mammography and breast ultrasound (the combination of which significantly increases the accuracy of the diagnosis). While the normal, non-suspicious mammography results were delivered directly to her physician (which falsely led him to assume all is normal without contradictory evidence), highly suspicious ultrasound results were given to the patient with a clear request to transmit them to her physician, a request she failed to follow.

Consequently, several months later she was diagnosed with advanced breast cancer. She sued her physician for failure to follow up on her.

The Supreme Court asserted that while the physician should have followed up on her, the Sick Fund (Israeli HMO) was in breach of its legal duty of care by asking patients to return test results to their physician instead of creating a patient-free flow of information, and hence liable in negligence. It is the responsibility of the medical system and healthcare providers to assure that patients are being treated and being followed. Even in the case of a non-compliant patient, this responsibility does not dissolve.

While the ruling of the Court had a positive outcome, as HMOs have since greatly invested in informational technologies and improved access to patients' data, a troubling sense of patient disempowerment emerges: Shouldn't the patient be responsible for insignificant yet essential parts of managing their own health? If the Patient Rights Act creates a host of rights based on patients' autonomy, it must be accompanied by a greater sense of self-responsibility. Evidently, this critique is limited to situations where the patient is well aware and well informed of the risks and medical procedure, as was clear in the case of Ms. Taig. The court did acknowledge contributory negligence on part of Ms. Taig, but only reduced her compensation by fifteen (15%) percent. Clearly, such a ruling defies our appreciation of autonomy as meaningful self-rule. Obviously, negative freedom, which was in fact practiced in this case, resulted in severe injury, but the Supreme Court's decision resurrects paternalism without answering the general plea for patient responsibility. Unless there is something else that could cloud rational decision-making and mitigate patient responsibilities, a much greater share of breach should have been allocated to the plaintiff (at least 50%). Interestingly, *inter alia*, in explaining the extenuating circumstances of Ms. Taig's harmful behavior, the Supreme Court alludes to such reasons in stating the she might have suppressed her concerns or was unwilling to handle the ominous news. Such argumentation lends itself to the next part of our paper, which deals exactly with such limitations on expected (both empirically and legally) rational behavior of autonomous individuals.

Negative Autonomy in Light of Empirical Behavioral Limits

The second challenge to negative freedom stems from contemporary understanding of human decision-making processes-volition and perceptions. Negative freedom posits that if only left alone, an individual will maximize their utilities. Indeed, the powerful influences of classical economists have advanced the concept of the "rational actor theory" (Epstein, 2006). People are expected to act as rational agents using available information to maximize their interests in accordance with their predetermined and stable goals and utilities. Therefore, the entire spectrum of human behavior and human institutions is subject to compelling strategies. The results of these strategies may be predicted, and measures can be taken to avoid suboptimal performance. These patterns of action could be sensitive to "sticks and carrots" - incentives or sanctions, supply and demand, and similar market forces. One needs to assume that rational agents operate in the free market settings, where information is available to all and agents are free to pursue their utilities.

In spite of its pervasive adoption, both in the United States and in Europe (for a detailed historical perspective on the Law and Economics Movement, that includes its European contributors and academic centers, see MacKaay, 2000), criticisms of the rational agent theory targeted, among others, the following (for a more thorough examination of this issue, see Siegal, forthcoming):

1. Ample empirical evidence of preferences that cannot be vindicated by expected rationality or maximizing utilities; (Kahneman, Slovic, & Tversky, 1982; Kahneman & Tversky, 2000)
2. Rational egoist strategies fail to appreciate patterns of behavior reflecting virtues, altruism, (Lehman & Keller, 2006) fairness, and other-regarding (Andreoni, 1995). In addition, many public goods are created and sustained even though, according to classical economists' predictions[2] they should have perished due to the expected self-interested behavior; (Ostrom, 1990; Posner, 2000)

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[2] Interestingly, when economists are the subject in these experiments, their behavior systematically comes much closer in accord with the predictions of their rational, egoist theory ...

3. In many instances, decisions are made under objective (no data available) or subjective[3] uncertainty, where rationality plays a more humble part. Importantly, if an agent's errors are random, their aggregated effect within a group could be zero. However, if these errors are systematic (as the argument is), a constant and predictable diversion is expected. In cases of public health, the cost could be significant; (Siegal, Siegal, & Bonnie, 2009)

4. It also fails to acknowledge that, in many cases, individual decisions are conditioned on the expected decisions of others, and that individuals are strongly seeking the group's norm;

5. Rational agents in their hypothetical stance are devoid of ethical constraints, thus it is inherently amoral or immoral, or empirically inaccurate (Kuklin, 1992).

Alas, such depiction of humans is too hypothetical and oversimplified to serve as a reliable predictor and assist in the policy design regarding real people and existing problems. Therefore, pertinent to our discussion, policymakers are in need of another model. Mainstream law and economics scholars have refuted some of the criticisms mentioned above (Hayden & Ellis, 2007; Mitchell, 2002; Posner, 1998). However, some cognitive psychologists and economists have adopted a more relaxed understanding of agents' behaviors to accommodate the aforementioned shortcomings of traditional economics (Jolls, Sunstein, & Thaler, 1998; Kahneman & Tversky, 1979; Korobkin & Ulen, 2000; Tversky & Kahneman, 1981). This field of research, *behavioral economics*, has become a cornerstone in contemporary policymaking scholarship.

Behavioral Economics

Behavioral economics is devoted to scientific research on human and social cognitive and emotional biases to enable a better understanding of human decisions. The salient point is that people's choices are subject to

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[3] In "subjective" we refer to a specific agent that does not have access to the data he requires to make the expected rational decision; nevertheless he allows himself to make such an individualized decision.

powerful and consistent influences, which in turn can explain "irrational" choices. As we have written elsewhere,

> Among the decision-making tendencies that have been documented are: *heuristics* (decisions are often made based on approximate rules of thumb and not strictly rational analyses); *framing effects* (decisions are irrationally influenced by modes of presentation and context – 10% of failure is perceived differently than 90% of success), *probability neglect* (e.g., overvaluing the risk of a low-probability event), *loss and risk aversion* (a preference for avoiding losses than seeking gains), and *endowment effects* (giving undue weight to avoiding losing something they already have), and the tendency to prefer the status quo. (Siegal et al., 2009).

Importantly, finding that individuals are so influenced does not imply unpredictable or chaotic choices. Quite the opposite; these influences are systematic and create stable biases. Hence, the main task would be to intentionally de-bias powerful yet detrimental influences, thereby allowing individuals to pursue their genuine "rational" interests. Such de-biasing should be reflected in policymaking in all aspects of our life, and again – health policy and promoting healthy behavior is no exception.

Let us dwell on one illustration of this new and exciting field: Should the sequence of events at an ATM (automatic teller machine) be pre-determined or rather left to the discretion of the ATM manufacturer or owner? Should you be given the money first and then your credit card or the opposite: your card first, followed by the money? In both cases, individuals act voluntarily, in complete negative liberty. If we remain agnostic to people's propensity for mistakes, we will let the manufacturer decide, without conformity across the board. However, if we realize that too many individuals will take the money and accidentally leave behind their credit card in the ATM (which is obviously a bad thing unless the thief spends less than you do ...),[4] most of us will uphold paternalistic policy that will mandate manufacturers choose the second option over the first one, thereby assuring that most people will leave the ATM with their credit card rather than without it.

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[4] For a general discussion – talk to my spouse ...

Behavioral Economics and Patient Responsibility

Recall our deliberation over the meaning of autonomy as a means for self-determination and not merely negative liberty. We join the position that regards negative freedom as an essential yet insufficient measure of autonomy. Self-determination is the aspired goal, and norms must give way to those norms that best promote the individual's more essential interest to act on her goals and aspirations. At the same time, we acknowledge individuals' "boundedness", which, as we have demonstrated, might require a paternalistic design to be employed in a situation where people are prone to make costly, irrational, and harmful errors. In our present discussion, we are interested in the reasons people fail to meet rational expectations in fulfilling their obligations and their genuine interests in preserving their own health. Therefore, what seems acceptable and is being advocated by the Libertarian Paternalism (Thaler & Sunstein, 2009) camp is the creation of safety-nets, where people should retain the choice of making an error (negative liberty), but policy design should strive to diminish the propensity to be influenced or hurt by irrational or detrimental factors (de-biasing), thereby reaching people's genuine aspirations. The ensuing question, when is "Paternalistic Libertarianism" warranted, remains to be explored, a quest beyond the limits of this presentation. It will suffice to make note of the following examples:

1. Setting the default rule: If we realize the powerful influence of legal defaults, the legislator could intentionally choose the most beneficial option as the default option, allowing individuals to contract around the default, erring by intention and not by mistake/omission/inertia. For example, all babies should be enrolled in newborn screening programs, unless their parents opt out; all should be offered first a healthy meal at school or workplace cafeterias, unless they specifically request unhealthy dishes (Loewenstein, Brennan, & Volpp, 2007).

2. Availability heuristics - since people discount remote events and over-evaluate near events, providing visible and effective information on recent outbreaks and dire sequelae of preventable infectious diseases could affect the perception of risks from non-immunization, thus increasing the likelihood of people submitting to vaccination.

As we have cautioned elsewhere (Siegal et al., 2009), while policymaking enables the use of state powers and resources to provide incentives for participation and disincentives for non-participation, the behavioral effects of such rules must be carefully assessed to avoid unintended consequences such as grass root resistance and feeling coerced. To this end, public education and campaigns might be carried for a long period to adequately prepare the citizenry, as was evident by the incremental, three-decade fight against smoking.

Conclusions

Behavioral and social sciences can shed light on decision-making processes by individuals and explain why some or most might choose the wrong decision (wrong from the decider's own point of view). This developing body of knowledge should be purposefully harnessed and systematically applied by public health leaders and policymakers. Such a position requires leadership, as it is bound to attract criticism as being paternalistic. It is our firm position that paternalistic legislation is warranted in selected instances to promote important goals, where people show proclivity to choose the option that makes them worse off. Future projects need to develop an elaborated ethical account of paternalistic legislation that will rely on contemporary public health ethics yet will incorporate an important cognitive attribution.

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Supporting Behavioral Change: Whose Responsibility?

Gene Bishop

> *"While comprehensive health-care reform needs to address a number of other key issues, we believe that personal responsibility and financial incentives are the path to a healthier America."* Steven Burd, CEO, Safeway (2009).

Introduction

Althea S. is a 55-year-old woman with high blood pressure and diabetes. Although in the past her pressure was controlled, she has missed several visits and recent readings have been uniformly high. I suspect she may not be taking the medication as directed, but I'm puzzled because the chart indicates that she sought an early refill but was denied by her insurance company because it was too soon. I ordered a screening mammogram, but there is no result in the chart. Althea tells me she missed the appointment. On physical examination, not only is her blood pressure elevated but she smells of tobacco smoke.

Althea is in my office – but she is also squarely in the middle of a health policy debate in the United States that has profound implications for individual health care providers and patients. Abstract ideas about personal and social responsibility for health – (Minkler, 1999) many of them ancient, some of them now repackaged for contemporary market economies – are likely to affect how Althea views her medical problem; how her doctor addresses her health conditions; and how the industry and practice of health care evolve in the coming years.

Steven Burd, CEO of Safeway, is only one of many voices arguing that health-related behavior-presumably one's own responsibility-should be linked to the personal cost of health care. According to these theories, smokers, heavy drinkers, people with diabetes or just plain obesity are responsible for high collective health care costs and are in need of financial carrots or sticks to incentivize their behavior to lower these costs. The possibility of assigning an actuarial risk to all human behaviors has American gun owners worried (Noah, 2009) and raises the question of whether other activities, including mountain climbing or bicycle riding, are healthy or unhealthy behaviors if judged by the health care services utilization of their adherents.

Ironically, as the United States moves to expand the societal safety net for health care, the "individual" is increasingly the focus of public and corporate efforts to reverse growing rates of chronic disease. Many of the new initiatives in the public sphere focus on the poor, whose coverage is often financed by taxpayers. In the corporate sphere, the rubric is "wellness" and the carrots and sticks appear more benign - although their implications are similar. The phenomenon of linking personal responsibility to the cost of health care has sparked important political and ethical discussions addressed in other conference presentations. However, too little attention has been paid to the real-world consequences for individual patients and doctors. The all-too-frequently ignored disconnect between policy and practice is brought into sharp focus by these policies and is the subject of this discussion.

Background: The Story behind this Paper

First, some personal background-and then I will return to Althea and some of my other patients and discuss in very specific terms how public policy choices may affect their health, for better or worse.

In the spring of 2006, a friend of mine who works as a health policy analyst sent me information about a proposed change in the Medicaid program in the state of West Virginia. Medicaid provides health coverage to the poorest and most disabled people in the United States, including about a quarter of the nation's child population. West Virginia's Medicaid program, with new flexibility granted by the federal government, was proposing two tiers of benefits-an enhanced package for patients who signed and complied with a "member responsibility agreement" and a reduced benefit package ("basic") for those who did not sign or did not comply (West Virginia, 2006).

West Virginia is a mountainous Eastern state previously dependent on coal mining. Seventeen percent of its population lives below the poverty level. In 2006, a mother with two children was eligible for Medicaid in West Virginia if her income was < 6142$/year (€4606). Among the stated goals of the West Virginia “Medicaid redesign” was to "provide members with the opportunity and incentive to maintain and improve their health" (West Virginia, 2006). The “basic” program eliminated coverage for inpatient psychiatric care, and limited participants to four prescriptions per month. Services reduced or eliminated in the “basic “program included chemical dependency and mental health counseling, diabetes education, tobacco cessation counseling, cardiac and pulmonary rehabilitation, and nutritional counseling.

My health policy colleague and others in her field were concerned about whether this program represented good public policy, but I was incredulous and deeply disturbed by its potential impact on ordinary patients and practitioners. I was, and am, a primary care doctor with an interest in public policy, and some experience working on Medicaid policy with a legal services agency. I thought about my own patients, and I wondered whether clinicians actually caring for low-income women and children in West Virginia, or patients themselves, had been consulted as this policy was formulated. As my concerns mounted, I worked with a colleague in psychiatry to author an opinion piece questioning the assumptions and practical impact of this new policy (Bishop & Brodkey, 2006).

A Widening Gap: Personal Responsibility Policies and the Practice of Medicine

In the three years since the piece appeared, the movement to link so-called personal responsibility to the cost – and, by default, the practice – of medical care has grown. In 2006 the Bush administration issued regulations governing worksite wellness programs that allowed employers and insurers to apply rewards or penalties to workers’ health insurance costs based on health status factors. Commercial insurers and employers are introducing a variety of programs linking behavior to cost, as detailed below. Despite the lack of evidence for the effectiveness of either the West Virginia program or similar programs in other states (Alker & Hoadley, 2008; Gurley-Calvez, Bone, Pellillo, Plein, & Walsh, 2009; Hendryx et al., 2009), an approach based on an incentive and individual responsibility framework is currently making an appearance in the health reform legislative proposals in the United States.

Politicians who made New Year's resolutions last year to stop drinking or smoking or lose weight, and many whose promises to themselves failed within weeks, are now lining up in support of policies to increase the economic burden of health care costs for those who fail to meet an insurance company's standards of "wellness". "Wellness", a word utilized by those outside the traditional healthcare system to distinguish themselves from a model of care oriented toward illness, has become a catch-phrase for a collection of programs and benefits to promote healthier behaviors often packaged and sold by entrepreneurial "wellness promoters". (See, for example, www.incentone.com, www.innovatewellness.com, or www.benicompadvantage.com)

The Patient Protection and Affordable Care Act of 2010 (in discussion in December 2009 during the Jerusalem conference and subsequently passed in March 2010) expands the 2006 regulations and permits employers to offer employees "rewards" of up to 30% of the cost of health insurance for participating in a "wellness" program and allows this reward to rise to 50% of the cost of coverage. Unstated is the fact that one employee's reward is another employee's penalty. The bill mandates an exemption for persons for whom participation would be "unreasonably difficult". "Unreasonably difficult" requires that an employee's physician disclose health information to an employer. The bill lacks standards for "wellness" programs or eligibility criteria, leaving these under the control of the employer or insurer. This amendment is being championed by a diverse group of businesses (seeking to cut their share of costs) and private insurance companies, who view it as a loophole around proposed prohibitions of discrimination on the basis of pre-existing conditions. It is opposed by a wide coalition of professional and community advocacy organizations.

The legality of these programs is open to question, and is beyond the scope of this paper (Mello & Rosenthal, 2008). However, to the extent that they are a tax, or surcharge, on predetermined "undesirable behaviors" they represent utilizing individual behavior to limit access to health care. They also represent an unfair and additional tax on the poor, who bear a disproportionate share of the targeted behaviors, and thus risk increasing existing health inequities. No one seems to be looking closely at how these policies actually play out in the critical interactions between individual patients and doctors.

Let's return to Althea, and see what some of the incentive policies in state Medicaid programs would do for her and her primary care physician.

In the clinical setting presented above, what choices would existing Medicaid plans offer Althea and her doctor? Here are some options:

a. Tell her that because of her missed appointments, her health insurance benefits will be reduced, limiting her to four prescriptions per month and removing smoking cessation benefits (West Virginia).

b. Ask her if she has any thoughts about why her pressure has been up, or what she sees as a solution (anywhere in the world).

c) Remind her that if only she had kept her doctor and mammogram appointments she would have accrued "points" that earn credits towards purchases at pharmacies for non-insurance covered items such as bandages or skin lotions (Florida) (Alker & Hoadley, 2008).

d) Offer to enroll her in a program where she will receive up to 200$/year to pay for smoking cessation medications or diet counseling if she can do better at keeping her appointments (Idaho) (Greene, 2007).

Althea is not a resident of Idaho, Florida, or West Virginia. She is one of my patients in Pennsylvania. I asked her if she any insights into why her blood pressure had suddenly gotten so difficult to control. She looked at me, took a deep breath, and started to speak. She had custody of a 16-year-old granddaughter with serious behavioral problems who was not attending school, and had threatened to set fire to the house. Althea felt afraid and unable to leave the house. On the day of the mammogram, she had a court appointment with the child, and forgot her own mammogram appointment. Althea was, in fact, so worried about her blood pressure that every time she felt upset she took an extra blood pressure pill. This is why she had needed an early refill.

The remainder of the visit allowed her to share the tremendous stressors in her life. She acknowledged that although she wanted to stop smoking that was an unrealistic goal in the near term. She agreed to take a toll-free quit smoking phone number. She was interested to learn that doubling her blood pressure medication was not a good treatment for stress or high blood pressure, and was agreeable to a new blood pressure regimen. She declined rescheduling the mammogram until her family situation was resolved, but agreed to trying the new blood pressure medication and returning to the clinic in two weeks (which she did). With help from her physician to set priorities and understand the implications of her decisions, Althea became an active, informed patient participating in her health care decisions.

When Dr. Mark McClellan, then director of the Centers on Medicare and Medicaid Services, approved the West Virginia plan he stated that "Medicaid enrollees in West Virginia will now become part of an emerging trend in health care that empowers patients to make educated, consumer-driven decisions related to their own treatment." (Daly, 2006). Yet true patient empowerment is not choosing among health plan deductibles or health plans, but is a sense of the ability to make a change in one's own life.

Althea presents with many of the medical conditions and administrative problems that are targets of the West Virginia "member responsibility" agreement: missed appointments, non-adherence to medication therapy, missed cancer screening appointments, and unhealthy behavior, i.e., cigarette smoking. Would "member responsibility agreements" enable her to make "educated consumer driven decisions" and would they help, or hinder, her care?

It is likely that because of the stressors in her life, she would have been one of the 90% of eligible West Virginia Medicaid enrollees who did not understand the rules of the new program, and who ended up in the basic plan not by choice but by default (Hendryx et al., 2009). I would have been forced to try to control her blood pressure and diabetes on only four medications, a near impossibility. Although I could counsel her on smoking cessation, she would have had no access to additional counseling or medication benefits, decreasing the likelihood of success and negatively affecting my own sense of potential effectiveness. She would have no mental health benefits in the basic program if she wanted behavioral health treatment. The child over whom she had custody was likely to be in the same situation.

Had she managed to sign up for the enhanced benefits, she had now missed two physician appointments and one mammogram appointment, and was not taking her medications as directed. These commitments were likely to be part of her negotiated "health improvement plan". The agreement stated that if she could not do that, she would lose benefits. The plan then asked physicians to act contrary to accepted models of practice. Instead of examining the inability to meet a goal, and then resetting the goal, the plan meted out a punishment. Shame and punishment lead to the vicious circle of missed appointments, and failure to adhere to medical regimens. Repeatedly telling our patients they have failed at weight loss, glucose control, or medication adherence re-enforces powerlessness, not empowerment. Patients cancel appointments because they have been unable to follow recommendations, and are embarrassed or unsure of the point of the next visit.

The West Virginia plan not only had serious consequences for patients, but also presented ethical dilemmas for physicians. The original West Virginia plan suggested, but never delineated (West Virginia, 2006), physician reporting requirements, and likely in response to published criticisms subsequently decided to use administrative billing and prescription refill data to enforce the plan. However, the plan asked physicians to violate three fundamental principles enumerated in the Physician Charter on Medical Professionalism: (Medical professionalism in the new millennium, 2002) – the principle of patient autonomy (failing to recognize non-adherence as a possible expression of autonomy), the primacy of patient welfare (reporting behaviors that result in loss of access to care), and the principle of social justice (discriminating against those who have less).

"Wellness", Personal Responsibility, and Corporate Health Benefits

Publicly funded health coverage is a major force in U.S. health policy, but most Americans still receive some or all of their benefits from the private market – where many of the same assumptions and practices are taking root, as noted in the epigraph by Steven Burd. These practices take two forms: high deductible health plans, and incentive programs linked to behaviors. Although arguments in favor of "making patients think about cost before going to the doctor" or "why not reward good behavior" at first seem to make sense, both have potential negative effects on clinical care.

As in the West Virginia program, where beneficiaries had a “choice” of health insurance plans, U.S. employers have begun using financial incentives (reduced up front costs) to shift employees to insurance plans in which the employee has higher cost sharing if they actually use health care services. A benefits trade journal celebrates this phenomenon: “… the increasing employee acceptance of personal responsibility for benefits choices is an emerging solution to the unsustainable cost-shifting and premium increases of past years.” (Domaszewicz, 2007). But as a practicing physician, I see patients with high deductible plans “choosing” to live with pain, worry, or fever because of the fear of incurring unknown or unaffordable financial risks. This clinical experience is confirmed by multiple studies demonstrating that patients are unable to distinguish necessary from unnecessary care, and critical from less critical drugs (Geyman, 2007; Goldman et al., 2004).

Commercial programs to influence health behaviors include discounting premiums or adding benefits for employees who score well on mandated health risk assessments, and rewards or gifts for engaging in measurable care processes – exercise programs, smoking cessation programs, diabetes education programs – but not necessarily for measurable outcomes (Kaiser Family Foundation and Health Research and Education Trust, 2009). Corporations have fired personnel who smoke. These “wellness” programs are either optional benefits with incentives (join a gym and attend 120 times per year and get 250$ back) or discounted premiums on health insurance. 93% of large U.S. companies and 58% of all employers offering benefits, offered employees at least one of the following programs as part of their health insurance package: weight loss program, gym membership discounts, onsite exercise facilities, smoking cessation programs, personal health coaching, classes in healthy living, web-based resources for healthy living, or a healthy living newsletter (Kaiser Family Foundation and Health Research and Education Trust, 2009). The stated goals of such programs include improving employee health and productivity and saving money on health care premiums. The structure of the benefits is of some concern; their promotion as a way to solve health care system problems is more troubling.

Commercial insurers and subcontracted “wellness” companies market these programs as potentially cost-saving to employers, although the evidence is controversial. Employers, utilizing their own company cost data not validated by independent study, are moving forward (Burd, 2009; Warner, 2009). Steven Burd’s own data has been challenged (Hilzenrath, 2010). A policy paper on employee programs issued by the American Heart Association cites a wide range of study results evaluating programs (Carnethon et al., 2009). A recent study noted economic savings to large companies based on decreased medical care and absenteeism costs (Baicker, Cutler, & Song, 2010). What is going on here? And what is the impact on patients and doctors?

Research indicates that people initially like these plans in the abstract, but become uncomfortable when asked about employers sending reminders for check-ups and prescriptions, and less comfortable still when asked about an employer charging differential amounts for insurance based on a health assessment. Employees in poorer health indicated they were less likely to participate in a program even with a 5-10% reduction in premiums (Employee Benefits Research Institute, 2007). A recent study confirmed that healthier persons are more likely to complete health risk assessments (Huskamp & Rosenthal, 2009), but given the continuing steep rise in health insurance rates in the United States, even reluctant employees may agree to complete health risk questionnaires to save several hundred dollars or more per year.

Research done in a primary care waiting room showed patients evenly divided over whether it was advisable to pay fellow patients to stop smoking or lose weight, and equally ambivalent about the fairness, or effectiveness, of rewarding people for certain behaviors (Long, Helweg-Larsen, & Volpp, 2008). Not surprisingly, responses were more favorable when statements were phrased as rewards, and less favorable when framed as punishments, confirming the importance of framing when asking questions or designing programs. I am unaware of surveys asking physicians’ opinions of commercial incentive programs. Commercial programs rarely involve physicians in their planning or execution, and may not be coordinated with an employee’s usual care. Providers interviewed in an evaluation of the Florida Medicaid reward points program expressed skepticism that the program had changed the behavior of patients; two years after the program began many providers remained unaware of its existence (Alker & Hoadley, 2008).

In West Virginia, most providers interviewed for an evaluation of the program believed that the program as implemented would not change beneficiary health behaviors. The evaluation also noted anecdotal reports of physicians declining to accept patients in the basic plan because of the inadequate benefit coverage (Hendryx et al., 2009).

The Choices for Doctors and Patients in a Commercial “Wellness” Model

George is a 50-year-old man who works as an engineer in a large corporation. He has always played tennis, and he belongs to a gym. He has been struggling to quit smoking for years, and recently relapsed with the stock market collapse. His blood pressure is now “borderline”, as are his lipids. His company will offer him a discount on his health insurance because of his gym membership and a discount on the gym membership, and will offer further discounts, including lower co-pays at the doctor, if he agrees to complete an online wellness questionnaire.

Manuel, also 50, works for the same company in building maintenance. He is a non-smoker, but has hypertension and his father died early of a stroke. He is overweight with a body mass index of 27. Unlike George, who sits at a desk all day, Manuel is constantly walking, mopping, and cleaning. When he leaves work at 4 pm, he goes to a second job cleaning offices, grabbing a fast food meal. He has gained 10 kilograms in the last year. The company offers him the same benefits as George but he doesn’t have a home computer, and doesn’t want to join a gym, nor could he afford it, even with a discount. He can’t afford to take off time from work to see his doctor, who has no evening or weekend hours, as the company offers limited paid sick time. He called to refill his blood pressure medication but the office refused to do so because he had missed two appointments. One Saturday he goes to the emergency room because he feels bad. His blood pressure is 170/110, and his sugar is elevated at 250 mg/dL.

George and I agree he will utilize his insurance’s online dietary counseling regarding a lower-fat diet, he will attempt to exercise three times per week, and we set a quit date for smoking cessation. I offer him a nicotine substitution product but he mentions that his insurance coverage won’t pay for it. Failure to cover tobacco dependence pharmacotherapy is a barrier – a dis-incentive equivalent to a punishment. More general studies on co-pays and pharmacotherapy have clearly demonstrated co-pays of any sort decrease medication usage (Hsu et al., 2006). Although as George's physician, I am unlikely to have any information about the content or quality of the dietary counseling he will receive, and I know that written/online materials are less efficacious than personal interactions, I am grateful that any structure outside the 1:1 patient/physician interaction is available to help George achieve improved health.

If I were only thinking about George, and not all of my patients, his employer program appears to be beneficial to both of us. It offers him resources to support mutually agreed upon health goals, and relieves me of some responsibility. However, once I consider Manuel the program appears in a different light.

The same employer program is much less helpful to Manuel, and less helpful to me as Manuel's physician. Manuel has no knowledge of his potential benefits; the brochures written at university-level literacy sit in a drawer. He has no access to online learning or questionnaires, and thus cannot obtain a discount on his insurance. Thus, despite his lower income, he will pay more for his health coverage than George. He works two jobs that involve daylong active physical labor, and even if he had the resources for a gym membership he wants to relax when not working. On his schedule, most workdays he eats 0-1 meal at home, consuming high calorie, high fat, fast food meals. He takes unpaid time from work to come see me after the emergency room visit.

If I do my job properly, I will see a proud, frightened, overweight man with no time to go to diabetes classes, or to buy and cook fresh vegetables, who is trying to work to support his family and live long enough to see grandchildren. If I'm having a rushed day, I may only see a man who misses his appointments, has gained weight, and now has diabetes and uncontrolled blood pressure. George and Manuel highlight the problem with the premise that employers, and not the larger society, are the stewards of health care resources. Even with the same "employee wellness program", all employees are not standing on the same level ground. No matter how large a company, the risk pool is not large enough to develop programs for workers with different skills, incomes, education, and health risks (Kaiser Commission on Medicaid and the

Uninsured, 2009). Companies in industries with primarily low-wage workers will have a disproportionate share of persons whose health is at risk but without programs targeted to this population. Because we lack data and information to create fair evidence-based programs, we are at risk of creating programs that will increase, rather than decrease, health inequities.

What would be Manuel's fate under the proposed Senate "wellness" amendment? Quite possibly he would have to pay more for his insurance because he couldn't participate in the offered programs. As his physician, I would be called upon to assess whether it is "unreasonably difficult" for him to comply, and to furnish his employer with confidential health information. The standard for unreasonably difficult is unclear, and subject to varying interpretation by physicians with differing personal values, or insurance companies with different standards, with adverse and unpredictable consequences for patients.

What does Responsibility have to do with it?

Thirty years ago, I would never have considered either diabetes or obesity to be a public health problem. Now, faced with a population of patients who are increasingly fatter, and with rates of diabetes that have skyrocketed, the evidence is mounting: our current approaches are not working.

Since the 1970s, obesity rates among U.S. children have more than doubled. The Institute of Medicine has suggested that marketing practices aimed directly at children contribute to the 30$ billion of their own money that American children spend on candy and snack foods (Nestle, 2006). Diabetes is the fifth leading cause of death in the United States. In 1960, 13% of the U.S. population was obese. This rose to 34% by 2005, driving concomitant increases in medical spending. Whether we are clinicians, legislators, CEOs of major corporations, or policy analysts, it is clear that in the United States, current approaches to improve individual and population health, particularly for possibly preventable conditions, are not working. What is it that I need, as a primary care physician, to care for Althea, George, and Manuel?

Whatever their philosophic legitimacy – and that, of course, depends on where one stands on a host of issues – recent attempts to control costs by linking personal behavior to access to health care are not going to help me to do my job. Although carefully designed incentive programs may be useful to subsets of well-informed people, they cannot be the only solution for the patients I see who are struggling with the most challenging aspects of the new epidemics. Take Carol, for instance.

Carol is a 60-year-old woman who was my patient for 25 years. A social worker and community activist, she was always overweight, and always on a diet. She enrolled in clinical weight loss trials at universities; she begged to try each new weight loss drug as it appeared despite my concerns about serious side effects. Her minister father had been an alcoholic and she saw parallels between his addiction, and her relationship to food, but insight did not produce weight loss. As she grew older, she developed hypertension, then diabetes, then arthritic knees. She went to Weight Watchers, and several other community self-help programs, in addition to frequent counseling/advice at physician visits. She became more depressed at her inability to lose weight, and more frustrated. She paid for psychotherapy and nutrition counseling when her insurance did not cover those services. She finally chose bariatric surgery. She lost 50 kilograms; her diabetes was gone, and her knees were less painful. Two years later, she had gained back most of the weight.

Carol kept trying – to walk as much as she could, to get her mammograms and colonoscopy, to monitor her sugars and adjust her insulin, to keep all her medical appointments. I was frustrated being Carol's doctor, because it was hard to feel successful, even when a combination of 8 or 9 medications controlled her blood pressure, diabetes, cholesterol, and arthritis. However, as a clinician, I am quite sure of two things:

1. Having to pay more for her health insurance, or having to pay higher co-pays to see me or to buy her medications would not be greater incentives than her discomfort and her diseases, and would not have altered the situation; and

2. Emphasizing to Carol that she was to blame for her condition would not have helped to advance her treatment. Assuming responsibility for factors that she perceived to be in her control is not the same as accepting causality for her condition.

No one who knew her would describe Carol as an irresponsible person; her situation exemplifies the limits of utilizing a personal responsibility framework to solve either health care delivery system problems or public health issues.

What is to be Done? Start by Asking the Right Questions

> *If they can get you asking the wrong questions, they don't have to worry about the answers.* Thomas Pynchon (2000) from *Gravity's Rainbow*

Is There a Right to Health Care?

As a physician trying to support behavior change, I need everyone to have access to care as a right, and not as a mandated responsibility to purchase insurance. A policy that places obstacles to medically necessary care based on individual behaviors places undue constraints on my treatment options. I fear a system that places an actuarial value on a variety of human behaviors and then allocates health care on the basis of that hierarchy. Others have addressed the ethical questions regarding personal responsibility and utilization of incentives in much more detail, and while this is a concern of mine, it is not my area of expertise (Civaner & Arda, 2008; Halpern, Madison, & Volpp, 2009; Minkler, 1999; Schmidt, 2007; Wikler, 2002). Patients cannot fear losing health care services if they acknowledge smoking or dietary indiscretion. There are already numerous reasons why patients are afraid to share needed information with physicians. Loss of access to care shouldn't be one. If physicians only took care of people who cared well for themselves, we would have a much smaller clientele.

Programs for supporting individual behavioral changes must start within the context of universal health care. The interest in the topic at an international conference that includes many countries with a commitment to universal access clearly demonstrates that access is necessary, but not sufficient, when considering resource allocation and approaches to support behavioral change, and that within the assumption of universal access, there is substantial room for discussion of the practical, ethical, and policy issues involved.

When does a Personal Health Problem Become a Public Health Problem, and How does that Change our Approach?

When I started in practice, no one taught me to ask whether a woman was safe at home, whether there were guns in the house, or fire alarms, or whether seat belts and bicycle helmets were in routine use. The recognition of domestic violence as a health issue came from the women's health movement; the recognition of the needs for seat belts came from a consumer advocacy organization. Both made their way into my one-to-one interactions with patients *and* became public health concerns. Car seat safety requires physician-patient counseling, public health education campaigns, government regulation of automobile manufacturing standards, and discounted purchase programs for low-income families. Parental responsibility is an important, but not a solo determinant.

Commercial or public programs that place the solution for diabetes, obesity, or tobacco dependence solely or primarily on the individual deprive me, as a physician, of the help I need to support behavioral change.

I have (almost) never met an overweight person who doesn't feel badly about themselves, and their weight, and who hasn't made multiple attempts to diet during his or her lifetime. In thirty years of practice, I can name those few who successfully maintained weight loss. Success rates are low and physician perception of hopelessness is born out in research studies showing that physician counseling on weight, in primary care offices, is often ineffective (Gilden Tsai & Wadden, 2009).

I've never met anyone who welcomed the diagnosis of diabetes; most of my patients immediately think of a relative with a lost limb, and vow they will do what they can to prevent such an occurrence.

Most smokers over the age of 30 wish they had never started, and they too can recount the multiple efforts and failures to rid themselves of their addiction. Yet while the government and private insurers continue to pay for the consequences of tobacco, coverage for pharmacotherapy or counseling is inconsistent and inadequate (Rigotti, 2009; State Medicaid coverage for tobacco-dependence treatments, 2009). In the name of prevention, both the Idaho and West Virginia Medicaid programs made it more difficult for patients to stop smoking. The real negative consequences of these policies are brought into focus by looking at the results of a policy change in Massachusetts. In 2008 the state Medicaid program began offering full coverage for smoking cessation treatment, and dramatically improved quit rates among a low-income population (Massachusetts Department of Public Health, 2009).

Public health concerns itself with populations and is foreign territory to most clinicians, who are taught to focus on the individual. But the “lifestyle” issues that plague a majority of Americans have become public health issues. And I can’t solve a public health issue in my office. Informed citizens by themselves will not be able to resist well-marketed, easy to swallow, easy to prepare, inexpensive sugar, salt, and fat. We may want to, but we can’t help ourselves. If 75% of global food sales in 2005, amounting to 3.2$ trillion, were of processed foods and beverages, consumer choice is an illusion (*New directions in global food markets,* 2005).

As a primary care doctor, I need my patients to find it more difficult to smoke, more difficult to gain weight, more difficult to remain sedentary. If I help them want vegetables, then I need for them to find it easier to buy vegetables that are cheaper than fast food. I need their workplace cafeterias to price healthy foods low, to post nutritional information, to make it easier to make the right choice. If I tell a teenager of the dangers of starting to smoke, I need the price high and the availability low.

If I continue to counsel patients without public health support, both the patients and I will continue to fail. Public health solutions do not exempt the individual from making healthy choices; they support the individual in making healthy choices. The Institute of Medicine’s 2009 report on local approaches to childhood obesity emphasize this approach (Parker, Burns, & Sanchez, 2009), as does Healthy People 2010 (U.S. Department of Health and Human Services, 2010).

Corporate “wellness” programs designed on this public health model are significantly different from those providing individual behavior-based discounts, and have an important role to play given the number of hours spent in the workplace. Such programs include reduced co-payments on medications for diabetes, asthma, or hypertension; changing the food and food pricing in the cafeteria; paid time for physician visits; onsite exercise facilities; and in-person counseling during working hours (Okie, 2007). By seeking to provide an environment that supports healthy choices, and by trying to create a supportive culture in the workplace, they are utilizing ideas far removed from an individual culture of economic incentives and addressing some of the deficiencies of programs like that created by George and Manuel's employer. Creating a workplace environment where it is easier to make healthy choices has been shown to make a difference (Carnethon et al., 2009).

What is a physician to do when her adolescent patient wins an academic award at school, and the prize is not a book but a coupon for a free ice cream cone at a store selling ice cream sundaes containing 1130 calories? (see http://www.baskinrobbins.com/About/InCommunity.aspx#scooper)

If we are seeking a healthier America or a healthier world, we need to look further than my examination room, but my examination room also needs changes.

If we want to Change Individual Behaviors, what do we know about this, and what Policy Initiatives Might Help?

There is profound disconnect between policymakers and practicing physicians in the United States, unless the issue is reimbursement for services. Physicians are increasingly talking about evidence-based medicine, but evidence-based health policy – based on clinical evidence – is also needed. Because politicians themselves change behaviors in response to monetary incentives does not imply that patients will also. If physicians or anyone else knew exactly how to motivate and support behavior change, the topic would be non-controversial. The incentives proposed by the Medicaid and corporate models raise questions not only of efficacy, but also of their appropriate place in a comprehensive strategy to support behavioral change.

The medical evidence does not provide definitive conclusions regarding the effectiveness of financial incentives as imagined by corporate CEOs. Without doing an injustice to a large body of literature, one short answer on incentives appears to be that incentives work for defined time-limited behaviors such as keeping an appointment, but work less well for sustaining behaviors over time (Dudley, Tseng, Bozic, Smith, & Luft, 2007). An employee benefits trade journal cautions that "Wellness programs represent both wisdom and naiveté, promoted with doses of 'true believer' enthusiasm and vendor self interest." (Fitch & Pyenson, 2008). It emphasizes that corporate programs are very difficult to assess in terms of both clinical effectiveness and return on investment because of the large number of variables involved. This has not stopped U.S. corporations from instituting new programs, and touting their benefits (Warner, 2009).

The use of incentives deserves further study. Investigators are now looking at whether they could be designed to work differently. One recent study showed that relatively large amounts of money (750$ in 9 months) improved the chances of sustained smoking cessation in an employed population (Volpp et al., 2009). As with other interventions, we will need to find out if they succeed at sustaining the behavior change, how to tailor them appropriately to meet the needs of varying populations, and then consider their effect on costs. The infrastructure costs of setting up and tracking incentive programs need to be included in analyses seeking to identify the role of incentives in health care policy and practice.

The narrow focus on personal responsibility and reward/punishment incentives as components of benefit packages presents other potential problems for patients and clinicians. In the United States, marketplace-based insurance and the structure of the Medicaid program mean there are no standard benefits available to all. Lack of uniformity among benefits is difficult for clinicians and patients. Public or private incentive policies implemented in the chaotic system in which I practice – where 10 different patients may all be operating under different coverage rules, different benefits, and different incentives – will have diminished effectiveness if only because they will be difficult to understand and utilize. I surely won't know whether Althea is entitled to bonus points for her mammogram, or whether she has lost her mental health benefits. It is time consuming, and not always possible, to determine whether Carol has access to unlimited nutrition visits, or diabetes classes, or what her co-insurance responsibilities might be. U.S. physicians and patients freely acknowledge their inability to understand and utilize the multiple different insurance plans currently offered publicly and privately (Khan, Sylvester, Scott, & Pitts, 2008); adding "wellness" incentives to this mix may decrease the usefulness of the benefits, and offset some of their potential for beneficial change, because they will either be underutilized or will incur additional administrative burdens for practitioners.

If incentive structures are created that are entirely external to physician practice, similar to insurance or corporate run “disease management programs”, they risk repeating the problems of those programs that have included poor communication with physicians, poor quality control, and increased fragmentation of care (Bodenheimer, 2000). A broader definition of incentives, consistent with that of the Agency for Health Research and Quality (AHRQ; Dudley et al., 2007) includes removal of barriers as a type of incentive and thus suggests other possible incentive programs to support behavioral change. Removing structural barriers at numerous health system junctures, from doctor’s office hours to mammography and colonoscopy scheduling systems to high deductible/high co-insurance for medications, all have the potential to change behavior without adding new layers of complexity or cost. We have improved mammography rates in our clinic by convincing the x-ray department to have a more flexible scheduling policy. Providing cardiovascular and diabetes medications without patient co-insurance helps patients who cannot afford essential insulin or lipid medication. Several studies have suggested this approach has clinical and cost effectiveness value (Choudhry, Avorn, Antman, Schneeweiss, & Shrank, 2007; Hsu et al., 2006) and should be included in the incentives discussion.

If we are interested in supporting behavioral change, we need to know what works. A U.S. researcher and advocate of incentives has suggested that comparative effectiveness research include research comparing behavioral interventions with other interventions such as medications (Volpp & Das, 2009). Such an approach could encompass a wide variety of behavioral interventions rather than the limited rewards and punishments envisioned by commercial companies, and would also produce information regarding relative resource allocation in health care delivery systems.

What about Physician/Health Care System Responsibility?

If the goal is a “healthier America” (or a healthier world, if we are not discussing U.S. health care reform), limiting discussions of behavioral change to the behaviors of patients is too limited a framework. Physicians can start by taking responsibility to change ourselves, and to demand structural changes in the financing of health care, in the availability of technological support, and in the training of health professionals to support new models of care delivery suited to the management of chronic disease.

Traditional physician models of care contribute heavily to the personal responsibility model. There is almost universal belief that patients get sick or do poorly because they don't follow our advice. This protects us from accountability for our own role in working with our patients. We scold patients for too much salt; we sigh when they don't take their medications. Physicians decry the "non-compliant" patient but never consider they themselves lack the skills necessary to improve self-efficacy, or that they did not adequately explain how to use a medication, or what a low salt diet really means. Inability to adhere to treatment recommendations has a differential diagnosis that is rarely explored. Althea's doctor could easily have seen her as a recalcitrant woman uninterested in her own well-being although nothing could be further from the truth.

Newer models of care, especially in relation to chronic diseases, emphasize self-management education. The contrast between supporting self-management and assigning personal responsibility is more than a semantic difference. Improving self-efficacy is necessary for self-management of chronic illnesses. The goal of self-management education is an improved sense, on the part of the patient, that she can affect health outcomes. Lower socio-economic status is associated with a lower sense of self-efficacy (Figaro, Elasy, BeLue, Speroff, & Dittus, 2009) and thus it is no surprise that in the evaluation of the West Virginia program, both enhanced and basic plan members were more likely to agree with the statement, "No matter what I do, if I'm going to get sick I will get sick." Respondents were much more likely to see an external locus of control, rather than themselves, as the determinant of their health (Gurley-Calvez et al., 2009). True patient empowerment means improving self-efficacy – the belief that change is possible.

Involving Althea in goal setting with realistic outcomes – adherence to a blood pressure regimen, but not yet to smoking cessation or mammography – improves her chance of success and consequent self-efficacy. It is investing for longer term success, rather than short-term failure. It requires that physicians, in their life-long learning, learn not just new pharmaceuticals, but also new models of interaction and patient care.

Traditional biomedical models of care are supported, at least in the systems in which I work, by reimbursement and other health care delivery models that are barriers, rather than facilitators, of patient self-management. The newer model of the patient-centered medical home, involving a team approach with physician leadership, requires both physician responsibility to be open to and adapting of new models of care, and health system change to pay for this model, and to provide the technological support systems that facilitate it. Changing physician practice models is no easy task. A study of Canadian family physicians demonstrated significant resistance to creating and utilizing chronic illness care management plans that included medication management and review, education and self-care, psychological and social assessment, community integration and social support, and prevention (Russell, Thille, Hogg, & Lemelin, 2008).

Despite these challenges, investing public money to support these changes at all levels of health care training, including medical, nursing, pharmacy, and social work, could have a significant impact in supporting behavioral change.

Supporting Behavior Change: Whose Responsibility?

Robert and Alice: I am speaking with the wife of my patient, Robert. Robert has mild traumatic brain injury following complications of cerebral aneurysm surgery, coronary artery disease, hypertension, and hyperlipidemia. He is on four blood pressure medications, three lipid-lowering medications, two seizure medications, and several others. His wife is angry and frustrated, because he is eating too much, gaining weight, and not exercising. She wants him to take more responsibility for his behavior; she blames me for not emphasizing to him his need to control his eating.

I'm frustrated also. I know he doesn't want to die; and I don't know if his brain injury explains why he can't control some aspects of his behavior. But like Althea, George, Manuel, and Carol, he is certainly ill-equipped to bear the personal responsibility of curbing health care costs, or solving the problems of the ailing U.S. health care system. Each one of them wants to be healthy. Althea, who missed her own appointment because of a court appearance with a mentally ill child, is not irresponsible. George, who has tried multiple times to quit smoking but has not succeeded, is not irresponsible. Manuel, who is holding down two jobs to support his family, and whose doctor has inconvenient hours, is not irresponsible. And Carol, who has spent her entire life running a social service agency, and tried every treatment available, is not irresponsible. As angry as Alice may be, she knows Robert doesn't wake up each morning glad to be fat.

As their physician, I continue to care for them despite frustration. I am eager for all the help I can get to support behavioral change, but the responsibility for this help must come from multiple arenas. I need a health care system that supports and reimburses practitioners for the hard work of supporting behavioral change. I am grateful for the programs that employers may offer, particularly the ones that change the environment, but these programs do not substitute for a comprehensive national health care and public health policy. I can recognize, in a way that corporate executives or legislators cannot, that limiting Althea to four medications, or charging disabled Robert higher costs for his medications, is unlikely to improve their health. I know that offering online counseling to those without computers, and gym memberships to those without bus fare not only will not support change for them, but risks labeling them as irresponsible, or uncooperative, increasing the likelihood of health inequities. I know that the most well-intended person cannot buy fresh vegetables and foods and cook while working two jobs and while frozen pizza and soft drinks are cheaper than broccoli and chicken. If diabetes is an epidemic, individual doctors and patients are not the appropriate intervention. Epidemics need population measures.

If I am asked to implement personal responsibility policies that limit medically necessary care, this is not consistent with my duty as a physician to uphold the primacy of patient welfare. Insofar as these policies promote discrimination on the basis of socio-economic status or diagnosis, they violate principles of social justice.

Surely doctors know better than anyone that telling people to behave differently does not always work. It leads to simplistic solutions – just say no, or try this reward, or this punishment. We can't hold people responsible for factors out of their control, and in the realm of human behavior, that is often difficult to measure. Acknowledging that some portion of change must be individual responsibility, we are still failing miserably at our real goal – how to improve people's perceived sense of health and well being, and actual health and well being. As legislators and policymakers and corporate executives and doctors craft new policy, each of them must sit down in an imaginary examination room, and consider the effects on the care they want to receive, or the care they have committed to provide. Each of them must consider their own personal resolutions regarding behavior change, and the challenges of success and failure. Elevating the principle of personal responsibility for health into a guiding principle of health care resource allocation diverts energy and resources from systemic and public health approaches to the problem. Limiting access to care on that basis places barriers in front of practitioners and patients. I will be left counting my behavior change successes on fingers and toes. That will be frustrating, sad, and unhealthy.

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Patient Empowerment and the Doctor-Patient Relationship

Leah Wapner, Malke Borow

Introduction

The patient-physician relationship has undergone seismic changes in recent years. The traditional model based on trust, paternalism, and extensive family involvement has yielded to a model of greater patient autonomy (Balint & Shelton, 1994). The reasons for this shift are varied. For one, there has been a change in attitude towards doctors – from all-knowing, implicitly trusted figures to dedicated, but fallible, individuals. The movement towards greater autonomy in the health care arena also represents a general trend towards greater personal rights in many areas.

The benefits of patient autonomy and its counterpart, patient empowerment, are well-known. On a general level, patient empowerment reflects respect for the person and his autonomy and places the doctor and patient on a more even footing. Empowerment helps more specifically as well: psychological distress is reduced when patients feel they are well-informed (Ellis & Matthews, 1997). Patients are more compliant following interviews in which the physician offers appropriate information to the patient Rosenberg, Liussier, & Beaudoin, 1997). Information provided prior to a medical or surgical procedure allows a patient to more fully participate in treatment decisions, improves postoperative recovery, and reduces situational anxiety (Luck, Pearson, Madden, & Hewett, 1999).

However, there are "risks" to patient empowerment as well, and these pose concern to the medical establishment and to the health system in general. Many in the medical establishment fear, among other things, the threat to their own autonomy including their right and corresponding responsibility to exercise medical discretion.

This paper seeks to explore what patient empowerment represents, its benefits and limitations, and its potential to strengthen the doctor-patient relationship and the health care system as a whole.

Risks and Limitations of Patient Empowerment

Patient empowerment is a potent tool for strengthening the doctor-patient relationship and, as mentioned, has many benefits. Nonetheless, it is not without risks and limitations.

Informed Consent

The first risk, paradoxically, relates to one of the great developments of the last century, the notion of "informed consent". The concept of consent to medical care is an outgrowth of patient autonomy and has existed for many years.[1] Informed consent goes one step further, and requires that the patient fully understands what is involved, including risks and alternatives, before he or she gives consent. It is based on the assumption that the patient knows best what he finds important, and can best assess what risks are acceptable to him. Therefore, even where the patient's decision appears to the doctor totally irrational – i.e., not based on the medical evidence – it must be respected. This is particularly so since what may seem to the doctor to be a “wrong” decision may simply be a decision based on factors extending beyond the medical facts and taking into account personal, ethical, religious, and lifestyle factors of the patient. These can be as important to the patient as medical factors.

In addition, attitude to risk is often as important as the statistical probability of its occurring. As the editor of a major medical journal stated, “Assessing risk is not simply a matter of statistics: it also involves factoring in the ‘horror’ of the risk.” (Smith, 2002).

In one study reported in 2006, researchers found that people make risk-based decisions differently depending on their relationship to the decision. The situation posed was as follows: a deadly flu was spreading, there is no cure, and each person has a 10% chance of dying from it. There is an effective vaccine with a 5% risk that a person will die from the weakened virus it contains. The questions asked were: Would you take the vaccine? Would you have your children take it? If you were a doctor,

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[1] See, e.g., the American case of Schoendorff v. Society of New York Hospital, 105 NE 92 (1914).

would you recommend that your patients take it? If you were the head of a large hospital, would you recommend it for all patients?

Although the statistics are identical in each of the scenarios, answers varied according to the role each person was asked to play. Only 48% of people said they would take the vaccine themselves, 57% would give it to their children, 63% said if they were doctors they would recommend it to patients, and 73% said if they were the medical director of a hospital they would recommend it for all patients. Clearly, although the risks are the same for everyone, people's perceptions of risk and attitudes toward risk differed according to their distance from the decision (Bakalar, 2006). This phenomenon can be noted today with the spread of the H1N1 virus – although most physicians advocate that their patients be vaccinated, relatively few of them choose to be vaccinated themselves ("Doctors may refuse", 2009; "Swine flu", 2009). Decision making is subjective, even for doctors, and cannot be reduced to mere numbers and probabilities.

Informed consent has grown increasingly relevant over the years, with the advent of technological medicine. Fifty years ago, with few treatment options available for any given condition, the issue of choosing among them and understanding the risks and benefits of each was less significant, and decisions were based largely on technical considerations best decided by the doctor. Faith in the doctor was as much a part of the treatment as the treatment itself.

Today, the choices can be overwhelming, for the doctors themselves, let alone laymen unfamiliar with medical concepts and probabilities. In order to make an informed decision, patients must receive sufficient and appropriate information, explained in a manner appropriate to their level of education and understanding; however, in practice this does not always occur.

Informed consent, a normally crucial element of patient empowerment, can sometimes be counterproductive. The doctor must inform the patient of all possible risks of a procedure, or the implications of a specific diagnosis, and yet he must take care not to cause unnecessary alarm. For example, information provided prior to a medical or surgical procedure allows a patient to more fully participate in treatment decisions, improves postoperative recovery, and reduces situational anxiety. However, while moderate anxiety may improve memory by motivating the patient to retain the information, high levels of anxiety may decrease the retention of information (Luck et al., 1999). Too much information may also unnecessarily deter the patient from treatment, for reasons not justified either by medical science or even the patient's own tolerance for risk, not to mention the direct adverse health effects of stress and anxiety, such as headaches, back pain, and heart disease.

The Patient as Consumer

Recent years have brought a shift from the concept of "patient" to that of "consumer". This is largely due to the general commercialization of modern society but has unique implications in the medical context. It brings with it ethical issues, infringement of the physician's own autonomy, and potential misuse of resources.

One phenomenon that has contributed to this shift in perception is the explosion of medical information accessible to the public. This abundance of information can be viewed as a mixed blessing. On one hand, it allows patients to become better informed about their conditions and treatment options, and to come to their doctor better prepared. As noted previously, a patient who spends more time with his or her doctor and receives more information is happier, more satisfied (Jadad, Rizo, & Enkin, 2003), and often shows better compliance with treatment (Rosenberg et al., 1997). Furthermore, in today's age of increasingly fragmented medical care, a patient's knowledge of his own medical history and treatment regimens is no longer a luxury but a necessity (Kane, 2002). On the other hand, the information available is sometimes of questionable quality and reliability, and even that which is reliable, often needs to be understood in a broader medical context and interpreted by a trained professional.

Direct to consumer advertising (DTCA) of prescription drugs, accepted practice in certain countries, is a specific example of the complexity of providing information that empowers the patient. While DTCA gives patients more information, allowing them to make better informed decisions *(Pirisi, 1999)*, motivating them to seek more information from doctors, and increasing adherence to treatment, it also medicalizes normal human conditions and may give the patient information that he does not know how to properly utilize (Mintzes, Bonaccorso, & Sturchio, 2002). Many also feel it has increased the use of drugs among patients, and has increased pressure on doctors to capitulate to requests by their patients for these drugs, even if the doctors doubt the advisability of taking the medication (Wilkes, Bell, & Kravitz, 2000).

Finally, there is concern that information conveyed through DTCA is not always presented in a fair, balanced, and unbiased manner, due to the inherent conflict – manufacturers have to provide information, but also sell their product (Mintzes et al., 2002).

Patient empowerment should not mean presenting the doctor with a list of demands, but rather being sufficiently informed and knowledgeable that the patient is able to cogently discuss with the doctor the various treatment options and the advantages and disadvantages of each. A patient might insist on a certain treatment based on information he downloaded, while the doctor clearly understands that this is inappropriate or even contra-indicated in the particular circumstances. Patient empowerment does not translate to a right to demand that the physician provide any treatment the patient desires where not medically indicated. As stated by one medical ethicist, “For patients to claim a right to any procedures they wish is to challenge a conscientious physician’s integrity as a physician. It depreciates his expertise, reduces his discretionary latitude in decision making, and makes him a technical instrument of another person’s wishes." (Pellegrino, 1994). Clearly, a doctor cannot be expected to capitulate to a patient’s wishes if they go against his medical discretion, and if he did so, he could be charged with negligence.[2]

A specific example of this phenomenon can be found in the rise of elective Caesarean sections. Clinical guidelines produced by the National Collaborating Centre for Women's and Children's Health on behalf of the NHS clearly states that "Maternal request is not on its own an indication for CS", and suggests discussing with the woman her reasons for the request along with benefits and risks of a surgical birth. In addition, an individual clinician has the right to decline such a request in

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[2] In cases where a doctor objects to treatment for moral, personal, or other reasons, he has an obligation to make sure the patient is properly transferred to another physician.

the absence of an identifiable reason; however, the guidelines go on to say that the woman's decision should be respected and she should be referred for a second opinion (National Collaborating Centre, 2004).

Similarly, guidelines of the American College of Obstetrics and Gynecology come out against maternal request C-sections but do not rule it out entirely (American College of Obstetricians and Gynecologists, 2008). This is line with the Israeli position as well ("The Boundaries", 2007).

In one Israeli case, the husband of a deceased woman sued the physician who acceded to the patient's request for a Caesarean section even though there was no medical indication for such and even though the patient weighed 127 kg during her pregnancy, a clear risk factor for surgery. Although no opinion was published in this case, it is clear that the road is paved for similar suits in the future.

Unique ethical issues may also come into play as a result of the shift from patient to consumer, such as arise when parents use pre-implantation genetic diagnosis (PGD) in order to deliberately select babies with what is commonly regarded as a genetic defect, such as deafness or dwarfism. A study performed by the **Genetics and Public** Policy Center at Johns Hopkins University showed that 3% of infertility clinics surveyed reported that they had intentionally used PGD to identify and implant embryos with a particular disability (Sanghavi, 2006). This case, like others, involves more than just the patient and the physician; it has implications for a third party (the child) and for society as a whole.

Personal Autonomy vs. the Collective Good/Misuse of Resources

The principle of patient autonomy and empowerment can sometimes raise larger issues, and may appear to cause more problems than it solves. One such difficult situation for doctors is the refusal of certain religious groups to accept blood transfusions. Several years ago in the *British Medical Journal*, Finfer, Howell, Miller, Willett, & Wilson-MacDonald (1994) discussed two patients brought to the hospital with severe blood loss following a car crash. Although both had a good chance of survival with received blood transfusions and a very poor prognosis without, both refused based on religious beliefs. The first patient ultimately survived, but required aggressive and expensive care that would presumably not have been necessary had he received the transfusion. The second patient, a previously healthy 30-year-old man, died, although his predicted survival with the transfusion was 99%.

Besides the human tragedy of such a case, exemplified by the unnecessary death of the second patient, this case also raises the moral conflict of personal autonomy infringing upon the collective good. The additional resources used to save the first patient were in a broad sense diverted from the care of other patients. To what extent should we allow the individual patient to dictate the course of his care even when it unnecessarily consumes scarce resources? This dilemma arises also in the case of maintaining a person with irreversible brain stem injury on life support at the family's request.

Another example of the conflict between the empowerment of the individual and the collective good can be found in the context of immunizations. Because immunization affects the individual, each person must consent to its administration. However, immunization is in effect primarily a public health measure. Perhaps the individual should be free to make "imprudent" choices, choices that don't accurately reflect the medical risks vs. benefits. However, when the "result of one set of parents deciding not to get their children vaccinated may be that somebody else's child suffers brain damage from measles" (Smith, 2002), the picture assumes different proportions.

The Physician's Role in Patient Empowerment

Physicians are one of the key agents of fostering patient empowerment. However, the most important factor affecting how actively a physician encourages empowerment among his patients is his own attitude towards it. Does he view an empowered patient as a partner or an adversary? As "knowledgeable" or "difficult"? However, even physicians' attitudes towards patient empowerment are not uniform and may depend on the circumstances. For instance, a study executed among 21 general practitioners in Southern Australia found individual inconsistencies with regard to physicians' attitudes and decisions regarding patient empowerment. The study presented four scenarios related to back pain – the use of narcotics, complementary medicine, x-rays, and approval for time off work – and the physicians were asked whether and how much they would acquiesce to patient requests in each of these areas. Not surprisingly, physicians were the most controlling and least respecting of the patients' autonomy when it came to the use of narcotics and, to a lesser extent, regarding the use of x-rays. They were most autonomy respecting regarding the use of complementary medicine and were fairly evenly split in their attitude toward time off work (Rogers, 2002).

Physicians must also be attuned to the needs of individual patients as well as to cultural differences. However, we cannot expect doctors to intrinsically recognize these cultural differences; someone must train them. Doctors must also be prepared for the ethical conflicts likely to arise when their personal notion of autonomy (as well as the one they were trained to extend) is challenged by a conflicting, culturally based, view. As one example, in Asian cultures the notion of autonomy differs markedly from the Western concept. In the West, autonomy means that each person has a right to self-determination, and therefore the right to make health care decisions (as well as the belief that he is in the best position to do so). In Eastern cultures, such as the Chinese and Japanese cultures, social relationships, rather than rationality and individualism, form the basis for moral judgment (Bowman & Hui, 2000). Therefore, it is often the family, rather than the individual, that will make key decisions, including the decision regarding the extent of information that should be offered to the patient.

It cannot be assumed that physicians will know how to deal with these issues unless they are prepared for such eventualities.

Physicians must also realize that the very fact of illness compromises patient empowerment (Pellegrino, 1994). Fear, pain, dependence, vulnerability, and physiological changes limit patient autonomy, and must be recognized and accounted for. Being ill may also reduce the importance people place on control (Salmon & Hall, 2004). Occasionally, as in the case of dementia, autonomy must be downplayed until the patient can be returned to normal sensory states and then such autonomy can be enhanced and empowered (Pellegrino, 1994). In addition, physicians have a role in ensuring that, whenever possible, patient empowerment is enabled – for example, holding discussions with the patient when he or she is properly dressed or at least covered.

The physician must be aware of his ability to influence decisions. The tone of voice used, the choice of facts emphasized, the use of statistics – all have an impact on how information is presented and what choices are made (Pellegrino, 1994). As an example, information is received differently if a procedure is presented as having an 80% success rate or a 20% failure rate, or the fact that "one in every five patients won't survive the procedure". In one study, researchers found that information for patients often omitted relevant data, ignored uncertainties, failed to give a balanced view of the effectiveness of different treatments, and adopted a patronizing tone (Coulter, Entwistle, & Gilbert, 1999).

It must be noted that there are various factors in the physician-patient relationship that may objectively influence the amount of patient empowerment offered and assumed. Limited time may make it more difficult for a patient to ask all the questions he or she would like or for the doctor to sufficiently explain things (Lau, 2002). The physician may underestimate or overestimate a patient's desire for information or his ability to understand and/or cope with it (Lau, 2002). The physician's own reluctance to involve the patient may play a role, but so may the patient's reluctance to be empowered. In fact, one thing that must be remembered is that patients are interested in information to different extents and patient empowerment is not "one size fits all".

Ironically, in some cases "patient empowering" can even be disempowering. One example that has been studied is the use of patient-controlled analgesia (PCA), a system where (subject to limitations) post-operative patients can press a button and administer to themselves a dose of pain medication, as needed. Although presumably empowering, in that this system frees patients of the need to rely on others for pain medication and gives them more control over their pain, when interviewed, most patients did not mention control as a benefit of the mechanism; rather, what was important was being pain-free and safe. Concerns about overdosing and side effects, mistrust of technology and ambivalence to avoiding pain all restricted patients' control to some extent. In addition, some patients reported liking PCA because it freed them of the need to "bother" nurses with their requests for pain medication, whereas one objective of patient empowerment is to enable patients to feel entitled to express their needs and ask for help, if they so choose, without feeling like they are "bothering" or "imposing" on the medical staff. In other words, while doctors and nurses saw the intervention as empowering, it actually disempowered patients by reinforcing their belief that it was wrong to ask nurses to tend to their needs. Furthermore, when professionals feel the patient is empowered, they may reduce their own responsibility and shift it to the patient (Salmon & Hall, 2004).

Finally, doctors must remember that patient empowerment does not mean abdicating all responsibility. As noted earlier, doctors are often reluctant to guide patients in decision making because of the increased emphasis on patient autonomy and the concomitant increased litigation. However, patient autonomy should not deprive the patient of guidance and recommendations if he or she desires them. Doctors can advise without imposing a final decision. Failure to do so is also a form of moral abandonment (Pellegrino, 1994) and may place an unwanted burden on sick people (Coulter, 1999). Often, physicians' fear of potential litigation will often cause them to refrain from expressing their opinion at all. In this situation it would appear that the loss to the patient outweighs any benefit. The array of choices, accompanied by cold medical facts and statistics are often insufficient - or too much - for the patient to arrive at a well-considered decision, and he actively seeks the physician's personal recommendation, only to have it denied. Of course the flip side is equally egregious - the patient who seeks complete autonomy and then blames the physician when things go awry.

Conclusion

Patient empowerment is a multifaceted concept, encompassing many aspects of the doctor-patient interaction. It is neither uniformly good for patients nor unquestionably injurious to physicians. Rather, it should be viewed as a healthy progression in the history of medicine and patient care, applied intelligently, and balanced with other social considerations.

It would appear that the optimum model of physician-patient relationship is one of partnership. Whereas twenty-five years ago the patient was supposed to be compliant, according to the empowerment model the term used is adherence, implying a contract with joint responsibility. Instead of persuasion and coercion on the part of the patient, physicians utilize discussion and explanation. Where in the traditional model, patients who are resistant are seen as difficult, under the empowerment model resistance is viewed as providing valuable information that can help the physician non-judgmentally determine, together with the patient, the reasons for the resistance and, as a result, strategies for overcoming it (Lau, 2002).

With greater respect for each side and a partnership model in decision making, both patient and doctor can benefit greatly in terms of greater trust, an improved doctor-patient relationship, and better care.

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Who is Accountable? The Never-ending "Perpetuum"

Yael Applbaum, Orna Tal

Introduction

Many countries face the dilemma of whether to invest in health services that will improve individual well-being and heath status, versus the need to emphasize services given in the community or on the national level contributing to public health. The efforts to balance these objectives are even more complex as many different stakeholders are involved in this arena.

Accountability in healthcare has always been a difficult issue. In 1996, Emanuel and Emanuel published a detailed article: "What is accountability in healthcare?". More than a decade later, this debate persists, and a solution is not in reach.

Both the insurers and the patient refer to the primary physician as being at the center of the system, concentrating in him or her accountability for a high standard and for effective medical care. They are the core of medical support for other actors on stage as well: the government, professional unions, health organizations, hospitals, managed care plans, lawyers, and the court.

Emanuel and Emanuel (1996) argued in their article that no single model of accountability is appropriate to healthcare, and advocated a stratified model. They claim, correctly, that there are at least six domains of accountability in health care: professional competence, legal and ethical conduct, financial performance, adequacy of access, public health promotion, and community benefit.

In the Israeli National Health System, various actors are accountable for a broad spectrum of healthcare aspects. Although they share a mutual vision of maximizing health, dissimilar pathways are chosen to achieve this goal. Nevertheless, identical quality measures and indicators are used to characterize their scope of responsibility.

Performance parameters aimed at assessing overall healthcare services are limited to measurable parameters. In the current system, one of the most potent performance measures leans on measuring physician performance. The outcomes of health are not only dependent on physician performance; however, the other determinants often cannot be quantified.

If health outcomes are found to be different in different areas of the country, those held responsible are the healthcare professionals providing services in those areas. In reality, physician performance may be medically identical, yet physicians with poorer outcomes, whether due to demographic characteristics or patient behavior, will be held accountable for their patients' poor health status.

Caught between these two players, the patient preferences on one hand, and the health system demands on the other, the physician is caught between both forces, but not necessarily in a balanced way. The agenda of the individual physician is mostly patient-centered, while the state and the health insurers have a social agenda - mostly population-oriented. As described, this difference between the agendas may cause conflict.

The health care organizations are accountable to the Ministry of Health; following the principles of the National Health Insurance Law (1995). The health funds must provide healthcare services in accordance with the concept of fairness of accessibility expressed in the law. They should be accountable to provide these services in a fashion that will promise equity in health outcomes, despite individual differences. Thus, inequity in healthcare measurements, secondary to geographic discrepancy and socio-economic gaps, are an undesirable outcome.

Healthcare systems seek a stable anchor within the system to bridge these gaps. In the current model of accountability, public accountability becomes personal responsibility - the personal responsibility of the physician.

In Israel, physicians are employees, mostly of the government or the healthcare funds. The moral and practical dilemmas that the physician faces are constantly growing as the cost restraints and political issues are passed on to them. Although medical practice is considered a free trade, and we regard health as a right more than a commodity, fiscal considerations are unavoidable.

Physician accountability to patients vs. accountability to employer is becoming harder in a system that uses primary care physicians as gatekeepers. One would argue that economic considerations should not be part of a physician's agenda; however, this argument cannot be considered acceptable in the current financial scenario as healthcare expenditure must be limited to allow provision of basic healthcare to all. Physicians realize this, even though it often positions them in a state of personal conflict and moral dilemma.

Gate keeping, while serving the interests of society as a whole, is for the benefit of each individual patient by allowing social medicine to endure. In this system the physician has to pair up with the employer to preserve the public interest, and team up with the patient to look out for the patient's interest. He is the main stakeholder in this equation and he has dual conflicting loyalties.

Ethical and professional dilemmas arising from this conflict challenged us to seek a solution, comparing with other models. In a review of the literature, we found that various models are used in an attempt to share responsibility. In Israel one of the ways to share financial responsibility with patients was to introduce extra insurance to cover parts of medical care that the state cannot or will not pay for.

We would like to take that model one step further and propose a unique model, which continues, once again, to share responsibility with the patient. Since the physician must team up with the patient to preserve the patient's interest, they should share not only the interest but the responsibility as well. Patients should be held accountable for their part of healthcare that is within their control, i.e., health care habits and compliance to medical recommendations (Buyx 2008; Volpp et al., 2009).

To do so, patients should be empowered to improve their health status. They should be given the knowledge and the support to do so. When they are held responsible for their health status they will be the ones to lobby for the subsidization of healthy foods, fruit, and vegetables. Then the buck will be passed back to the health ministry.

Patients will be able to influence legislation on taxation of cigarettes and alcohol, and they will be pressured to rightly present to the government and media that education level is the best predictor of health outcomes (Winkleby, Jatulis, & Fortmann, 1992). The health minister can share the burden of accountability with his colleagues: the minister of education, the sports minister, and the minister of finance.

With responsibility should come reward. We propose a unique model of sharing not only responsibility, but the rewards as well.

Current performance is treated with a stick rather than with a carrot. However, pay for performance systems are becoming widespread. Introducing a pay for performance system along with the patient responsibility system would allow a fair and motivating movement towards a true partnership.

Just as personal responsibility should be shared, so should the rewards be shared. Budgets assigned for "Pay for Performance" should be distributed to the doctor-patient team achieving preferred health outcomes. This shall come as a reward for their shared efforts and for ultimately reducing the burden of disease both financially and socially.

Physicians should get half the amount as a reward for health education, encouragement, treatment, and achievement of goals, and patients achieving target measures of control on chronic disease should get their share as well. It can come as a reduction on the price of their health insurance fees or the price of their medications. Alternate forms of reward might come as a subsidization of a fitness club membership, coupons for a bicycle store, or other benefits.

Would the customers accept this approach? A literature search came up mostly with articles on cost sharing rather than sharing medical responsibility or personal accountability. Review of the literature reveals that engagement of the patient in both cost and quality of healthcare may be a useful way to share responsibility. The successful use of cost sharing presumes that individuals have access to information on cost and quality, and respond appropriately to prices of medical interventions (questionable assumptions when applied to healthcare) (Fendrick & Chernew, 2007).

Hall and Schneider (2009) examined physicians' standpoints when helping patients make better cost-conscious choices. They claim that in public policy forums doctors may argue against governmental or market initiatives, but in clinical forums, there is a professional obligation to cooperate with prevailing social policy - especially when the policy forges the interests that patients bring into the examination room.

However, the applications of economic analysis to health policy have been hampered by a number of problems, including those that consider public health policy. One must pay special attention to a growing area of inquiry and application to the overall coverage of health services (Banta & de Wit, 2008).

Differences of standpoints and opinions were found while comparing the attitude of policy-makers, physicians, and patients toward obesity - a medical status defined as "self-inflicted" in the UK. Health professionals were more inclined towards individual-orientated weight management interventions as effective responses. Policy makers considered environmental and social policy changes as most likely to make a substantial difference to current obesity trends, but considered it unlikely that such policies would be implemented without political will and popular support. The dissonance between policy maker, health professional, and public obesity perceptions points to a challenge for those who believe that wholesale systemic change is required and possible (Greener, Douglas, & van Teijlingen, 2010).

In South Africa a conjoint model combining the efforts of the physician and the patient was developed to implement physical activity in disadvantaged communities. This "community development model" combined scientifically sound program content, appropriate activities, intrapersonal and interpersonal factors, program leadership, and encouragement of staff. The program had positive impacts on the quality of life, perception of the role of physical activity in health, and personal responsibility for health of those involved (Draper, Kolbe-Alexander, & Lambert, 2009).

Schmidt, Gerber, and Stock (2009) reviewed the German incentive schemes, which include rewarding patients in four different programs: Incentives for “health-conscious behavior”, Incentives for complying with dental check-ups, Incentives for the early detection and treatment of chronic diseases, and Incentives for minimizing healthcare utilization. The purpose for implementing these incentives was to improve population health, maximize efficiency of services, and enhance competition between sickness funds. They found that these programs pose new questions regarding the effectiveness of the programs to reach their intended goals, the effect these programs have on the physician-patient relationship and to what extent different socioeconomic groups use incentive systems.

Discussion

Accountability in healthcare in Israel acts like a pendulum, shifting from one stakeholder to another, often focusing on the most responsive and compliant link of the chain – in our current system – the physician.

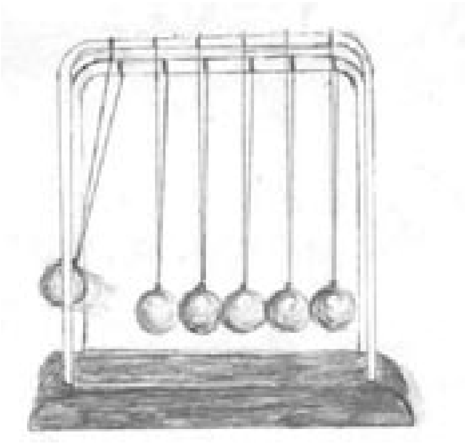
The new model described, sharing both responsibility and reward, can reinforce positive behavior, reduce burden from physicians, give incentive to patients, and ultimately create positive movement in the healthcare system. One might visualize this model, in accordance with Newton's cradle.

In layman's terms, Newton's laws of motion are defined as follows:

> First Law: "An object in motion will stay in motion and an object at rest will stay at rest unless acted upon by an external force."
>
> Second law: "Force equals mass times acceleration."
>
> Third law: "To every action there is an equal and opposite reaction."

Newton's cradle, named after Sir Isaac Newton, is a device that demonstrates conservation of momentum and energy. The device is also known as an executive ball clicker or balance balls (Figure 1).

Figure 1: Newton's Cradle.



The device consists of a series of identically sized metal balls suspended in a metal frame so that they are just touching each other at rest. Each ball is attached to the frame by two wires of equal length angled away from each other. If one ball is pulled away and allowed to fall, it appears to come to a dead stop and the ball at the opposite side acquires the speed of the first ball and swings in an arc that one would expect of the first ball. Further intrigue is provided by starting more than one ball in motion. With two balls, exactly two balls on the opposite side swing out and back. When discussing this model of personal responsibility and accountability, one can use Newton's cradle as a wonderful analogy. The current situation is like the cradle with three balls. The first ball put in motion is that of the state, transferring the accountability to the second ball - the health funds. They subsequently transfer all the energy to the third ball - the physician. Someone watching this motion would be intrigued by the lack of motion on the part of the health funds. However, if the cradle now consists of four balls, adding the extra ball, which represents the patient himself, the motion will be entirely different. The patient and physician partnership, when put in joint motion, can now activate equal movement of both other balls, those representing the state and the funds.

Other models of sharing accountability might be between two ministers (for example the minister of health and the minister of education) and may enhance health outcome and narrow the gap based on socio-economic status. This cooperation may be regarded as a risk-sharing mechanism, in which two participants invest some effort without risking too much, to get a synergistic effect on the system.

Furthermore, adding more players, or more balls, will distribute the energy even further and cause even more movement in the arena.

Of course, unwisely involving too many players may result in complete chaos. Hence, "passing the buck" should be carefully planned, estimating the role of each player, and adapting changes with caution.

In conclusion, we propose a policy that removes some of the burden of responsibility from the physician and shares it with the patient, while proposing that they share not just the responsibility but the reward as well.

Quality measures of physicians should not be confused with quality measures of systems or of populations, even when the physicians share the vision of public interest.

And why should we transfer some of that responsibility to the patient? For one, because the physician cannot continue to hold the burden alone and secondly – as Samuel Shem (1978) declared in his book *The House of God*: "The patient is the one with the disease".

Joint efforts of all the stakeholders will ultimately promote better health outcome results – a desirable outcome for all!

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Personal Responsibility versus Responsible Options: Compliance meets Public Health in the United States

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Background and Context: The U.S. Healthcare System

Healthcare Insurance

The United States has a patchwork of health insurance that combines private and limited public systems. The private system, which is dominant in the USA and is primarily composed of employer-based health insurance, provided health insurance to 58.5% of Americans in 2008 (DeNavas-Walt, Proctor, & Smith, September 2009). In this system, employers offer health benefits to their employees, purchased through and managed primarily by commercial health plans. Health benefits can range from the employer completely absorbing their employees' health care costs at one end of the spectrum, to charging employees a premium that is deducted from their wages and absorbing the remainder of health care costs incurred at the other. Most commonly, employees have a premium deducted from their wages, and they are also responsible for a co-payment when they see their health care provider and for other health services such as prescription drugs and surgeries. Again, the level of coverage, premium costs, and co-payments vary with employer and insurance provider, creating a wide spectrum of health coverage and costs.

The public system - a combination of federal and state government programs - offers health insurance to specific populations through four programs: Medicare, Medicaid, the State Children's Health Insurance Program (CHIP), and medical benefits packages through the Department of Defense (DoD) and Veterans Affairs (VA). Medicare, an entitlement program, provides health insurance to all individuals 65 years or older, as well as individuals with renal failure, and those with specific disabilities. Health insurance is provided without regard to income or past medical history, and is administered and managed by the U.S. Centers for Medicare and Medicaid Services (CMS) directly and in contracts with commercial health plans. Medicare provides health insurance to approximately 45 million Americans, is divided into parts that cover hospital costs, provider costs, and prescription drug costs, and also certain durable medical goods and services. Medicaid, a combined federal (CMS) and state-funded and -administered program provides health insurance to individuals who are part of low-income families or who are elderly or suffer from certain disabilities. Medicaid covers approximately 55 million Americans and, similarly to Medicare, covers hospital costs, provider costs, prescription drug costs, as well as certain durable medical goods and services. CHIP, a federal-state program, was developed in 1997 to expand health insurance to children of families whose incomes are too high to qualify for Medicaid but for whom insurance is unavailable. CHIP covers approximately 7.3 million children in the USA. The DoD and VA offer health insurance to those currently enlisted in the military (as well as their families), and veterans, respectively. This program covers 8 millions veterans, and provides a full range of medical services at VA facilities across the country.

Despite these health insurance options, approximately 17% (48 million) of the U.S. population remain uninsured for a variety of reasons that include some combination of being unemployed, working at a job that doesn't provide employer-based health insurance, or not qualifying for one of the public system programs described above, among others. To make matters worse, given the economic downturn, and increasing health care costs, the number of the uninsured is expected to grow. Minority Americans (African-Americans, Hispanic/Latinos, Native Americans/ Asian Pacific Islanders, and Asian Americans) are more likely to be uninsured than their majority white counterparts. For example, in 2008, 28% of Hispanics under the age of 65 were uninsured for more than 12 months compared to 11% of Blacks and 8% of whites (National Center for Health Statistics, 2009).

Healthcare Expenditures

The USA, one of the only industrialized nations that does not provide universal health insurance, spends more on health care than any other country in the world, even with 17% of its population uninsured.

According to data from the Organisation for Economic and Cooperation and Development (OCED), in 2007 health expenditures in the USA reached 2.3$ trillion USD, accounting for 16% of the Gross Domestic Product (GDP) (OCED, 2009), a number which is expected increase to 19% by 2019 (Centers for Medicare and Medicaid Services, 2008). In 2007 the USA spent 7,290$ USD per capita on health care compared to 4,417$ USD for the second highest spending country (OCED, 2009). The development and use of costly technologies (such as MRIs), pharmaceutical prices, regional variation in care (health care being used more, and costing more, in certain regions of the country), and end-of-life expenditures (use of expensive resources that may not change the outcome in the last year of life) all contribute to the current and increasing costs of health care in the USA (Fisher, Bynum, Skinner, 2009; McNeil, 2001). In fact, experts predict that if the U.S. Healthcare system remains unchanged, in 2019 the number of uninsured will increase to 57 million, Medicare will be bankrupt, national health care costs will increase from 2.3$ trillion USD to 4.7$ trillion USD, and the average cost of an employer-sponsored health insurance plan for a family will increase from approximately 10,000$ USD a year to 20,000$ USD a year (Herszenhorn, 2010).

Research shows that these greater health care expenditures do not translate into better quality of care. For example, *The World Health Report 2000,* ranked the U.S. health system 37th in the world (World Health Organization, 2000) and the USA lags in comparison to other countries in important health indicators. In 2006, the USA ranked 39th in the world in infant mortality, and 36th for life expectancy (Murray & Frenk, 2010). Not only are the current and future costs of health care in the USA not sustainable, but the nation is not getting its money's worth when benchmarked against global health indicators. This issue has taken on greater importance in the last year given the realization that escalating health care costs are taking a toll on U.S. business in the global marketplace, and making them less competitive, given the costs they have to absorb compared to other nations that have universal health insurance coverage. In this past year the issue of health reform has been debated broadly and widely on the national stage, particularly given that the president made health care reform a key part of his domestic agenda. Initially there was hope that reform targeted at increasing access to affordable health insurance (and thus decreasing the rolls of the uninsured), improving public health and health care quality, and determining strategies to "bend the cost curve" and decrease the rate of health care cost growth in the USA would be successful. Models emerged that had become the foundation for national discussion, including recent health care reform in the state of Massachusetts. However, the economy and politics have significantly scaled down what is possible, and there is simply hope that something will be done to address access to health care.

The Epidemiological Transition

As the USA aims to improve the health of its population while controlling costs – leading to greater effectiveness and efficiency – it has undergone an "epidemiological transition". For example, in the last century, the USA has experienced improvements in health and life expectancy largely due to initiatives in public health, health promotion, and disease prevention. This has included efforts in water and food safety, sanitation, and vaccinations, to fend off our previous greatest health threat, infectious disease. These initiatives took into account the environment, the workplace, and the community, bringing the best of public health principles into practice. Data now suggest the leading causes of death in the USA are no longer those related to infectious diseases, but instead we have transitioned to an epidemic of chronic disease, such as hypertension and cardiovascular disease, diabetes, and asthma. Now that we have made progress in reducing the burden of infectious diseases (absent HIV) by being attentive to public health, many are seeking to abandon these principles in favor of the medical model – focusing particularly on treating conditions with medications and high-tech procedures – as we tackle the epidemic of chronic disease. This approach to the epidemiologic transition certainly has led to our conundrum of higher costs and poorer health outcomes when compared to other industrialized nations. This has had a disproportionate impact on minority populations, for example, as we see that in 2001, deaths due to diabetes were highest among African-Americans, American Indian/Alaska Natives, and Hispanics (Table 1). Obviously preventing and addressing the chronic disease epidemic is especially important for minority and other vulnerable populations in the USA.

Table 1: *Deaths due to diabetes, by race and ethnicity, 2001.*

Group	Death Rate*
Whites	22.1
Blacks	49.9
Asian/Pacific Islanders	16.9
American Indian/Alaska Natives	45.3
Hispanics	36.3
United States Total	25.2

*Deaths per 100,000 population, age-adjusted

Source: Centers for Disease Control and Prevention (2004).

Key Determinants of Health

The origins of chronic disease are complex and multifactorial. As we develop new strategies to curb the growing rates of chronic disease, three key facets of health should be considered: social determinants, access to health care, and health care quality. Social determinants – such as lower levels of education, overall lower socioeconomic status, inadequate and unsafe housing, racism, and living in close proximity to environmental hazards – impact a patient's health and disproportionately impact minority populations, thus contributing to their poorer health outcomes (Andrulis, 1998; Antonovsky, 1968; Flores et al. 2002; Muennig, Fiscella, Tancredi, & Franks, 2010; Pincus, Esther, DeWalt, & Callahan, 1998; Williams, 1990). For example, individuals who have diabetes might live in communities where it is unsafe to be outside and exercise, where no gyms are available, or where they cannot get recommended foods for their condition (such as fresh fruits and vegetables) either because they aren't available in their community, or are priced higher than in other communities. Even if these individuals are following the tenets of the medical model and taking medications for their condition, their health outcome is still likely to suffer. Lack of access to care – including health promotion and disease prevention interventions – also takes a significant toll on health, as uninsured individuals are less likely to have a regular source of care (Giacovelli et al., 2008; Stevens, Seid, & Halfon, 2006), are more likely to report delaying seeking care (Becker, 2004; Van Loon, Borkin, & Steffen, 2002), and are more likely to report that they have not received needed care (Hargraves, 2002). Again, a diabetic who is uninsured and cannot get routine diabetes screening, monitoring, and management will be at a disadvantage. Finally, once a patient has access to the health care system, they may have trouble navigating it (certain populations may be afraid to seek care due to language barriers or cultural differences) (Cheng, Chen, & Cunningham, 2007; The Robert Wood Johnson Foundation, 2002), or they may receive a lower quality of care than their counterpart based on some personal characteristic such as race/ethnicity or gender (Agency for Healthcare Research and Quality, 2008; Committee on Quality of Health Care in America, 2001; Smedley, Stith, & Nelson, 2003). These disparities in quality of care have been extensively documented in the USA.

Personal Responsibility Versus Responsible Options

As the focus has shifted towards primarily addressing chronic disease using the medical model, there has also been a greater call for “personal responsibility” on behalf of patients – the idea they must take care of their health, including exercising regularly, eating nutritious foods, and being adherent to their health care provider’s recommendations. While the concept of personal responsibility is an understandable and, some would argue, fair expectation, as we make a push in this direction we must ask, “Do our patients have responsible options?” Can the diabetic patient in fact get the healthy foods we instruct them to? Are they available and affordable in their community? Can the patient with heart disease exercise safely in their community? Do they even have a sidewalk where they live? Can the asthmatic patient rest assured that even when they take their medications, the mold and dust in their apartment, or the incinerator one block down, or the diesel bus that passes on their street thirty times a day, won't make them acutely short of breath? Addressing the root causes of chronic disease, such as obesity, will require *both* personal responsibility *and* responsible options.

The development of responsible options to address the key determinants of health requires long-term community improvement and health promotion efforts – few would argue with this. The challenge is, how do we emphasize the important role of long-term community health promotion and investments in addressing the social determinants of health in an atmosphere that demands evidence of health impact and return on investment, especially in the short term?

In an interesting turn, as the health policy debate turns to reform, two significant concepts have evolved that begin to lay the groundwork for bridging medical model approaches to addressing chronic disease with the principles of public health practice with economic consequences in mind – payment reform, and the need to "bend the cost-curve" and decrease the rate of health care spending in the USA (Massachusetts Hospital Association (MHA), 2009). As these two issues are actively being discussed and addressed, it seems that there is a greater realization that we will not be able to address chronic disease solely through the provision of traditional medical care, but in addition need to consider how to address the social determinants of health as an essential part of the strategy. In sum, the "business case" for public health is being incorporated in these movements, reflecting the need to grow from demanding personal responsibility, to considering leveraging responsible options in communities. Several initiatives and case examples prove noteworthy in this regard:

- ***The move to accountable care organizations***

  The discussion on payment reform has yielded the theory that as a health care system, we should no longer solely pay for discreet events such as hospitalizations for particular conditions (which we now do via the DRG system), as the incentive is to compensate hospitals for multiple, potentially short admissions without attention to what it might take to prevent future admissions. Instead, the idea is emerging to hold health care organizations more financially accountable for the *health outcomes* of their patients, shifting the incentive from compensating per admission to compensating for admissions that include significant efforts to promote effective transitions back to the community, and strategies that improve overall health and prevent readmissions (MHA, 2009). Although certainly not without its critics, this strategy is already taking root at CMS, for example, moving towards limiting hospital reimbursement for a patient who is readmitted within 30 days after a discharge for congestive heart failure (CHF). The idea is that by paying this way, and holding hospitals accountable, they will spend more time assuring that they have the services in place, and work with communities so that the patient can have an effective discharge. This fully supports the concept of expecting personal responsibility (such as medication adherence) as well as responsible options (such as having the appropriate low-sodium foods and exercise opportunities available in communities, both items that are essential to the management of CHF). Thus, the financial case is built and return-on-investment more apparent.

◆ *The Medical Home*

Another area that has been on the health policy fast track over the last year has been the concept of the medical home. In sum, research has shown that patients have better health outcomes if they have a “medical home” - a link to a primary care provider, health information technology, and a set of integrated services to meet a broad set of needs for patients (including education, care management, nutrition, etc.) (Beal, Dot, Hernandez, Shea, & Davis, 2007). Major accrediting bodies in the USA are now certifying practices that have these key components as “medical homes” that are then in position to benefit from grants and payment reform experiments that provide significant financial benefit. A key cornerstone of the medical home is a practice that goes beyond the traditional medical model and considers how aspects of public health can be implemented so as to improve patient health (American Academy of Pediatrics, 2002). This is yet another financial incentive and example of a concept that can demonstrate return-on-investment and link personal responsibility to responsible options.

◆ *Pay-for-Performance*

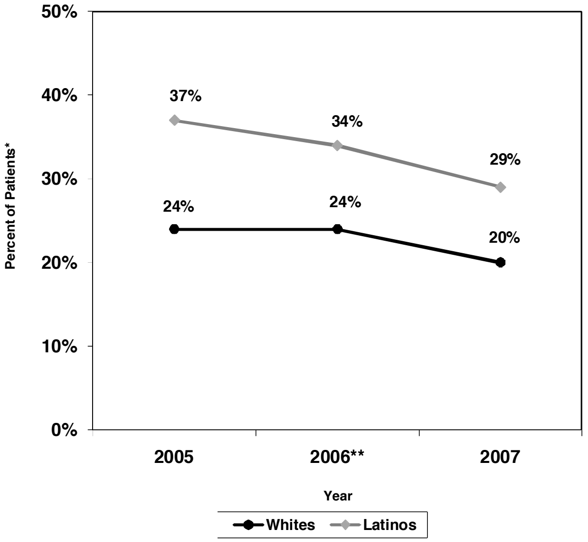
Pay-for-performance contracts have been developed by commercial health plans in order to provide financial reward to hospitals and physicians who demonstrate the provision of high-quality healthcare (MHA, 2009). For example, a hospital or provider group can have a pay-for-performance provision written into their contract that will provide a bonus payment if they can demonstrate that a specific percentage of their diabetics have met certain performance standards (e.g., routine hemoglobin A1C testing) and have their condition under control (hemoglobin A1C level under 7). In order to achieve these goals, hospitals and provider organizations have realized the need to go beyond the medical model and assure adherence to prescription medications, for example, to providing patients with additional services that incorporate public health principles such as culturally and linguistically appropriate health coaching, case management (which focuses on linking to community-based services), and group education (focusing on nutrition and exercise). These efforts have expanded to include activism around food availability in communities, and advocacy for safe and available exercise space (e.g., opening school gyms after hours) - linking personal responsibility to responsible options.

Case Example and Lessons Learned

In response to the key drivers described above, several programs have been developed around the country to address the long-term health needs of communities by blending a public health approach with the medical model to improve quality and eliminate disparities. For example, Massachusetts General Hospital (MGH) has pay-for-performance contracts with health plans that include financial incentives for achieving certain clinical and process measures to improve diabetes management for its patients. To achieve these goals, MGH has invested in bilingual case managers, group education classes, and "culturally competent disease management", which focus on nutrition, exercise, and how to address sociocultural and environmental barriers to health management. The Chelsea Diabetes Management Program (CDMP) was developed in response to data from 2005 at the MGH Chelsea Health Care Center, which revealed that 37% of Spanish-speaking Latinos were more likely to be in poor diabetes control (HbA1c>8.0) compared to 24% of English-speaking white patients. To address this disparity, MGH developed a culturally competent and comprehensive diabetes management program for patients with poorly controlled diabetes at the MGH Chelsea Health Care Center. The program has three primary components: telephone outreach, individual coaching, and group education classes. The telephone outreach component aims to encourage patients to receive HbA1c testing, especially targeting patients who have not been tested within the last nine months. The individual coaching sessions, offered in English and Spanish, identify and address the patient's individual barriers to maintaining diabetes control. This part of the intervention particularly integrates public health principles into the program, as the coach routinely helps patients address issues that relate to the social determinants of health, including accessing food availability and developing cooking classes to ensure patients can follow their dietary recommendations, and piloting community walking groups so as to address the importance of exercise while addressing safety concerns. Expanding on the individual sessions, the group classes, led by a bilingual nurse educator, provide diabetes education based on the American Diabetes Association national standards. The group sessions also provide a strong and valuable community-based peer support system.

As of June 2009, approximately 442 patients have participated in the program, over 50% of whom are Latino. Over 2,000 coaching sessions have been conducted with a mean of five coaching sessions per person. Results show that mean HbA1c levels have improved for all groups, and notably that the gap between Latinos and Whites is closing. HbA1c levels significantly dropped by 1.48 points for enrolled patients, and mean HbA1c values for all Hispanic patients with diabetes dropped from 8.3 to 8.0 from 2005 to 2008 compared to Black (8.3 to 8.1) and white patients (7.5 to 7.4) over the same time period (Figure 1).

Figure 1: *Diabetes control improving for all.*



*Percent of patients with poorly controlled diabetes (HbA1c > 8).
**Chelsea Diabetes Management Program began in first quarter of 2006.

Initial estimates demonstrate the cost of the CDMP to be approximately 170,000$ USD a year. National models of diabetes hospitalization costs based on the cohort of 400 individuals in the CDMP, project that 44 would be admitted with diabetes if they remained in poor control, at a cost of 374,000$ USD; if the CDMP prevents 60% of these admissions (a very conservative and reasonable estimate), then there is a cost savings of 54,000$ USD; if the CDMP prevents a second admission during the year, cost savings increase to 134,920$ USD (Betancourt, 2009). In summary, the CDMP demonstrates how a culturally and linguistically competent disease management model that uses public health strategies can improve care for all patients while working to reduce disparities – all while linking personal responsibility to responsible options, and demonstrating a good return-on-investment.

Several key lessons have emerged from the CDMP:

1. ***Allied Health Professionals are Effective***

   Individuals from the community being served, and who have the cultural and linguistic competency that can help them communicate effectively with the intervention population, can be very effective. Given they can spend more time with patients, explore and address the social and cultural barriers they are facing, and engage in community advocacy, these individuals are essential adjuncts to the traditional medical model of care. They can link personal responsibility to responsible options, and provide a significant return-on-investment.

2. ***Health Information Technology is Essential***

   Health information technology that allows you to create patient registries focusing on different clinical conditions and then stratify by race/ethnicity or other personal characteristics gives you the opportunity to identify, monitor, and track progress in addressing health outcomes.

3. ***Barriers can be Social and Cultural – not just about improving medication adherence***

   Many of the barriers that contribute to poor diabetes control relate to the social determinants of health, as well as cultural perspectives. Addressing these issues via a blended public health medical model provides the greatest chance for success. Neither can stand alone, and combined they help foster the need for personal responsibility while assuring there are responsible options in communities.

Looking Toward the Future

There is no doubt that these efforts are in their nascent stages – beginning with expanding the medical model to address public health issues through the use of a broader health care team. Simultaneously, there are some very preliminary efforts to really make substantive changes in communities, and to truly provide responsible options. For example, some of the funding within health care reform would provide for the creation of new parks and play spaces in disadvantaged communities; tax breaks would be provided so that supermarkets would invest in placing stores in poor communities that are currently fresh food “deserts”; stimulus funding would support green energy and environmental policies that would contribute to cleaner air in areas currently affected by traffic smog and old decrepit housing with asbestos. All of these efforts would go a long way in addressing chronic conditions such as heart disease, diabetes, and asthma – yet they have not yet been linked to payment reform or efforts to bending the cost curve, as described above. Many critics still question whether providing resources such as those mentioned here really affect health care, so instead a slower transition that expands public health aspects of the medical model has become more palatable from a policy and political standpoint. A merger of these initiatives – those that focus on medical treatment, individual counseling, group counseling, and contextual/environmental changes – remains both the gold standard and the final frontier we’ve yet to reach.

Conclusion

The USA faces many challenges – from a complex, patchwork health insurance system to an unsustainable rise in health care costs – which, combined, does not deliver top-notch health outcomes. To complicate matters, the epidemiological transition from infectious disease to chronic disease as the prevailing cause of morbidity and mortality in the USA has been met with a shift in focus from the public health strategies of disease prevention and health maintenance to those principles of a primarily medical model. Yet this epidemic can not be met solely with a medical approach that focuses on adherence to medications and a call for personal responsibility. Public health strategies, and creating responsible options for patients, must be an essential component of any effort to address chronic disease. Although previously it was felt that we could not make a “business case” for such an approach, new policy shifts such as the move to accountable care organizations, pay-for-performance, and the medical home have restructured the landscape so that addressing chronic disease through a blended public health medical model not only is the right thing to do, but also the financially smart thing to do. There are certainly many models out there – among which the MGH CMDP is just one – that demonstrate that this new approach can be successful and financially sound. As new lessons continue to emerge about how to carry out these interventions, one overarching theme will remain clear – we must incorporate public health into chronic disease management, and call for personal responsibility as we provide responsible options for patients.

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"Diabesity" & Positive Deviance: The Challenge of Adherence to Long-term Therapies

Elliot M Berry, Sabina De Geest

Introduction

The major pandemics of the 21st century are the non-communicable diseases of obesity, diabetes, and the consequent insulin resistance syndrome. Since some 85% of non-insulin dependent diabetes is associated with obesity, it is convenient to use the neologism "diabesity". This problem has emerged in developed countries since the end of the Second World War, but it is now also increasing in developing countries. Whereas in the former, obesity is more common in lower socio-economic sectors, in the latter it is a sign of economic (and nutritional) prosperity.

That this pandemic has occurred in such a relatively short time period from an evolutionary perspective – a time too short for genetic changes – means that the major incriminating factor must be the environment. Therefore, obesity can be considered a "normal" response to an "abnormal" obesogenic environment – one that encourages and facilitates infringements on both sides of the energy balance equation of the first law of thermodynamics (Dubnov-Raz & Berry, 2008; WHO, 2006). There is an excess of energy-dense portion sizes with a diminution in energy expenditure and active living, as everything is designed to be "energy saving". The result inexorably is obesity. While this public health phenomenon is well (almost too well) documented, the prevention and treatment of diabesity is far from successful. It is not a question of awareness but of finding the right way to intervene. Since this involves lifestyle and personal choice over a very long time frame, the problem reduces to that of compliance and adherence. The problem is further complicated by the fact that the target population most in need of help comes from the lower socio-economic sectors. They have less time and money to devote to modifying food choices and activities necessary for implementing lifestyle changes.

The overall success for weight reduction is extremely limited, partially because of a lack of consideration of the interplay of the different levels of the health care system. Indeed, in tackling the issue of obesity a system perspective is needed in which multilevel interventions are implemented. McLeroy, Bibeau, Steckler, and Glanz (1988) recognize a systems approach at three levels: the patient-provider dyad (micro), the health care organization and community (meso), and the health care system (macro). Thus, interventions should not only target the patient level but also the level of the health care provider (e.g., competencies for behavioral change management, communication skills), the level of health care organizations (e.g., adoption of a chronic illness management), and at the policy level (e.g., laws and regulations) (WHO, 2002).

The New Paradigm

Management of chronic illness will be the challenge of the 21st century. Chronically ill patients have different needs than patients with acute illnesses. Since clinical outcomes in the chronically ill are very much dependent on adequate patient self-management (defined as continuous active involvement in own care (Kane, Priester, & Totten, 2005)) and adherence to usually complex therapeutic regimens, support for patient self-management and adherence, as well as continuity of care, should be integral parts of the care for this growing patient group. Yet, little innovation has taken place so far in revamping the prevailing acute care driven system, which includes little or no attention to preventive measures, behavioral and psychosocial interventions, or continuity of care, toward a system of care that is more conducive to the needs of the chronically ill (WHO, 2002).

Paradigms for the chronically ill have been developed, implemented, and tested such as, for example, the Chronic Care Model (Bodenheimer, Wagner, & Grumbach, 2002) adapted by the WHO to the “Innovative Care for Chronic Disorders” framework (WHO, 2002). Fundamental to this kind of model is the planning of care as a close interplay between different levels of the health care system, starting with connected, prepared, informed, and motivated patients, families, health care teams, and communities. Further, they also integrate continuity of care, endorse quality through leadership and incentives, organize and equip health care teams, support self-management and problem prevention, develop and encourage the use of information systems, and create positive policy environments (WHO, 2002). Excellent examples of how changing systems of care can drive health care improvement can be derived from the literature on diabetes or heart failure (Nolte & McKee, 2008; Sochalski et al., 2009).

Moreover, increasing evidence associates evidence - based models of chronic illness care with improved health outcomes (Bergeson & Dean, 2006; Nolte & McKee, 2008).The success of any chronic illness care model depends on interdisciplinary collaboration. It requires health care providers who share certain core competencies (i.e., patient-centered care, partnering, quality improvement, information and communication technology, public health perspective) (Pruitt & Epping-Jordan, 2005; WHO, 2005a). These competencies should be integrated into health care professions' curricula, as well as guiding continuing post-graduate training.

Support for Patient Self-Management/Adherence in Chronic Illness

Support for patient self-management is seen as an essential building block in the chronic illness models (Bodenheimer, Lorig, Holman, & Grumbach, 2002) and should be integrated in clinical practice, especially of those working in primary care. All clinicians involved in the care of these patients should get trained properly in the first core competency of the WHO, i.e., patient-centered care. Patient-centered care is linked specifically with "supporting patient self-management". Patient-centered care refers to (1) interviewing and communicating effectively, (2) assisting changes in health-related behaviors, (3) supporting self-management, and (4) using a pro-active approach (Pruitt & Epping-Jordan, 2005; WHO, 2005b). Specifics of what a shift towards a chronic care paradigm for patient self-management entails, in contrast to the prevailing acute care driven one, is indicated in Table 1.

Development and implementation of strategies for self-management emerge from a vast behavioral science literature providing theoretical approaches and empirical evidence for behavioral change. We will highlight three of these approaches (e.g,, the 5 As, motivational interviewing & positive deviance), but will first shed light on one specific health behavior in diabesity, that of exercise.

Table 1: *A comparison between the traditional and New paradigm for patient care.*

Traditional	New Paradigm
Therapeutic relationship: PS experts, P PASSIVE Problems identified by PS="bad behaviors" Goal = Compliance Principal problem Solver: PS for P External Motivation: Behavior Change	Shared Expertise with ACTIVE P. PS expert about disease, P expert about his/her lifestyle Problems identified by BOTH PS & P Goal = Shared Decision Making Both PS & P share responsibility: Problem solving skills Internal Motivation: Motivational Interviews Positive Deviance

After Bodenheimer, Lorig, Holman, and Grumbach (2002).

PS – Professional, P – Patient

Exercise as Part of Patient Self-Management for Diabesity

Recent guidelines provide information for an exercise prescription in the chronically ill and the elderly in four areas (Nelson, et al., 2007). *Aerobic* activity: moderate-intensity aerobic physical activity for a minimum of 30 min on five days a week, or vigorous intensity aerobic activity for a minimum of 20 min on three days a week, guided by exercise capacity. Further, they recommend *muscle strengthening activity* for a minimum of two days a week; *flexibility activity* at least two days a week for at least 10 min each day, and also *balance exercises*. Self-management support for the diabetes patient should include these activity guidelines and, in addition, give guidance on energy intake (diet) and other relevant aspects of the diabetic treatment regimen. Pedometers are excellent devices for encouraging active living.

Many patients have problems with following their clinician's health advice (Sabaté, 2003). Effective behavioral intervention requires that barriers are assessed among the other potential determinants of health behavior, since personal and environmental barriers might negatively influence the adoption, or successful execution, of specific health behaviors (Fishbein, Hennessy, Yzer, & Douglas, 2003). Barriers to exercising illustrate the multilevel interplay of factors (personal and environmental) that determine health behavior as described earlier. According to the Canadian Fitness and Lifestyle Research Institute (http://www.cflri.ca/eng/index.php), over 50% of subjects cited lack of time (69%), energy (59%), or motivation (52%) – all individual considerations, while 30% considered lack of facilities, safety (24%), partner support (21%), and transport (17%) as the environmental constraints. These factors will change according to the subject population and its location.

Overcoming these barriers and engaging patients in a healthy lifestyle requires a multilevel approach. Recommendations for *clinicians* include gaining knowledge on state of the art of physical activity in treatment & training in behavioral management, and mentioning the value of an active lifestyle during patient visits; health care providers should personally engage in an active lifestyle to familiarize themselves with the issues involved and to set a good example (role models) for patients and the public alike; they should also use their influence to enhance school and community exercise programs (Fletcher & Trejo, 2005).

At an *organizational level,* the following interventions have been shown to increase the level of physical activity: large-scale, intense, highly-visible community-wide campaigns, point-of-decision prompts that encourage people to use stairs instead of elevators or escalators, physical education programs in schools, social support programs such as walking groups, individually adapted programs to change behavior, and enhanced access to places for physical activity (Fletcher & Trejo, 2005).

Primary care physicians may not be the most experienced or appropriate advocates for health promotion including support for patient self-management. There are personal, environmental, and organizational barriers for medical practitioners to this, involving many factors including knowledge, self-confidence, time required, volume of information, and remuneration. Cabana et al. (1999) have in fact identified some 293

[sic] reasons for such failures. This point was brought out nicely by two studies researching whether medical practitioners can help promote physical activity in the setting of primary care. They reached contradictory results – one positive in New Zealand (Elley, Kerse, Arroll, & Robinson, 2003) and the other negative in the UK (Hillsdon, Thorogood, White, & Foster, 2002). The implication is that one cannot necessarily transfer conclusions from one intervention setting to another, since “one size does not fit all”. Lifestyle interventions must be tailored to the needs and specific weaknesses of the target population.

The public health approach to lifestyle promotion requires a multidisciplinary task force involving schools, the work place, the community, food & advertising industry, local government and legislation, amongst others. In the HMO setting, lifestyle changes require a new paradigm in the doctor-patient relationship where the doctor becomes more of an advisor/coach, and the patient must take more responsibility for his or her health and adherence to long-term treatment. These topics must also become part of the medical school curriculum. Contract relationships and shared decision-making are appropriate, auxiliary health profession staff may be the most suitable case managers for these objectives and group work is probably the most cost-effective treatment approach.

At the *patient level,* a personal action plan, after Whitlock, Orleans, Pender, and Allan (2002) and Glasgow et al. (2002), can be developed involving the 5 As. (1) Assessment: Patient’s knowledge, attitude, and practices; (2) Advice: Information concerning health risks and the benefits of change; (3) Agreement: Collaboratively setting goals based on patient preferences; (4) Assistance: In problem solving, identifying barriers and strategies to overcome them; (5) Arrange: Follow-up plans.

Motivational interviewing techniques are most useful to help the patient initiate behavior and sustain the behavioral change. The key features of motivational interviewing should be taught and practiced in nursing and medical schools (see Table 2).

Table 2: *Behavior skills and motivational techniques for health professionals for tackling diabesity.*

- Self-monitoring – keep records of frequency, intensity, and type of physical activity
- Goal setting – defining realistic goals, e.g., loss of 300-500gm/week
- Stimulus control and exposure – controlling exposure to overeating and inactivity
- Problem-solving – identify weight-related problems, BRAINSTORM solutions, plan & implement healthier alternatives, evaluate outcomes
- Involve Spouse and Social Support networks
- Don't talk about Compliance/Adherence – rather Shared Decision Making, Self-Management
- Health Professional as a COACH
- Be Non-Judgmental

Space does not allow going into all the details of the technique, which may be found in the literature (Miller & Moyers, 2002; Rollnick, Miller, & Butler, 2007). Examples of cultural inappropriateness are to suggest outdoor exercising for traditional Arab or Jewish women, or losing weight for women in some African countries, which may be considered as a sign of illness or infertility. Positive Deviance is a practical method for applying motivational techniques at the level of the community.

Positive Deviance

PD is a refreshing approach to the problem of behavior change involving partnering with communities (Marsh, Schroeder, Dearden, Sternin, & Sternin, 2004). The premise is that in every community there are certain individuals whose uncommon practices or behaviors enable them to find better solutions to problems than their neighbors who have access to the same resources. These successful individuals are called the "positive deviants" and are somewhat akin to the "early adaptors" in the diffusion of innovation (Moore, 2002). The challenge is to find those behaviors that are applicable and accessible to the rest of the community and to try and get the less successful to adopt them. A comparison of PD and traditional problem solving is shown in Table 3.

Table 3: *Traditional vs. positive deviance approaches for problem solving.*

Traditional	Positive Deviance
Deficit Based	Asset Based
"What's WRONG here?"	"What's RIGHT here?"
Analysis of underlying causes of PROBLEM	Analysis of successful SOLUTIONS
Externally Driven (by "experts" or external authority)	Internally Driven (by "people like us", same culture & resources)
Top-down, Outside-in	Bottom-up, Inside-out

The four steps of PD are: Define the problem, Determine the deviants, Discover their successful behaviors, and Do the intervention with the necessary monitoring. The advantage is that the solution is community valid and already works, and thus is based on action rather than theory. The concept of PD, akin to that of salutogenesis of Antonovsky, was first used in tackling nutritional problems such as child malnutrition in Vietnam. Investigators would go into villages and look for children who did *not* have it. Then, they interviewed their parents to see what behaviors succeeded such as breast feeding, boiling water, or the use of mosquito nets, and what could not be used at the community level – e.g., stealing or receiving monies from relatives. Intervention programs based on PD (and summarized in the article by Marsh et al., 2004) are, of course, not universally successful but do add a more constructive approach to the research aims by focusing on the "half full, rather than half empty, glass".

As far as the authors are aware, PD techniques have yet to be specifically applied to tackling interventions for obesity. Rather, PD should be tried in specific communities such as inner cities or marginalized areas to find out who is not obese there and why not. Considering the problem of exercise motivation, the PD approach would be to find those members of the community who are fit and active and to learn how they incorporate such behavior(s) in their every-day life. This might be through using little tips such as wearing a pedometer, walking with a friend, parking far away, exercising a dog, or avoiding elevators. The next step is to see if other less fit subjects could adopt some of these behaviors. In contrast to sedentary behavior, such active living may be shown to save some 9,000 calories over a month, which translates into about 1.2 kg body weight (Blair & Nichaman, 2002).

Positive Deviance methodology can be applied to any public health or medical problem – such as improving diabetic control, reducing traffic accidents or violence in schools. Researchers learn from the situations, settings, and people who have successfully dealt with the problem. The challenge of diabesity is to see how such management on the individual level may interact with the environment to produce *long-lasting* changes in a population's BMI to combat the obesity pandemic. Therein lies the rub – because to change behavior is one thing, to preserve and persevere over time is quite another. This involves re-enforcement by different modalities, whether by phone, e-mail, or social support. However, ultimately the responsibility is with active follow-up by the health-care team and their positive attitude to help the subject succeed not only in his or her mission but also to influence the surrounding family and community.

Summary

The major cause of morbidity and mortality in western countries is related to obesity (the pandemic of the 21st century) and the insulin resistance syndrome (IRS). These diseases are responsible for up to 6% of health care expenditure in European countries. Many physicians (encouraged by the drug marketing industry) prefer to prescribe medications that may correct the biochemical abnormalities without doing anything for the underlying cause. Weight loss of only 5-10% is sufficient to significantly improve the IRS, thereby decreasing the need for multiple drug therapy. However this “simple” goal is usually unattainable by the conventional medical approach. The key message is so simple – “eat less and exercise more” – yet so hard in practice. Exercise may improve metabolic abnormalities even without weight loss. Other holistic advice relates to diet, particularly the Mediterranean-type lifestyle with its social networking. Mental activity and a sense of humor are also important, but as yet unproven, requisites for success.

The public health approach to lifestyle promotion requires a multilevel approach in which health care disciplines join forces with other stakeholders, i.e., schools, the work place, the community, food & advertising industry, local government and legislation, and patient organizations, to alter the obesogenic environment. A paradigmatic shift from an acute care driven paradigm towards a chronic illness care paradigm in which preventive and therapeutic measures to tackle the obesity epidemic are integrated at all levels of the system is required. In such a paradigm, the patient is seen as an active partner who is in charge of his or her therapy in daily life, and needs to be supported by clinicians to take more responsibility for his or her health and to adhere to long-term treatment. This approach implies that clinicians acquire the knowledge and skills for behavioral assessment and intervention, elements that need urgently to be integrated in health care professionals’ teaching curricula. The clinician thus becomes more of an advisor or coach within a clinical encounter. One way to work collaboratively with patients in behavioral change is “the positive deviance approach”. In this, behaviors of successful people (positive deviants) are used to help others succeed *within the same community* to combat obesity. The four steps are Define the problem, Determine the deviants, Discover their successful behaviors, and Do the intervention with monitoring. Special emphasis should be given tackling diabesity in the lower socio-economic groups where problems and challenges are greatest.

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The Change of Personal Responsibility in the Kibbutzim – Medical Aspects

Eytan Hyam, Yaniv Sherer

Introduction

Kibbutz is a collective community in Israel that was traditionally based on agriculture. Nowadays it includes other economic branches, including industrial plants and high-tech enterprises. Kibbutzim began as utopian communities, a combination of socialism and Zionism. In recent decades, most Kibbutzim have been privatized and no longer practice communal living. Currently, less than five percent of Israelis live on kibbutzim. In this manuscript we review most of the medical studies conducted in the kibbutz, and discuss the change of personal responsibility and the health status and medical aspects that follow kibbutz privatization.

Studies Done in Kibbutzim

Literature search discloses that kibbutz members served as a homogeneous population for several genetic studies. Kibbutz members have in most cases good health measures in all aspects. Both lifestyle and healthcare in the kibbutz contributed to the health status of kibbutz members. A few examples of these studies and their conclusions follow.

Elderly Life in the Kibbutz

Retired members of Israeli kibbutzim were interviewed in an open-ended fashion concerning their early history, their decision to join the kibbutz, their working life, and their post-retirement adaptation. In this study, only little evidence of significant psychopathology was found (Gutmann & Shkolnik, 2007). In another study, kibbutz members were found to be less disabled, defined as needing help with at least one of five activities of daily living, than the other groups compared. They also had 30% lower risk of disability compared with the other groups. The authors suggested that lower disability among kibbutz members may be due to the social, economic, and instrumental support provided on the kibbutz, as well as to an active life style, suggesting features of kibbutz life that can be replicated elsewhere to reduce disability (Walter-Ginzburg, Blumstein, & Guralnik, 2004). In a third study, there was significantly lower depressive symptomatology among women residing in kibbutz communities (Blumstein et al, 2004). Women's lower level of depressive symptoms was considered a result of better physical and mental functioning among kibbutz members and of favorable lifestyle characteristics, such as frequent contact with their children among old-age kibbutz residents.

Posttraumatic Stress and Growth

In this study, posttraumatic stress and posttraumatic growth symptoms were found to be more common among town residents than among kibbutz residents (Dekel & Nuttman-Shwartz, 2009).

Chronic Diseases

A community-based survey of 124,400 kibbutz residents disclosed that the prevalence of ulcerative colitis in this Israeli population has increased and reached the upper range for European and American populations. Nonetheless, the mean annual incidence rate of ulcerative colitis was in the lower range of that reported for Western countries (Niv, Abuksis, & Fraser, 2000). In another study of the prevalence of chronic diseases in kibbutz members, diabetes mellitus and primary hypothyroidism were found to be common disorders in elderly subjects in the kibbutz. Diabetes mellitus in the elderly can usually be handled with diet and oral hypoglycemic drugs, and the authors recommended that elderly subjects should be screened for hypothyroidism (Flatau, Trougouboff, Kaufman, Reichman, & Luboshitzky, 2000). With respect to Parkinson's disease prevalence in kibbutzim, residents in 270 kibbutzim in Israel were screened, and the prevalence of Parkinson's disease in the Israeli kibbutz population was found similar to that reported in most other population-based studies (Anca, Paleacu, Shabtai, & Giladi, 2002). However, it seemed that there was older age at symptom onset in the Kibbutz Movement than most other epidemiological studies.

Preterm Delivery in Kibbutz

In a case series examining obstetric and demographic data of 17,493 deliveries that occurred between June 1994 and May 1999, the overall preterm delivery rate was 8.5%. Style of living was associated with the preterm delivery rate ($p < 0.00001$): kibbutz 5.5%, Jewish towns 7.8%, non-Jewish towns 8.7%, Jewish villages 6.7%, and non-Jewish villages 11.0% (Eliyahu, Weiner, Nachum, & Shalev, 2002).

Genetic Studies in the Kibbutzim

As the population of the kibbutzim is relatively easy to follow up, and as several generations usually can be traced within the same geographic region, several genetic studies have been done in the kibbutzim. One example is that of familial aggregation of heart rate variability characteristics, which was found to be determined mostly by genetic factors and less by environmental factors, thus providing a basis for continuing the investigation into the underlying genetic influences on heart rate variability (Sinnreich, Friedlander, Sapoznikov, & Kark, 1998).

Attitudes of Kibbutz Members

Attitudes toward domestic violence of people living in communal secular and religious kibbutzim were studied (Shoham, 2005). Most of the kibbutz members view the kibbutz as almost totally lacking any problem of violence toward women by their partners. Surprisingly, the belief that the kibbutz home is a secure place for women within the family framework appears at a greater frequency among women than among men (ibid.). Regarding the tendency to be vaccinated, as demonstrated in a single study, kibbutz membership positively affected the decision to take the flu vaccine (Shahrabani & Benzion, 2006).

Kibbutz Privatization and Health Status

The last decade was characterized by enhanced privatization of many kibbutzim in Israel. The kibbutz society turned from one that takes care of one's condition without any self-autonomy, to a society in which one should take care of himself in most aspects. Kibbutz members are responsible to various extents now for their budget and expenses, and have to pay taxes for services that were free of charge in the past. The impacts of health status in the kibbutzim can be speculated and be concluded by yet a few unpublished data based on novel findings (personal communication). In general, privatization outcome regarding health status in kibbutzim include:

1. Health services are currently sponsored to a greater extent by kibbutzim members than in the past.
2. The number of health system employees decreased, albeit there was an increase in the number of cases treated.
3. The socioeconomic inequality between members worsens as the number of years post-privatization increases.
4. Decreased employment options (due to privatization) are of concern, as being in a "working state" is associated with better health.
5. There is a direct connection between socioeconomic status of kibbutz members and their health status. This difference is more prominent in kibbutzim that underwent privatization.

Before the privatization process the kibbutz nurse was responsible for organizing all healthcare management in the kibbutz. She controlled the disease management as well as preventive medicine. For example, a sick child was taken care of by the nurse even without parents' knowledge about the child's situation. The nurse also used to visit daily the children and the elderly and notice if any of them became ill. The kibbutz belonged mostly, and also today, to the Clalit HMO. Kibbutzim had a special health committee that approved special health-related expenses. Nowadays, as opposed to before privatization, kibbutzim mostly do not have an attending physician, as he can only be located in a nearby city. Some of the kibbutz members today have private health insurance programs.

Hence, whilst personal responsibility increases in the kibbutzim, the health is at risk. In view of the changing kibbutz atmosphere several actions should be taken by various players in the field of kibbutz health: the government, the HMOs, and the kibbutzim themselves. Examples include: HMOs should guarantee the presence of adequate personnel even in small and distant kibbutzim. Special emphasis should be given to populations at risk such as the elderly. Importantly, health status in the periphery is of special concern to the Ministry of Health in general, as part of its measures to reduce health inequality in Israel, and the kibbutzim in the periphery are an important part of it.

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Personal and State Responsibilities in Vaccination: A Two-Way Road

Baruch Velan

Introduction

In recent years, more and more attention has been focused on personal behaviors and healthy lifestyles as substantial contributors to public health (Wikler, 2002). Various campaigns were introduced to encourage personal responsibility in order to counteract the adverse effects of cigarette smoking, alcohol consumption, unprotected sex, and reckless motorcycle riding. This new perspective in health should also have an impact on policies aimed at achieving increased immunization against infectious diseases.

Notably, the immediate personal benefit from vaccination is in many cases less than the cumulative benefit to society from vaccination programs (e.g., establishment of herd immunity). Mandatory vaccination, which can overcome the tension between personal and societal interests, is losing much of its moral ground in the liberal industrialized world. On the other hand, promotion of vaccination by health care authorities is often scrutinized, accused of being paternalistic, and not accepted *prima facie*. All this underlines the importance of redefining the personal responsibilities of individuals for vaccination, and conveying these responsibilities to the public.

In this article I shall review the distribution of responsibilities for vaccination among the various pertinent parties, and define the constituents of personal responsibility in vaccination. I shall then identify motives for the reluctance of the public to comply with vaccination, and delineate the role of the state in bridging personal responsibilities and public reluctance.

Responsibilities in Securing Protective Immunity Against Infectious Diseases

Protective immunity against prevailing infectious diseases is rightfully considered a common public good. Therefore, vaccination of populations against such diseases should be viewed as a common target for all parties involved, and be dealt with as a cumulative effort.

Four requirements (Table 1) should be met in order to achieve effective protection of the population:

1. Effective vaccines have to be developed;
2. Public vaccination programs should be implemented;
3. Vaccines should be tolerated by the persons being vaccinated, without causing harmful effects; and
4. Vaccination programs should be accepted by the public.

Table 1: *Agents and responsibilities in vaccination.*

Task	Agent	Responsibility
Vaccine development	Scientists	Contribute ingenuity & commitment
	State	Provide infrastructure support and funds
	Biotech. companies	Funding
Vaccination programs	State	Design, implement, and fund programs
	Expert committees	Define needs and options
	Biotech. companies	Provide vaccines
	Healthcare community	Execute vaccination
Tolerability evaluation	State	Establish adverse effect reporting systems
	Lay individuals	Participate in reporting
	Biotech. companies	Improve vaccines
Acceptance by public	Lay individuals	Comply with vaccination program
	State	Encourage and facilitate compliance
	Healthcare community	Motivate, provide example

Vaccine Development

Development of new vaccines is mainly within the responsibilities of

the scientific community, which should be aided by state institutions providing infrastructure, modalities, and funding for the research. Biotechnology companies and non-profit organizations are expected to share the burden of the state in support and funds. In general, the responsibilities in vaccine development have been met successfully during the last century. Vaccination history is dotted with glorious achievements beginning with the seminal work of Jenner and Pasteur through the development of toxoid vaccines and polio vaccines, up to the more recent success in developing recombinant vaccines such as the hepatitis B vaccine and the vaccine against the human papilloma virus.

Vaccination Programs

Translating vaccine developments into vaccination programs relies mainly on the efforts of the state, which is expected to design vaccination programs, execute them, and communicate to the public the need to be vaccinated. The state should rely on expert committees in defining needs and targets, while commercial companies are expected to supply stocks of validated vaccines. Health care workers are responsible for actively administering the vaccines. It should be noted that most industrialized countries are very effective in meeting their responsibilities towards vaccination, and successfully incorporate effective vaccination campaigns into their public health programs.

Tolerability

Evaluating physiological tolerability of vaccination by individuals (no harm) is currently an integral part of all strategies for introducing new vaccines. Vaccination adverse effect reporting systems are controlled by heath authorities and are known to provide reliable information about potential side effects. While the major responsibility here is held by the state, the lay public has a substantial responsibility in submitting to vaccination, as well as in reporting any observed effect (Slade et al., 2009).

Public acceptance

The last crucial building block in establishment and maintenance of population protective immunity is the readiness of individuals to comply with vaccination. Each individual is expected to exercise personal responsibility and to contribute personally to the collaborative effort required for attaining effective population immunity.

Personal Responsibility to be Vaccinated

The personal responsibilities related to infectious disease bear unique features rooted in the victim/vector status of infected individuals. Every person within the infection web of a communicable disease is a victim of the disease and therefore should be treated as such, to alleviate his or her suffering. At the same time, every infected person may also be a carrier of the disease and is able to infect his or her contacts (Battin, Francis, Jacobson, & Smith, 2009). Therefore, individuals are expected to minimize their exposure to pathogens not only for their own sake but also for the sake of others (Dale, 1998; Dawson, 2005; Verweij, 2005). Preventive vaccination appears to be the most effective measure for combating infection, and should be therefore used by individuals as the method of choice for exercising their responsibility to prevent contagion. Vaccination is nevertheless often associated with risk. This can stem from the extremely low, yet inherent, probability of serious side effects of the modern validated vaccines, the potential unknown risk of newly developed vaccines, and the groundless "phantom risks" often attributed to vaccination in general. In spite of all this, the proven benefits of vaccination programs call for personal responsibility, which is grounded on a multilayered stratum (Table 2) of moral obligations.

Table 2: *Moral obligations and vaccinations.*

Responsibility toward	Feature
Oneself & family	Obligation to be healthy
	Promote healthy lifestyle
	Lesser burden on family/friends
The other	Do not infect the other
	Prevent third party harm
Community	Enhance community health
	Save money for health authorities
	Generate herd immunity
	Provide protection to the more vulnerable
Global interests	Facilitate movement of people
	Facilitate international trade
	Allow immigration
	Contribute to freedom
Future generations	Enhance disease eradication
	Free future generations from epidemics

Respoensibility to be Healthy

The first constituent of personal responsibility in vaccination relates to the well-accepted moral obligation to be healthy: People should be healthy for their own good. Individuals should be able to fulfill their expectations from life, and have the capabilities to pursue their goals and agendas in society, without the physical constrains resulting from infectious diseases.

Promotion of healthy life style is being considered now as a standard tool for ameliorating the well-being of people. An infection-free life style is at least as valuable as life styles that emphasize exercise, balanced-diet, or refraining from smoking. Since the most effective measure for maintaining an infection-free life style is preventive vaccination, one can consider the promotion of vaccination programs justifiable, even if it is done for the sake of personal health.

Responsibility Not to Infect Others

In addition to the personal responsibility to minimize any potential infection-based victimhood, we have the basic moral obligation to minimize our infectious vectorhood, so as not to inflict harm on a third party.

We are all aware of the obligation to not knowingly infect others while harboring an infectious disease. This is manifested by a set of accepted behavioral norms, such as refraining from attending public gatherings while carrying a respiratory infection, or being considerate to one's partner when carrying a sexually transmitted disease. Nevertheless, intrinsic features of infectious disease create situations when a person does not manifest clinical symptoms of the infection, yet is still a carrier. Thus, during the incubation period of the disease or during an asymptomatic infection people can still endanger others, while unaware of their vectorhood. The optimal way to counteract these situations would be through preventive vaccination.

Preventive vaccination can thus be considered a direct outcome of the obligation not to harm others. Nevertheless, various counterarguments can be raised to lessen the personal obligation to get vaccinated. These include: a) the *remoteness argument*, which suggests that harm resulting from non-immunization is conveyed by the disease and not by individuals, who therefore cannot be accused of causing it; b) the *omission argument,* which claims that creating evil by omission is less serious than creating evil in an active manner; and c) *the baseline argument,* which suggests that by failing to be immunized one does not actually worsen the welfare status of his fellows. All these arguments are valid, yet in my opinion, they fail to provide a justifiable excuse for not getting vaccinated.

The moral obligation not to infect others becomes even more pronounced in the case of health care providers (HCP). HCP have direct contact with patients, and therefore are prone to be infected and to transmit the disease to others. Actually, being infected by one's physician during a visit to the clinic shatters the very basic principle of healthcare: "First do no harm".

It is deplorable that accumulating evidence indicates that even in the case of highly promoted vaccination programs, compliance rates of medical staff tends to be low (Stewart, 2009).

Responsibility towards the community

Combating communicable diseases calls for collaborative efforts. Preventive measures that are not directed towards the entire population are often limited in their effectiveness. Individuals are expected to take part in the process of mass vaccination in order to contribute to the population's well being.

A unique feature of vaccination as a health measure is its ability to confer herd immunity (John & Samuel, 2000). Once a certain percentage of the population is vaccinated, disease incidence becomes negligible and non-vaccinated individuals escape the dangers of contagion. It is true that herd immunity protects conscious free-riders, and provides a ground for non-compliance; however, herd immunity also protects individuals that cannot be vaccinated for medical reasons, or individuals that failed to acquire immunity in spite of vaccination. Thus, herd protection attained by high vaccination coverage underscores the personal responsibility in compliance with immunization programs.

An additional component of our moral obligation to enhance vaccination stems from the fact that vaccination is considered among the most cost-effective medical technologies available (Ehreth, 2003). In many vaccination programs every sum of money spent on a vaccine shot is at most one-tenth that spent on treatment. The saved money can, obviously, be allocated to other healthcare interventions. Therefore, by complying with vaccination programs each of us can contribute indirectly to public health in general.

Responsibility towards the more vulnerable

In many cases the burden of infectious diseases is not distributed equally among individuals in a given population. Certain infections are more common in specific segments of the population (e.g., hepatitis B; Toy, Veldhuijzen, Mostert, de Man, & Richards, 2008). Certain infections affect specific groups more than other groups (e.g., the elderly in seasonal flu; Dushoff et al., 2007). Other infections entail gender-specific sequelae (e.g., rubella, human papilloma virus), which essentially affect only one-half of the population. Therefore the benefit from vaccination is not always equal, and individuals are often faced with a situation where they are requested to be vaccinated for the benefit of the more vulnerable.

This situation becomes even more complex in the case of infections that are related to risky behavior of certain groups (e.g., hepatitis B in those that practice promiscuous unprotected sex or in i.v. drug users; François, Hallauer, & Van Damme, 2002). These individuals are often difficult to reach or identify as they are prone to stigmatization. This creates a situation where mass vaccination becomes more effective than target-group vaccination, again leaving the burden of getting vaccinated on the entire population. As demanding as vaccination for the sake of others appears to be, values such as solidarity and communitarianism put the responsibility for vaccination on all of us.

Responsibility Towards Global Intrractions, Freedom, and Cultural Exchange

Protective immunity achieved by vaccination allows people from different “infectious habitats” to congregate.Thus, vaccination is a key facilitator in international trade and cultural exchange. The consequences of infection-related impairment of movement became apparent in the last decade when the SARS scare had a major impact on the economy of Eastern Asia (Keogh-Brown & Smith, 2008) and more recently when the early association of H1N1 with Mexico was estimated to affect the country's GPD.

Vaccination is a pre-requisite for movement of people from one country to others. The actual or potential importation of infectious disease by immigrants, migrant workers, or illegal immigrants has always been of major consideration, and often led to stigmatization and marginalization of the alien (Courtwright, 2009). One cannot envision the future without the globalization-related traffic of large groups of people between various parts of the world. One may argue rightfully that responsibilities related to globalization are more relevant to state action. One should realize, however, that we all are taking part in the process of globalization through everyday actions, such as our trips to developing countries or our interactions with household workers from abroad. It is, therefore, the personal responsibility of each individual (the immigrant and the resident of the host country) to minimize the potential infectious consequences of globalization through preventive vaccination.

Moreover, vaccination could help promote social and cultural interchange between people from different social backgrounds and ethnicity in the same country by removing barriers caused by fear of infection by the "other". In addition, vaccination mitigates the need to practice freedom-restricting steps during epidemics. In a highly vaccinated population the need to use measures of movement-restriction, coercive social distancing, or confidentiality-breaching through notification of contacts is spared.

Taken together, vaccination appears to promote laudable social values such as equality, freedom, and justice. If we cherish these values, we have the personal responsibility to comply with vaccination.

Responsibility Towards Future Generations

Immunization programs strive for disease eradication, for the benefit of our generation as well as that of future generations. Successful eradication of smallpox was achieved in the mid-'70s. Currently attempts are being made to eradicate polio (Thompson & Tebbens, 2007). It is also believed that eradication is theoretically attainable for other infectious diseases.

One has to admit that full elimination of infectious diseases appears to be more complicated than previously believed, and will probably not occur in the near future. Nevertheless, the successful eradication of major infections within defined geographical areas indicates that global eradication of specific infections is achievable. Thus, by adhering to recommended vaccination programs, at present, we are actively creating the building blocks for a future that is free of major infectious diseases (Caplan, 2009).

Reasons for Non-Compliance with Vaccination

Mass immunization is a highly effective approach in fighting infectious diseases, and the personal responsibility of individuals is expected to be an essential incentive for compliance with vaccination. Nevertheless, considerable dissidence has accompanied vaccination from the very early beginning. The reasons for opting-out of vaccination programs appear to be variable and complex but can be essentially attributed to fear, mistrust, self-interest, conviction against vaccination, and indifference (Table 3).

Table 3: Reasons for non-compliance with vaccination.

Motivation	Feature
Fear	Concern about actual risk
	Misconception of risk
	Fear of the unknown
	Vaccination controversies
Conviction	Religious grounds
	Philosophical grounds
	Ideological grounds
	Divergent perception of medicine
indifference	Apathy
	Ignorance
	Behavioral biases
	Difficulty to cope with burden
Rational argumentation	Risk/benefit evaluation
	Value given to other countermeasures
	Reluctance to take burden of others
	Selfish free riding
Mistrust	General mistrust of authority
	Concern about commercial forces
	Aversion of paternalism
	Separatism

Fear

Infectious diseases, in general, tend to raise fear and panic. This fear also extends to vaccination against infectious diseases, and often results in non-proportional concern about the risk of vaccination. As a consequence, the history of controversies related to vaccination risk appears to be as old as the history of vaccination itself. Controversies over the safety of smallpox vaccines were reported in England and the United States in the late 19th century and the early 20th century (Albert, Ostheimer, & Breman, 2001). Vaccination with BCG in Lubeck, Germany, in 1930 resulted in a notable disaster leading to the death of over 200 vaccinees from Tuberculosis (Bonah, 2005). Controversy over the safety of whole cell pertussis vaccine in the United Kingdom led to low compliance and re-emergence of whooping cough (Baker, 2003). Recent years are marked by the association of MMR vaccines or thimerosal-containing vaccines with autism (Baker, 2008; Gross, 2009). While these associations proved to be false, the specter of autism still mars all vaccination programs today.

Thus, grounded as well as groundless fears of risk associated with vaccination are a major deterrent in public compliance with vaccination. Recently, the widespread concern about swine flu has been met by intense public scrutiny of side effects. Media and Internet chatter provoked public anxiety (Ofri, 2009) and is resulting, at present, in low vaccination rates.

Indifference

Low vaccination coverage is often the result of non-motivated lack of behavior. This can be the result of ignorance as well as apathy or indifference. Non-compliance can also be driven by a variety of biases that often characterize human action. These include the "omission bias", which leads people to prefer non-action to action, as well as the "present bias", which results in neglecting future consequences of present action or non-action. These biases are accentuated by the inherent fear of vaccination risks.

Another factor that contributes to lack of action as a factor in non-compliance is the practical burden conferred on parents by child-immunization protocols. Parents are faced with a seemingly endless list of recommended vaccinations (amounting to close to 20 shots during the first five years of a child's life) and are expected to comply with a demanding vaccination schedule. Parents in certain segments of the population find themselves unable to fully comply with such demands, and this leads to only partial protection for their children.

Conviction

Non-compliance with vaccination programs can also be rooted in strong personal convictions against the vaccination concept itself (Asveld, 2008). Certain religious groups would claim that the remedy for infectious diseases should be brought by spiritual salvation and not by practical interference. Philosophical arguments can lead people to believe that vaccination is against the rules of nature and impairs bodily integrity. Extreme libertarian ideologists could claim that the state has no right to make vaccination decisions that infringe on the bodily autonomy of competent individuals.

Recent years have been marked by the resurgence of groups that advocate divergent perceptions of medicine and immunity (Singh & Ernest, 2008). These people believe that infectious diseases are not as harmful as claimed, and that the "cure" (vaccines) is worse than the disease. Moreover, disease is believed to strengthen the immune system, whereas vaccines ruin it. Thus, alternative medical methods such as homeopathy are offered as a more effective method in tackling disease. It should be noted that this alternative ideology is gaining popularity and constitutes, nowadays, one of the more pronounced dangers to vaccination programs.

Rational Refusal

Non-compliance with vaccination can often be attributed to rational argumentation. Individuals often evaluate the risks and benefits of a given vaccine, and argue that vaccination does not serve their personal interest, or is not justifiable as such. The success of classical vaccination programs has led to the situation where individuals are not faced with the devastating consequences of diseases such as diphtheria or poliomyelitis, and fail to appreciate the potential risk of non-compliance with vaccination. In other cases vaccine-preventable diseases are not perceived as severe (e.g., chickenpox or seasonal flu), and do not create an urge for vaccination. Moreover, in certain cases other preventive measures are perceived to be as effective as vaccination and appear to be less demanding. Rational non-compliance appears to be a major argument used by health care providers to justify their reluctance to be vaccinated as a requirement imposed by their occupation.

Another aspect of rational refusal characterizes free-riders who consciously argue that the collaborative effort of others in contributing to maintaining herd immunity allows them to refrain from vaccination. Free riders benefit from the low recurrence of disease in a complying community, without being exposed to the low yet potential risk of vaccination.

Mistrust

Lack of trust in authorities is, nowadays, a major contributor to non-compliance with vaccination programs. Interestingly, mistrust occurs in non-developed countries where vaccination campaigns are often considered a mischievous intervention of international forces (for example the failure of the polio campaign in Nigeria; Jegede, 2007), as well as in democratic industrialized countries where visceral mistrust in the establishment often feeds skepticism about vaccination programs. In this context one should take note of the effect of political and cultural separatism on vaccine compliance. Low immunization coverage and consequent disease outbreaks mark certain Jewish ultra-orthodox groups in Israel and Europe (Anis et al., 2009; Lernout, Kissling, Hutse, De Schrijver, & Top, 2009). At least part of the non-compliance by these groups can be linked to their conscious detachment from the social norms in their countries of residence.

More recently, mistrust has been fed by concerns about the increased influence of commercial forces on health decisions (Sade, 2009; Sismondo, 2007). Recent revelations about the very tight interactions between international pharmaceutical companies and research groups, as well as the powerful lobbying for vaccination against human papilloma virus in the United States have contributed to such concerns. The media interest in these interrelationships, together with the fluctuations in the human papilloma virus vaccination policies in the United States can definitely affect public opinion on vaccination.

The Role of the State in Enhancing Personal Responsibility

Benefits to society from vaccination are believed to be greater than the sum of the benefits to individuals. The state is therefore expected to focus on policy measures aimed at overcoming certain personal self-interest-based attitudes to vaccination, and increase coverage to reach social optimum. This could be achieved through mandatory vaccination. Mandatory vaccination is accepted as the preferable mode of operation in the United States and certain other countries, yet it appears to collide with the prevailing social and political culture in other countries. It should be noted that mandatory vaccination is very much justifiable when the threat of an epidemic is imminent, or when herd immunity depends on very high levels of compliance (e.g., measles and pertussis).

Not withstanding all this, substantial emphasis should be put on directing the individual's free choice towards compliance with vaccination. It has been often argued that the outcomes of individual free choice in vaccination would diverge from the required social-optimum (Sadique, 2006). Nevertheless, the new discourse on personal responsibility in health may provide new dimensions to promoting compliance with vaccination.

Motivation of individuals to comply with vaccination could be based on underlining the profound personal moral responsibility towards vaccination (Table 2), and should employ newly formed social mechanisms designed to enhance responsibility towards other health issues. The major obstacle to this approach is the inherent deep resistance of individuals to vaccination (Table 3). Bridging the considerable personal responsibility in vaccination and the not less considerable personal resistance to vaccination should be within the duties of the state. Having the comprehensive responsibility for enhancing protective immunity, the state is expected to employ straightforward measures such as subsidizing vaccines or providing them free of charge. At the same time the state is also expected to be *responsible for assisting individuals in their efforts to assume their own personal responsibility.*

One way of addressing the difficulties related to personal responsibility is relieving some of the vaccination burden. Utilitarian evaluation of vaccination programs leads, by definition, to maximalization. Programs that prevent all harmful infections could all be regarded as beneficial, thereby leading health care professionals to advocate vaccination against a large repertoire of pathogens. Moreover, since universal vaccination appears to be more effective than vaccination of target populations, mass vaccination appears to be the preferable choice. Maximizing immunization can create a back-lash by enhancing the inherent antagonism of individuals to vaccines. Therefore, authorities are advised to replace their quest for an ideal optimum in protective immunity by settling for a feasible optimum (Sadique, 2006), which balances health requirements and the foreseen consequences of individual behavior.

Another approach towards enhancing personal responsibility is to create an honest and trustworthy dialogue between health care authorities and the public in all matters related to vaccination. The considerations leading to implementation of specific vaccination programs by the state are often complex and require a profound background in several very specific disciplines. Officials are therefore inclined to convey the message of vaccination in an over-simplified manner, which is actually a form of paternalism. This attitude may lead to increased skepticism about vaccination and more resistance. Mechanisms that enhance direct public engagement in infection control may prove to be important for creating public trust and ultimately improving compliance with vaccination. Recent attempts to conduct focus-group discussions with members of the public on issues related to public responses to the H1N1 pandemic (Baum, Jacobson, & Goold, 2009) may prove to be a valuable example.

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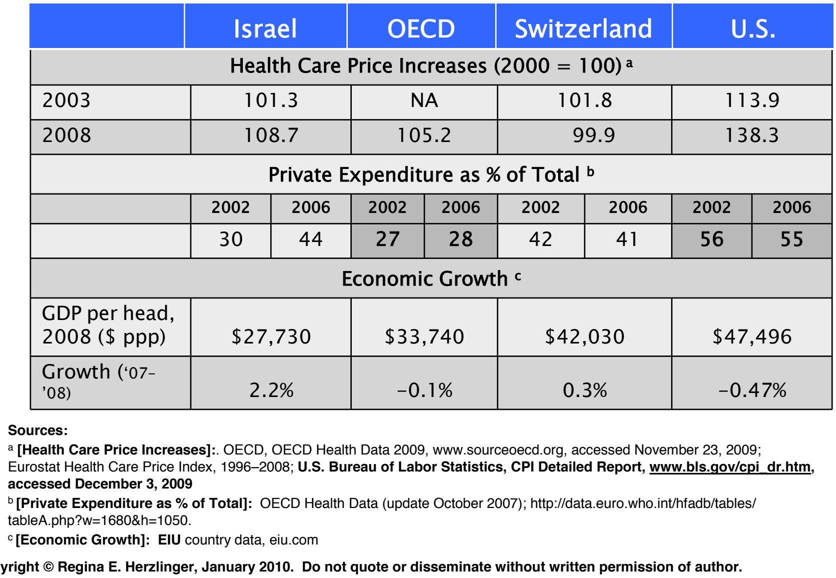
Consumer-Driven Health Care: Conquering Health Care Cost and Quality Demons

Regina E. Herzlinger

Introduction

Large and rapidly growing health care costs, which outstrip the rate of growth of GDP, challenge the economic welfare of virtually all developed counties (Organization for Economic Co-operation and Development (OECD), 2010). Many nations, like the United States, are additionally burdened with the substantial unfunded liabilities of their public health care programs. The U.S. Medicare program's unfunded liabilities, for example, stand at roughly three times the U.S. GDP (Congressional Budget Office, 2010). When it comes to price increases, Israel is no exception. As shown in Figure 1 below, the rate of health care price increases in Israel exceeds that of the OECD.

***Figure 1:** Health care costs – international comparisons.*



	Israel		OECD		Switzerland		U.S.	
Health Care Price Increases (2000 = 100) [a]								
2003	101.3		NA		101.8		113.9	
2008	108.7		105.2		99.9		138.3	
Private Expenditure as % of Total [b]								
	2002	2006	2002	2006	2002	2006	2002	2006
	30	44	27	28	42	41	56	55
Economic Growth [c]								
GDP per head, 2008 ($ ppp)	$27,730		$33,740		$42,030		$47,496	
Growth ('07–'08)	2.2%		-0.1%		0.3%		-0.47%	

Sources:

[a] **[Health Care Price Increases]:**. OECD, OECD Health Data 2009, www.sourceoecd.org, accessed November 23, 2009; Eurostat Health Care Price Index, 1996–2008; **U.S. Bureau of Labor Statistics, CPI Detailed Report, www.bls.gov/cpi_dr.htm, accessed December 3, 2009**

[b] **[Private Expenditure as % of Total]:** OECD Health Data (update October 2007); http://data.euro.who.int/hfadb/tables/tableA.php?w=1680&h=1050.

[c] **[Economic Growth]: EIU** country data, eiu.com

There are three ideas about how to control theses costs. Two of them are **supply-driven**, with either the government (as a single payer) or private insurers (managing care) acting to constrain costs by limiting usage and payments, while the third is **consumer-driven**. All three have their downsides.

Single payer systems often exact such severe deprivations that the more affluent citizens buy private health insurance to escape them. Over half of the Irish and 40% of the Australians, for example, purchase private health insurance whose benefits duplicate those of public insurance but provide enrollees with quicker access to what they believe is better care (OECD, 2010). Again, Israel is no exception. As shown in Figure 1, it has experienced a more rapid rate of increase in private spending than the OECD countries.

For this reason, among others, the vexing and troublesome inequity between rich and poor in the United Kingdom in health status and access has lingered for decades, for example (The Marmot Commission, 2010; Townsend & Davidson, 1982). As for managed care, whatever its merits may be, the U.S. populace revolted against stringent HMOs in the 1990s and it is unlikely to resurface as a well-received cost-control option in most other countries (Herzlinger 1997; Robinson, 2001).

But the policy analysts and technocrats who lead single-payer systems do not embrace a consumer-driven cost-control strategy. Rather, they question consumers' ability to shop for health insurance and, perhaps unconsciously, may be loath to relinquish their unusually powerful role in driving the health care sector.

The Swiss Consumer-Driven Health Care Experience

A review of the results in Switzerland, a nation that is roughly the population size of Israel and is the prime example of consumer-driven health care, may alleviate these concerns. All the Swiss have been required to purchase their own health insurance since 1996. A poor person in Switzerland receives a transfer of funds sufficient to enable her to buy health insurance for herself. Consequently, Swiss physicians do not discriminate, because the poor are indistinguishable to the provider from the average Swiss person. Contrast this with Medicaid in the United States, where often as many as 50% of physicians will not see Medicaid patients because reimbursement rates are so low (Cunningham & May, 2006; Fuhrmans, 2007).

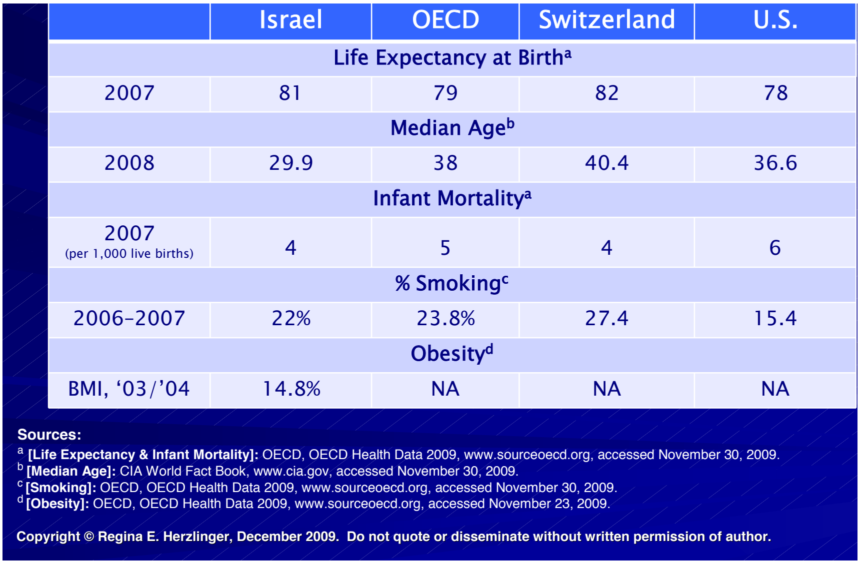
To avoid excessive prices for the sick, Swiss insurers price health insurance by modified community rating – that is, premiums are primarily determined by the average expected expenses in a given community. A 30-year-old woman who lived in Zurich would thus pay the average expected cost for a woman of her age. The insurer who enrolled a healthy version of her at the average price would do well, whereas the insurer who got a sick version would lose its shirt. To resolve the potential adverse selection problem, insurers in Switzerland, with the support of the government, have formed a reinsurance pool, which plucks excess profits insurers earned from healthy customers and redistributes them to insurers who enrolled sick customers.

Switzerland has 87 competitive health insurance firms. Substantial competition among them has caused their general and administrative expenses to average 5% of their premiums, compared to 13-15% in the United States (Statistik der obligatorischen Krankenversicherung, 2007, Table 5.01).

The Swiss have universal coverage, yet they spend only 11% of their GDP on health services and have world-class outcomes and the highest consumer satisfaction (Herzlinger & Parsa-Parsi, 2004). The Swiss system also achieves excellent health status and the greatest health equality in the OECD across socio-economic classes (Leu, Rutten, Brouwer, Rutschi, & Matter, 2008). Because the system relies entirely on private health insurance, Switzerland has no health insurance-related unfunded liabilities. Further, from 2005-2009, Switzerland was the only developed country to achieve no increases in the EUROSTAT health price index (European Commission, 2010).

Although Israel and Switzerland achieve roughly comparable general health care outcomes, as shown in Figure 2, Figure 1 indicates how much faster Israel's health care costs have inflated, relative to those in Switzerland. Further, the growth of private spending on health care, among other data, make it dubious that Israelis enjoy the same level of equality across socio-economic strata as the Swiss when it comes to health care.

Figure 2: *Outcomes of health care systems – international comparisons.*



	Israel	OECD	Switzerland	U.S.
Life Expectancy at Birth[a]				
2007	81	79	82	78
Median Age[b]				
2008	29.9	38	40.4	36.6
Infant Mortality[a]				
2007 (per 1,000 live births)	4	5	4	6
% Smoking[c]				
2006-2007	22%	23.8%	27.4	15.4
Obesity[d]				
BMI, ‘03/’04	14.8%	NA	NA	NA

Sources:

[a] **[Life Expectancy & Infant Mortality]:** OECD, OECD Health Data 2009, www.sourceoecd.org, accessed November 30, 2009.
[b] **[Median Age]:** CIA World Fact Book, www.cia.gov, accessed November 30, 2009.
[c] **[Smoking]:** OECD, OECD Health Data 2009, www.sourceoecd.org, accessed November 30, 2009.
[d] **[Obesity]:** OECD, OECD Health Data 2009, www.sourceoecd.org, accessed November 23, 2009.

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Nevertheless, the relatively large numbers of Swiss hospital beds, physicians, and technology resources per capita are viewed as excessive by experts such as the OECD (2006). The “inefficiency” stems, in part, from consumers’ preferences. Only 25% of the Swiss chose to enroll in HMOs, for example. Had all of them chosen HMOs, Swiss health care costs could have declined by 39% (Bundesamt fur Gesundheit, 2008; Statistik der Obligatorischen Krankenversicherung, 2007, 2008). Tight governmental control of prices and subsidies has caused inefficiency as well (Steinmann & Zweifel, 2003). The Swiss government has limited price competition by mandating a variant of the U.S. fixed price hospital DRG system, enabling collective bargaining for physician prices, and created an unlevel playing field by subsidizing public hospitals (Herzlinger, 2007).

Absent these constraints, the innovations in demand and supply discussed below could take place.

Innovations in Demand: Consumer-Driven Health Insurance

Private health insurance is a remarkably standardized product. Virtually all Americans who receive coverage through their employers are enrolled in a PPO, an insurance policy that imposes additional costs on enrollees who obtain care outside a preferred network of providers, for example. Yet, consumers want much broader varieties of insurance (Deloitte, 2008a)

High Deductibles

The first recent innovation in insurance was the high-deductible policy. In the United States, about 10 million people are currently enrolled in such health insurance policies, which are coupled with tax-advantaged health saving accounts and typically cover 100% of preventive care. Monthly average premiums ranged from a high of 361$ for single coverage and 925$ for family coverage in Massachusetts, to a low of 210$ for single coverage and 461$ for a family in North Dakota (HSA census, 2009). Nearly 30% of those who chose these plans had previously been uninsured because they could not afford more expensive health insurance products ("January 2007 census shows", 2007). Unsurprisingly, roughly half of those with HSAs live in areas whose average income is in the bottom 40% of U.S. communities ("Estimated income characteristics of HSA", 2009).

These plans are not for everyone. In Switzerland - where they have been offered for more than a decade - they represent only 36% of policies, even though they are much cheaper and the Swiss pay for health insurance out of their own pocket (Bundesamt fur Gesundheit, 2008; Statistik der Obligatorischen Krankenversicherung, 2007, 2008). Further, the participants are on average healthier and wealthier than those in other plans (Herzlinger & Parsa-Parsi, 2004).

A RAND study that examined the expenditures and health status of enrollees in high deductible policies, found that middle and upper income people with high-deductible policies spent less on health care without affecting their health status, but low income people enrolled in high deductible policies experienced reduced health quality (Brook et al., 2006).

Paying for Health Promotion

Another new, consumer-driven insurance innovation is that of rewarding financially for healthy behaviors. For example, an entrepreneurial South African firm offers an insurance policy that financially rewards behaviors such as joining gyms, screening for chronic diseases, and smoking cessation. An analysis found that highly engaged members (up to 38% of those enrolled) achieved significant cost reductions resulting from such outcomes as lower rates for cardiovascular disease (7.2%), cancers (5.1%), and endocrine and metabolic diseases (21.4%) (Patel et al., 2010).

Focused Factories: Paying for Innovations in the Care of Chronic Diseases and Disabilities

A third insurance innovation that is likely to emerge in a well-functioning, consumer-driven market is an insurance policy that offers the victims of chronic disease and disabilities a choice of different integrated networks for their ailments, at different prices. Insurers will compete by offering what I have dubbed as health care “focused factories”: providing personalized, integrated health services that focus on the prevention and treatment of chronic disability and disease, personalized diagnostics, and personalized therapy (Herzlinger, 1997).

Business people talk about Pareto’s Law when they say “I’m going to go after the low hanging fruits: the 20% of clients who account for 80% of the market” (Persky, 1992; Stanton, 2006). In health care too, 20% of health care consumers account for 80% of the costs. Many of them suffer from chronic diseases and disabilities. Because their medical needs are so complex, and because typically no single, integrated team for providing all their complex needs exists, their care frequently falls between the cracks (Cohen & Rodhe, 2009; Cohen & Yu, 2009).

As an example of the complex care required, consider diabetes. All body parts with extensive vascularization can be adversely affected by diabetes: the eyes, the heart (the number one cost of diabetes is that of treating heart disease), the kidneys (the number one consumer of kidney dialysis centers are diabetics), the skin, and the feet (Nichols & Brown, 2002). A devastating disease like diabetes also exacts a toll on the psyche: patients need not only medical support but also support for their psychological well-being. Diabetics thus require a network that includes an ophthalmologist, cardiologist, nephrologist, neurologist, dermatologist, podiatrist, exercise physiologist, nutritionist, a social worker, and perhaps a mental health professional. But where can it be found? In most parts of the world, it does not exist, and, because of its absence, only 7% of patients control the primary factors that could alleviate the condition-blood sugar, blood pressure, and cholesterol levels. Poor compliance with diabetes treatments can cause blindness, renal failure, amputations, and other serious and costly complications (Saydah, Fradkin, & Cowie, 2004).

The absence of integrated care for diabetes exacts profound human and financial costs. One program demonstrated that support for behavioral changes, such as nutrition and exercise, could save about 600$ to 900$ annually per patient (Wagner et al., 2001). Is integration of care economically feasible? Consider, for example, a hypothetical small town of 50,000 residents of whom a sixth - about 8,300 people - are typically diabetic. The average diabetic costs 10,000$ a year, so this town spends 83$ million on diabetes per year, a sum that should attract a number of competitive providers interested in providing integrated care.

Duke Medical Center's program for congestive heart failure provides another illustration of the results an integrated network can achieve. Physicians, nurses, and almost everyone else involved in caring for patients with congestive heart failure designed new care protocols so successful that in one year Duke reduced the number of hospital admissions and mean length of stay by improving the health status of the enrollees. The Duke University Health System saved a median of 8,571$ per patient per year (Whellan et al., 2001).

The implications of introducing health care focused factories are profound. Consider, for example, the cost of noncompliance with care regimes. Doctors' advice on a course of treatment is too often misunderstood by patients or ignored. Poor adherence to treatment can have expensive consequences for the patient's health and the costs of care (Sokol, McGuigan, Verbrugge, & Epstein, 2005). Approximately 177$ billion could be saved by improving medication compliance and reducing errors ("Following doctor's orders", 2008).

Policies that promote health and offer integrated care for chronic diseases require a long-term relationship between insurer and insured because destructive behaviors or lack of compliance with regimens for chronic diseases cannot be reversed overnight. In the United States, employers typically prefer not to provide such long-term policies for employees for two reasons. First, they cannot be assured that their employees will remain with them for five years; thus, the employer may never be repaid for costly, early investments in health promotion such as, for example, bariatric surgery for the morbidly obese. Second, employers want to solicit bids for employee-based insurance periodically in an effort to control costs. In contrast, in a consumer-driven health insurance market with individual purchasers of insurance, insurers would face a large market of those who want rewards for healthy behaviors and more effective, convenient sources of care for chronic ills.

The major barrier to the formation of such integrated services is the payment system that currently pays only for fragments of care and primarily for treating sick people (Herzlinger, 1997; Hill, Anerios, & Hogan, 2010). As a result, Duke Medical Center lost substantial sums as it improved the health status of those enrolled in its congestive heart failure program (Whellan et al., 2001). An appropriate reimbursement system would reward health care providers for making people healthier, rather than penalize them, by paying a flat fee, adjusted for the patient's health status (NRHI, 2008). For example, insurers would pay a flat five-year fee, adjusted for the person's health status, to a diabetes-focused factory. This payment rewards providers for improving health status, thus reducing costs, rather than penalizing them, as in the present system. Further, it allows them sufficient time to produce results. Last, the outcomes achieved in a focused factory for diabetics are more amenable to measurement than the outcomes under the existing fragmented system in which no single provider is wholly accountable.

Innovations in Supply: Consumer-Driven Health Services

Two fundamental changes in health services would be accelerated by a consumer-driven system. These are medical tourism, spawned by global competition, and the application of retailing principles to health care delivery.

Global Competition and Medical Tourism

One inevitable transformation resulting from a consumer-driven system is the globalization of health services. The U.S. and European health care systems are so costly that health care providers in countries such as India and Thailand or those in Eastern Europe and South and Central America can easily under price them (Herzlinger, 2009). McKinsey predicts that up to 190$ billion of health care services will leave the United States (Ehrbeck, Guevara, & Mango, 2008). In 2007, 750,000 Americans traveled abroad for medical treatment and an estimated 10 million will do so in 2010 (Deloitte, 2008b).

In India, for example, the price of hospital care is generally 20% of U.S. prices (Deloitte, 2008a). This competitive advantage does not occur solely because the cost of living in India is lower than in the United States. Rather, because India has very little infrastructure – it currently spends only 49$ per person per year on health care – it can create a fundamentally more efficient way of delivering hospital services. Instead of the massive tertiary hospitals that characterize the U.S. and European systems, for example, some of the Indian hospital chains have constructed a hub and spoke model, in which a tertiary hospital is ringed by spokes of specialty hospitals. Some providers also offer fixed prices for every service connected with a medical procedure and a money-back guarantee, in contrast to the United States and European open-ended, a la carte system. This kind of pricing has forced the Indians to carefully engineer their protocols for delivering medical care and to create monitoring and incentive systems for implementing them (Richman, Udayakumar, Mitchell, & Schulman, 2008).

Retail Medicine

A consumer-driven system will also foster two retail innovations: concierge medicine and retail clinics, such as those located in U.S. supermarkets, like Wal-Mart, and drug stores, like CVS.

Concierge medicine enables people to see their doctors 24/7. Many patients have their doctors' cell phone numbers and can schedule same-day appointments. MDVIP, one concierge medicine chain, expects to add more than 80 doctors to its network of 300 this year and claims 93% annual renewal rates among its 100,000 patients. Each MDVIP doctor is limited to 600 patients, who pay them 1,500$ to 1,800$ a year (Sack, 2009). Concierge providers reduce costs by not taking health insurance for non-catastrophic expenses. One study found that physicians' interactions with insurers consume 31$ billion annually (Casalino et al., 2009).

Retail clinics, another retail innovation, are heavily used by underserved populations: in the United States, 40% of its customers are non-white versus 18% for non-users; 28% have a household income of less than 40,000$ versus 16%; 28% do not have a primary physician versus 15% for non-users; and 12% are uninsured versus 6% for non-users (Deloitte, 2008b). These clinics are typically located in retail outlets such as pharmacies and discount department stores, and offer lower costs than emergency rooms or urgent care clinics. Retail medical clinics, in contrast to other providers, also post their prices. One study noted costs 30-40% lower than physician's offices and 80% lower than those in emergency rooms, while quality was equal or better (Mehrotra et al., 2009). Further, because retails clinics are usually part of a chain, they can afford the information technology that allows deployment of the carefully delineated treatment protocols that are often missing in other health care delivery settings (Deloitte, 2008b; MinuteClinic, 2007; Olson, 2008).

The growth of retail clinics should help take pressure off over-crowded expensive emergency rooms, which suffer from overuse at 90% of hospitals (Liebenrood & Pond, 2003). It will also reduce health care costs because care can be provided much more cheaply in such settings, especially care for chronic diseases that these clinics are newly offering (Fast Company, 2010).

Promoting Transparency in Health Care

Health care lacks the kind of data we rely on to make decisions in every other part of our lives. Some who doubt the efficacy of consumers managing their own health insurance thus ask, "How is the consumer going to find good networks or insurers when there is no information?"

To observe what happens in markets without transparency we need only look to the equity markets in 1933, when choosing a stock was like selecting a doctor today. Although accounting was developed in the 15th century, in 1933 there were no generally accepted accounting principles, no transparency, few financial statements, and what financial information existed was virtually impossible to access. Franklin Delano Roosevelt was elected President of the United States in the midst of the Great Depression, and was strongly advised to regulate businesses to cure the problems of the Depression; but he rejected this advice and instead created the Securities and Exchange Commission, which he called the "truth agency" because, to Roosevelt, its purpose was to reveal the truth.

The SEC was supposed to ensure the existence of generally accepted accounting principles, audited financial statements, and ready access to the data (Seligman, 1982; Skousen, 1991). Although it has failed in some of its regulatory functions, the SEC is an acknowledged success in creating the transparency that has reduced the cost of capital and improved the allocation of resources (Baiman & Verrecchia, 1996; Diamond & Verrecchia, 1991; Hail & Leuz, 2006; Kim & Verrecchia, 2001; Lambert, Leuz, & Verrecchia, 2007; Leuz & Verrecchia, 2000; Verrecchia, 1999, 2001).

The key to achieving these desirable characteristics is legislation for a health care SEC that replicates these essential elements of the SEC model:

- Create an independent agency with a singular focus. The SEC is an independent agency charged solely with overseeing the integrity of securities and the exchanges on which they are traded. Because of these clear goals and organizational characteristics, the SEC's mission is not muddied and it can be held clearly accountable for its performance (SEC, 2009).

- Focus on outcomes, not processes. The SEC focuses on measuring the *performance* of organizations. President Franklin Delano Roosevelt firmly rejected dictating business *processes* or rating businesses as appropriate roles for the SEC.

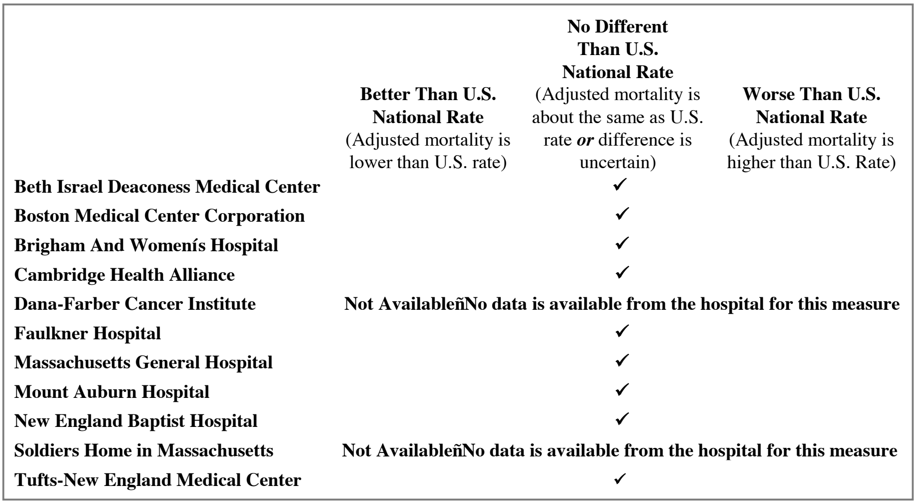
- Perform private-sector analysis. The evaluation process is primarily conducted by private-sector analysts, who disseminate their frequently divergent ratings. To encourage similar private-sector health care analysts, the new agency should require public dissemination of all outcomes for providers, including clinical measures of quality and related transaction costs.

- Make effective use of penalties. The SEC requires firms that trade their securities in interstate markets and all such market makers to register with the agency. A corresponding health care agency would oversee the integrity and require public disclosure of information for entities that provide health insurance and services. Like the SEC, it would be armed with powerful penalties for undercapitalized and unethical market participants, including imprisonment, civil money penalties, and the disgorgement of illegal profits (SEC, 2009). These penalties would have the serendipitous benefit of making the independent agency self-supporting financially. The SEC is essentially a profit center, generating a substantial surplus from its filing and penalty fees that offset its billion-dollar budget. A health care version of the SEC could be similarly self-financed, offsetting its expenses with filing fees and fines collected from its constituency.

- Mandate private-sector disclosure and auditing. The SEC relies heavily on private-sector organizations that contain neither governmental nor business representation. The new health care agency should similarly delegate the powers to derive the principles used to measure health care performance to an independent, private, nonprofit organization that, like the Financial Accounting Standards Board, represents a broad professional constituency and is squarely aimed at consumer protection. The agency should require auditing of the information by independent professionals who would render an opinion regarding the accuracy of the information. Also, because such independent organizations are organized as partnerships, not corporations, partners would bear personal legal liability for failure to disclose fairly and fully.

Some commentators question whether the United States should create an independent agency that provides data on health care pricing and quality. To answer this question it is instructive to examine data provided by Massachusetts with its brave, consumer-driven experiment in universal health insurance, to inform consumers who are buying health insurance or looking for a network. Table 1 contains data for hospitals' 30-day-risk-adjusted mortality rates for heart attack, indicating whether they are above average, average, or below average.

Table 1: *Hospital 30-day risk adjusted death from heart attack.*



	Better Than U.S. National Rate (Adjusted mortality is lower than U.S. rate)	**No Different Than U.S. National Rate** (Adjusted mortality is about the same as U.S. rate ***or*** difference is uncertain)	**Worse Than U.S. National Rate** (Adjusted mortality is higher than U.S. Rate)
Beth Israel Deaconess Medical Center		✓	
Boston Medical Center Corporation		✓	
Brigham And Womenís Hospital		✓	
Cambridge Health Alliance		✓	
Dana-Farber Cancer Institute	**Not AvailableñNo data is available from the hospital for this measure**		
Faulkner Hospital		✓	
Massachusetts General Hospital		✓	
Mount Auburn Hospital		✓	
New England Baptist Hospital		✓	
Soldiers Home in Massachusetts	**Not AvailableñNo data is available from the hospital for this measure**		
Tufts-New England Medical Center		✓	

The rates displayed in this table are from data reported for discharges August 2006 through August 2006.

It seems implausible that every single hospital would be average, as indicated in the table. These data provide an example of what may happen when a political entity issues outcomes information: the data may become so nonspecific that they are essentially meaningless; perhaps because of political pressure from providers. The visibility of an independent transparency agency, on the other hand, would minimize the agency's ability to water down the data.

The Role of Government in Creating a Consumer-Driven Health Care System

What is the appropriate role of government in consumer-driven health care?

Normally, a government's role in sectors of the economy is that of enforcing anti-trust and consumer protection laws, guaranteeing transparency, preventing fraud and abuse, and enabling income redistribution, so the poor and disabled can participate equally. In contrast, the role of government in virtually all current health systems is to set prices, coverage limits, and benefits. Increasingly, it also tells physicians how to practice medicine.

In a consumer-driven health care system, government would return to its normal functions of protecting the consumer through regulation of anti-trust, fraud, and abuse, and enabling transparency and redistribution, rather than managing the delivery of their medical care.

If a consumer-driven health care system were implemented in Israel, consumers could continue to enroll in HMOs, if they chose; but they could also select from high deductible and health-promoting private insurance plans, which control costs by encouraging consumer responsibility. Because the health insurance industry is highly entrepreneurial and not very capital intensive (Herzlinger, 2008), new private firms could easily originate to offer these policies. And, unlike the existing HMOs, these new plans would be supported by private capital.

Israel's health care expenditures, at 2,048$ per capita and 7.7% of GDP in 2007, are substantially lower than those of Switzerland, at 4,417$ and 10.8% of GDP. But Switzerland has the greatest equality among OECD countries across income strata, unlike Israel, which experienced massive growth in its private expenditures, and has experienced no inflation from 2005-2009 (Central Bureau of Statistics, 2009), again unlike Israel, which has experienced substantial price growth.

The ideas and recommendations presented in this paper are relevant to countries such as Israel. Clearly, in light of cross-national differences in health system organization, culture, and social policy, any transference of ideas cannot be made automatically. I invite Israeli government officials and policy experts in other countries to work with me to explore the potential of the consumer-driven health care approach there.

To Your Good Health!

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Individual-level Incentives: Equity Issues

Harald Schmidt

Introduction

Incentives increasingly play a role in the organization of health systems internationally. A range of pay-for-performance initiatives seek to maximize quality and efficiency of hospitals and physicians by rewarding specific results rather than just service provision. Incentives are also of growing interest for guiding the behavior of individual healthcare users. Value-based insurance design seeks to steer patients toward the right interventions through differential co-payments, with the aim of reducing both over- and under-utilization. So-called wellness incentives offer individuals monetary or in-kind benefits as rewards for looking after their health, or for taking part in prevention or health promotion programs. Typically, the assumption behind such initiatives is that the respective activities help promote good health and contain healthcare expenditure. Whether or not such schemes can be seen as fair policies depends significantly on the way they are implemented. They can become unfair where the benefits at stake are substantial, and where some groups of people find it significantly more difficult than others to make use of them.

In the U.S.A., formal cross-departmental policy on wellness incentives was introduced in 2006 by the Departments of Labor, Treasury, and Health and Human Services (DoL, DoT, & DHHS). In considerably expanded form, wellness incentives also feature in the Senate Health Reform Bill (the “Patient Protection and Affordable Care Act” of December 24, 2009). Current and proposed policy distinguishes between two principal forms of incentives. First, in what can be called “participation-incentives”, a premium discount, rebate, or reward may be given for participating in a scheme such as an exercise, weight-loss, or smoking cessation program. Secondly, in what can be termed “attainment-incentives”, a reimbursement may be given for meeting certain health status targets relating to risk factors such as Body Mass Index (BMI) or blood pressure. Currently, for attainment incentives the law permits insurers to provide reimbursements of up to 20% of the total cost of an employee's coverage (i.e., the employee's premium plus the employer's contribution) (DoL, DoT, & DHHS, 2006). Under the Senate proposal, these levels would be increased to 30%, with the option of 50% for particular initiatives, subject to approval by the relevant Departments. Other countries, such as Germany, have similar systems in place, although the levels of incentives are usually much lower than in the U.S.A., and there is no explicit recognition of different issues being raised by attainment and participation incentives (Stock et al., 2010).

The use of incentives to influence individual behavior has been implemented widely outside of health policy, especially for marketing purposes. For example, many airlines and supermarkets provide discounts for frequent flyers and shoppers in the hope that this will encourage customers to become more loyal. Levels of incentives are calculated in such a way that their costs are offset by customers' increased purchase of goods and services. Enrollment in these programs is generally easy and straightforward, and customers usually agree (or not) to take part at the point of purchase. Those not wishing to make use of the offer generally lose out on some benefits, such as reduced prices. On the whole, equal access and the voluntary nature of the agreement mean that no significant fairness issues are raised. However, problems can arise when this model is applied to the healthcare context. One of the main reasons is that it is not equally easy for all groups who are offered incentives to avail themselves of the opportunities. The impact of incentives on behavior change also differs across groups.

Questions Around Behavior Change, Desert, and Luck in Five Different Groups

Below, I suggest that it is useful to distinguish between five groups of people when we consider the impact of wellness incentive schemes (whether these are attainment or participation incentives). These are: (1) the "lucky ones", (2) the "yes I can" group, (3) the "I'll do it tomorrow" group, (4) the "unlucky ones", and (5) the "leave me alone" group. Depending on the exact characteristics of the scheme, the effect on these groups will, of course, differ, and some policies may affect some groups more than others. Nonetheless, a somewhat more abstract consideration of the features of different groups is still useful for bringing clarity to the ongoing debate about how to assess the acceptability of different incentive schemes.

First, the “lucky ones”: for practically any program that universally offers benefits for certain behaviors or meeting health indicator targets, there will be a group of people who would qualify without changing their behavior in any way. Some people may simply enjoy eating healthily and exercising regularly, and they do so quite effortlessly. Their behavior is hence compatible with the spirit of a wellness incentive program, but the availability of an incentive has no effect on their actions. Others whose actions may remain unaffected may include people whose dispositions are not as well aligned. For example, some people may eat in the most unhealthy ways, never exercise, and still have a favorable Body Mass Index (BMI) or cholesterol level, or meet other criteria judged to be positive health indicators. Despite the dissonance between their motivations and the spirit of the incentive program, they too may reap the exact same benefit as their health-conscious counterparts. For both, therefore, a financial or other benefit is no doubt welcome, but it may not alter in any way their motivations or behavior. Especially in the latter case, it makes little sense to call the benefit that is offered a reward, and questions may also be raised about whether it is appropriate to offer benefits to people who do not need them in the first place.

Secondly, there is the “yes I can” group: in this group there are people who would not normally have performed the benefit-qualifying behavior, but they see the incentive as a welcome occasion (though not the main reason) for trying to overcome inertia or weakness of the will. Their underlying motivation, coupled with the incentive benefit, which provides a helpful “nudge”, creates an effective basis for action. For this group, incentives are likely to feel like a deserved reward, and may help them initiate behavior change in the first place, or sustain it, where their intrinsic motivation is not yet sufficiently developed. It is not uncommon for planners of incentive programs to tacitly assume that all people exposed to incentive programs are either in the “yes I can” group, or otherwise simply refuse to participate. However, this can often be a mistake, as the next group illustrates.

The “I’ll do it tomorrow” group comprises people who are similar in motivation to the “yes I can” group, in the sense that that have a desire for behavior change. But, for a range of reasons, they simply cannot bring themselves to act on this desire. They fail regularly when they try, and may often not even feel able to try. The reasons may include unfavorable opportunities they face in their everyday life, such as poor access to affordable and healthy food, or insufficient time to prepare it. Equally, it may be that they have no safe and readily available facilities for physical exercise, or very little time, in view of other commitments. And people differ in the way they have been brought up: some received more encouragement to be self-motivated and -efficacious, and others less. The benefits offered as a reward may be extremely tempting for many in this group, yet they are as far out of reach for them as the branches of the fruit-laden trees were for the proverbial Tantalus. Although the incentives may be a helpful carrot for the “yes I can” group, for the “I’ll do it tomorrow” group they may have more of a frustrating “stick” character. They see that the “lucky ones” and the “yes I can” group reap benefits – but this advantage is their disadvantage, as they find themselves penalized for being unable to secure the benefit. Moreover, while they might even agree that people who voluntarily pass up an opportunity to secure an advantage should suffer a penalty, what makes the stick in their case unfair to them is that they differ in no way in their desires from the “yes I can” group, but just find themselves unable to act on them, due to strong constraints that have a powerful grip on their agency.

Fourth, there are the “unlucky ones”: here we have people who, for biological, medical, or other reasons that are completely external to their volition, face such strong constraints that, whatever they would do, they are simply unable to meet the criteria associated with particular attainment- or participation-incentives. For example, some people with genetic mutations will always be obese, regardless of how much they exercise or control their energy intake. As for the “I’ll do it tomorrow” group, carrots that are simply out of their reach will not make sense to them, and will feel more like penalizing sticks. However, while, in the case of the “I’ll do it tomorrow” group there may be arguments about the extent to which people are or are not in fact able to secure the carrot, there is simply nothing the “unlucky ones” could possibly do to meet the standards required for the benefit. And the measures are likely to feel even more unfair to them, for not only do they face poorer health associated with their condition, but they also have to accept higher healthcare costs, if they have no other chance to meet the program criteria required to access the benefits. Lastly, there is a fifth section, that can be called the “leave me alone” group: here, as in the first group, we have people who, in principle, would qualify for incentives that are offered, either because they already meet the required thresholds for health indicators, engage in activities that have a reimbursement attached (such as an active gym membership), or could easily do so. However, for a range of reasons they may not wish to make use of the offer, perhaps because they cannot be bothered to comply with the relatively minimal bureaucracy; or because they feel patronized or nannied; or because they object to introducing competitive elements in a scheme that they might view as being based on a principle of fair risk-sharing or solidarity, which may be undermined, if some stand to reap greater benefits than others.[1]

Equity Issues

As this conceptualization shows, depending on the precise implementation, universally offered wellness incentive programs may face several general problems, including the following:

- Some people may receive benefits, even if their motivation and behavior run counter to the spirit of wellness programs;
- Some people may receive benefits, even though the incentive does not function as an incentive: the benefit is given for default behavior – whether this is the result of deliberate prior choice or unreflective habit;
- Some people face constraints due to weakness of the will, poorly developed self-efficacy, or strong medical or societal constraints. Where they fail to achieve the requirements of an incentive program

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[1] Of course, such reasons may also play a role in the deliberations of the “I’ll do it tomorrow” group and the “unlucky ones”. The purpose of setting out the groups in this way was, however, to bring out the clearest distinguishing features between the main groups, rather than to try and provide a wholly exhaustive and exclusive set of categories.

> (or fail to attempt to achieve it) they must forgo the benefit in the same way as those who had sufficient opportunity of choice but consciously decided not to take part.

To some extent, differences between groups have already been recognized, but in terms of preventing unfairness this recognition is limited in significant ways. For example, in the U.S.A., the current policy specifies that where it is “unreasonably difficult due to a medical condition .... [or] medically inadvisable” to take part in attainment incentive programs, a reasonable alternative standard must be provided, so that individuals can qualify for a reimbursement (DoL, DoT, & DHHS, 2006). Accordingly, where BMI targets are used, and reaching these is judged inappropriate, individuals may be asked to follow physician-designed diet and exercise programs, which can serve as an alternative standard. Plans are not required to offer alternative standards on their own initiative, but are obliged to advertise their availability, and to respond to individuals who feel they cannot meet the standards with appropriate options.[2] The aspiration behind the provision is laudable, but whether it is sufficient to ensure fairness is not clear and at least subject to empirical confirmation. First, the response-mode action may disadvantage people who generally find it challenging to act in self-efficient ways – and people in need of an alternative standard may be more likely to have this problem. Secondly, people may feel that such petitioning is embarrassing or humiliating, and perhaps not come forward for these reasons. While the U.S. approach therefore has some problems, it needs to be noted that in Germany, where a broad range of incentive programs has been offered since 2004, law and policy have no provisions whatsoever on alternative standards – here people who are unable to meet attainment standards simply lose out on the opportunity.

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[2] The regulations specify that the following wording is sufficient: “If it is unreasonably difficult due to a medical condition for you to achieve the standards for the reward under this program, or if it is medically inadvisable for you to attempt to achieve the standards for the reward under this program, call us at [insert telephone number] and we will work with you to develop another way to qualify for the reward.” (DoL, DoT, & DHHS, 2006).

The provision of alternative standards also draws attention to the wider question of which factors should count in responding to people who find it challenging to meet attainment incentive standards. On this issue, both the U.S. and German regulations seem to be content to view the "I'll do it tomorrow" group as equivalent with the "leave me alone" group, for they treat as equivalent those who try and fail, and those who could try, but decide against it. In other words, they equate failure to begin or complete an incentive program for reasons of lack of opportunity or self-efficacy with the voluntary choice that is based on ideological opposition to the goals or means of the program. This is problematic, in particular in view of the fact that poorer people are generally less healthy and more likely to face external constraints. Although they would be more in need of health improvement, they are less likely to benefit. Additionally, by losing out on the benefit they may face an economic disadvantage that matters more to them than to those who are better off. The social gradient is certainly noticeable if we consider uptake of incentive schemes. For example, in Germany, approximately 30% of the most privileged used incentive programs in 2009, as opposed to 14% of the least well off, while health was generally poorer among the worse off (Schmidt & Doran, 2010). Moreover, both German and U.S. policy also permit people who did not actually change their behavior (the "lucky ones") to receive the same benefits as those who did. While, arguably, behavior change is always difficult, overcoming this difficulty is not rewarded in proportion, as incentive levels are identical for all. Therefore, those facing fewer obstacles stand a much better chance at securing benefits than those for whom it is harder.

Of course, to some extent, the responses of the five groups (and the extent of the fairness or unfairness of policies that determine the chances of individuals to benefit – or not – from incentive programs) will also be affected by the size of the benefit, and the exact way in which a program is implemented. For example, using the above example of the U.S. policy on wellness incentives, employers could simply hold premiums constant for all, and offer some modest rebates for those taking up the programs, perhaps under the assumption that future savings that may result from better health will be such that they offset the reimbursement costs. It is also conceivable that incentive benefits are not linked to insurance contributions at all, for example where a third party, such as a charitable foundation, provides the funds for the reimbursements. Such situations would alter the playing field, and perhaps we should not worry too much about the possibility of unequal uptake. However, the 2006 Regulations also explicitly note that incentives may be implemented by imposing, in effect, differential premiums: accordingly programs may shift costs “from plan sponsors to participants who do not satisfy the standards, from participants who satisfy the standards to those who do not, or some combination of these.” (DoL, DoT, & DHHS, 2006). If we draw on the current 20% thres hold and assume the average cost of coverage is 4,500$, the regulations would therefore, in principle, permit an increase in premiums of 940$ (30% would equal 1410$ and 50%, 2350$), which could be reduced only by meeting the criteria of the incentive program. These amounts are considerable, and are likely to have a significant effect on affordability of healthcare.

Policy Response Options

Irrespective of the question of determining the right levels of incentives – which generally simply have the function of amplifying ethical tensions, where levels are higher – there are four principal ways for responding to unequal distribution of benefits: (1) to continue to offer incentives universally, (2) to offer them universally but with modifications, (3) to offer targeted, instead of universal schemes, and (4) to abandon incentive programs altogether, and focus instead on other ways of improving population health, such as public health measures.

Accordingly, with a view that is similar to the German situation, one could argue that as in other areas of social policy, people simply differ with regard to their uptake of opportunities, and that differences between groups do not matter sufficiently to warrant a response in policy to level out the benefits. In this view it is acceptable to continue to offer incentive schemes universally, with identical benefits for all. However, proponents of this view ought to justify on what grounds it should be acceptable for the “unlucky ones” to lose out, and equally, whether it should be acceptable for some among the “lucky ones” to reap benefits if they comply with the letter of the policy, but not its spirit. It would also be desirable to justify why the “I’ll do it tomorrow” group, with the same aspirations as the “yes I can” group, should be treated identically to the “leave me alone” group.

Secondly, one could accept that differences between groups do matter, and that they demand a response in policy. One could adopt a modified version of the U.S. policy and offer incentives universally, but seek to adapt the system in such a way that it is more responsive to the particular circumstances of people's motivation and agency. In this view, the provisions for alternative standards go in the right direction in preventing unfairness, but, as noted above, require further thought. Moreover, they also beg the question of whether similar provisions should not be offered to some or all in the "I'll do it tomorrow" group. Clearly, however, in seeking to make adjustments for people's individual circumstances, the approach faces administrative and other challenges that need to be considered, as making assessments can be time consuming and would need to be done in a way that does not introduce any arbitrariness. Further modification could include a change in focus from attainment to participation incentives, which raise fewer of the thorny issues related to the social determinants of health. Alternatively or additionally, incentive levels could be adjusted in a way that is responsive to the need for behavior change, with higher incentives for those who need to make considerable changes, and lower ones for those who already comply with the criteria of schemes. De-coupling reimbursements from the direct cost of healthcare coverage, for example through external funding for the reimbursements, could also help in preventing affordability issues for those who are least well off in terms of health and wealth.

Third, one could again accept that inequalities in circumstance and capacities matter and demand a response in policy, but go further and conclude that the most appropriate way to avoid unfairness would be to abandon universal schemes, and focus on targeted ones instead. For example, one could argue that incentives for the "lucky ones" at the expense of the "I'll do it tomorrow" and the "unlucky ones" are highly inequitable, and merely exacerbate existing inequalities in terms of health and economic status. Furthermore, as incentives are generally touted as a means of improving health and reducing cost, it could be argued that it only makes sense to focus efforts on those most in need, as, after all, the "lucky ones" do not need further encouragement. Instead, resources could be invested to provide stronger and more adequate incentives for the "I'll do it tomorrow" group and to provide proactively adequate alternative standards for the "unlucky ones": for if the health of these groups could be improved, overall healthcare expenditure might be reduced, paying off the reimbursements. Insofar as incentives are financed through cost-shifting among insurance holders, this approach would turn the current situation on its head: whereas currently, people of poorer health indirectly finance the benefits of the better off, the inverse would be the case here – a move that is, of course, likely to be controversial.

Fourth, and most radically, from an “abolitionist view”, one could argue that the concern with eliminating inequity should be thought to its ultimate logical consequence: if there are no incentive programs, there is no inequity that would arise from them. Moreover, resources that would not be used for incentive reimbursements and their administration would be available for other interventions, such as public health programs. However, an important objection to this approach would be to argue that it is not clear that incentives could not be used in a way that promotes equity. Equally, human psychology is notoriously complex, and – complementing genuine efforts at the level of the social determinants of health – incentives may well be highly effective tools for some people to initiative behavior change. This approach would therefore be strongest if it was able to demonstrate the equally effective alternatives that are available.

Conclusion

As briefly noted above, there is a very wide range of activities that can be the subject of incentive programs. Equally, there is a range of ways in which incentives can be implemented, for example with or without cost-shifting and thereby indirectly increased insurance contributions, with high or low levels of benefits in cash or in kind, and so on. In addition, I have suggested elsewhere (Schmidt, 2008, 2010) that further to an equity assessment, a fuller review of the appropriateness of incentive programs also needs to scrutinize several other factors, including: evidence and rationale (what are the policy’s principal goals?); intrusiveness and coerciveness (can the objectives be achieved in less obstrusive means?); and affected third parties (does the implementation interfere with relationships such as those between physicians and patients, or employees and employers?). Clearly, then, a case by case assessment is required, and it is difficult to come to general conclusions in the abstract. However, the principal point to be made here was simply to clarify that in planning, conducting, and evaluating incentive programs it is necessary to understand that there are groups beyond the “yes I can” and “leave me alone” groups, and that fairness requires us to consider the impact of policies on all relevant groups. Whereas incentive programs in the case of loyalty card schemes raise few, if any, fairness issues, as all are broadly equally able to avail themselves of the benefits, the transfer of the approach to the health context does raise significant fairness issues, as health-status is deeply correlated to the genetic lottery and peoples’ socio-economic position, which also influences their capability for self-effectiveness and agency. The outline of the four policy options above was intended to illustrate some of the equity implications of different responses to inequalities between the five groups.

While I am most sympathetic towards the second option, which clearly would require fuller justification than can be given here to be persuasive, it needs to be emphasized that justification for any stance depends both on clear conceptual arguments and sound empirical evidence. However, regarding evidence on the uptake of different socio-economic or health status groups, countries such as Germany or the U.S.A. do not require those implementing wellness incentives to gather and analyze data. In Germany, in particular, the emphasis is almost exclusively on economic aspects. Sickness funds are required to demonstrate that the programs have led to cost savings, as the law provides that incentive reimbursements may only be provided if overall costs as a result of program participation have been reduced.[3] This focus is misguided, not only because of the questionable assumption that prevention will always save cost (Cohen, Neumann, & Weinstein, 2008), but also because it would seem bizarre and counterproductive to wind up incentive programs that prove to be effective in motivating behavior change and improving people’s health simply because costs have not been reduced. It would therefore be desirable if future provisions for evaluations focused less on return on investment, and more on the effect of

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[3] Cf paragraph 65a in Sozialgesetzbuch V - SGB V (Social Security Code), 1988, last revised Jan 2007.

programs on factors such as health status, behavior change, implications for the physician-patient relationship, and uptake of different groups. Data in these areas are as crucial for the justification of individual incentive programs as for assessments of the appropriateness of the approach in general terms.

While incentives are often framed as uncontroversial as they merely provide opportunities that people are free to take up or not, the brief discussion above has illustrated that this assumption must often be questionable. Carrots can rapidly turn into sticks, and simply insisting that, nonetheless, they are carrots, is less helpful than demonstrating that all have a fair chance at securing the benefits. One aspect of providing such a demonstration would be to justify explicitly how the different attitudes, capacities, and needs of the five groups noted above should be considered.

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Personal Responsibility – Is it Ethical?

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Introduction

The practice of medicine had changed greatly by the dawn of the 21st century, necessitating a reciprocal transformation in healthcare policy. Rising costs due to increasing numbers of chronically ill patients, the costs of novel technologies, and public expectations require skillful allocation of healthcare budgets. Responsibility for a patient, once solemnly imposed solely on the physician, is now considered to be shared by the patient himself. This co-responsibility is the prevailing idea currently emerging from Western health economies such as Germany and the United Kingdom.

The German Social Security Code, Book V, clearly states the insured has co-responsibility for their health – a statement that sounds both logical and applicable, as patients who do not adhere to a healthy life style or their physician's advice, must bear some responsibility for the consequences of their behavior. What seems logical, however, is not always ethical. The question of personal responsibility imposes grave ethical dilemmas on healthcare policymakers.

In this chapter we discuss the changes in healthcare practice over the 20th century that have led to the philosophy of co-responsibility. We challenge this social democratic approach to healthcare delivery by elaborating the ethical dilemmas that arise, mainly feasibility, cultural and religious views, personal freedom, equity, and evidence-based medicine.

The goal of this discussion is not to rule out the concept of co-responsibility but, rather, to put the ethical problems arising from it on the agenda in order to further the discussion. Only an open-minded debate and awareness of the inherent problems involved with the imposition of co-responsibility can create an ethical outcome.

“Reform in the Age of Romanticism”

At the end of the 19th and beginning of the 20th centuries, the face of the health care system underwent a change (Ben Nun & Afek, 2009). Scientific discoveries expanded the physician’s knowledge and insights into patient complaints and disease processes, giving the doctors new and effective tools to treat patients and prevent sickness. Improved hygiene, living conditions, and diet each contributed towards lowering the rate of sickness from many of the infectious diseases.

The advancement of technology and science during the same period made it possible to provide effective treatment for illnesses that just a few decades ago caused high mortality rates, even in healthy people. The medical world refrained from disclosing the budgetary constraints for these treatments. Decisions regarding who would receive medical treatment and how much were made on the basis of professional medical expertise. Most health needs were provided by the expansion of health resources. The most important factor in the non-provision of medical service was the doctor’s shortcomings in knowledge, and technological ability to provide it. There was no significant disparity between the abilities of medical science, the doctors, and their ability to operate accordingly. The Romantic period was characterized by a vision that believed that the right to life and health is a basic right to be guaranteed to the whole population, without regard for the cost of medical treatment (Beveridge, 1942).

Health services, as characterized during the “Romantic” era, expressed the zenith of medicine as a profession of limitless horizons. Physicians were surrounded by a halo of professional confidence and trust. The physician gave his opinion and in his hands was the power to determine the appropriate medical treatment for each patient, without taking economic considerations into regard when making medical decisions (Afek, Milek, & Rotstein, 2009)).

The End of the 20th Century and Beginning of the 21st Century – The Decline of the Romantic Era

Like other idealistic world views, the "Romantic" period in medicine shattered in the face of reality.

In the second half of the 20th century, especially towards the 1970s, a number of demographic, economic, and scientific developments began to encumber the Romantic approach to health care: mainly the aging of the population, the accelerated pace of developing technology, improved quality of life and greater public request – all of these factors increased the demand for health services, resulting in substantially larger national expenditures for health care, as one of the largest expenses in western countries (Ben Nun & Kidar, 2007).

For example, in 1970, Switzerland spent 5.5% of its Gross Domestic Product (GDP) on health, by 2006 its level of spending had more than doubled to 11.6% (Ben Nun & Kidar, 2007). Life expectancy increased significantly during this period, and led to increased numbers of elderly and those afflicted with chronic illnesses among the population. The increase in life expectancy is a result not only of improved clinical care but rather to improvements in sanitation, nutrition, and widespread public education.

Decreased fertility rates led to negative population growth in Europe and intensified the economic problems involved in these demographic changes. Along with the rise in the age 65 and over population (in Italy 19.3% in 2005) (Ben Nun & Kidar, 2007) and those suffering from chronic disease, the active and productive population fell. These factors contributed to the rise in national health expenditures, and to the decrease in the tax-paying population burdened by the need to finance the health care needs of the entire population.

The second significant factor in rising health care costs is the remarkable pace at which technology is developing. Science places more and more diagnostic and treatment tools at the disposal of the doctor, the cost of which only continues to rise. The cost of developing new drugs today reaches hundreds of millions of dollars. What were once considered technologically innovative machines become rapidly outdated.

The third reason for the rise in national health care expenditures is the rise in the standard of living with the public's increased expectations and demands from the health system. At the beginning of the 20th century, medicine was practiced by the individual physician, autonomous in his practice and his judgment. Patients usually accepted their physician's opinion without question or appealing to another physician. Today's physicians are part of a team that includes a wide range of medical professionals, which affects the therapeutic outcome. All medical teams undergo lengthy and complex training procedures with an emphasis on continually improving their ability to perform. While medicine continues to try and encourage the "halo" surrounding the integrity and professionalism of its physicians, the world in which they practice demands they change their approach. Today's physicians treat patients who are educated, exposed to the media and the Internet. Many patients request explanations and will consult with other physicians.

The transformation from suffering patient under treatment to informed consumer increased the demand made on the world's health systems.

In summary, demographic changes, the rise in the rate of the elderly population and those suffering from chronic disease, the technological advancements in diagnostic and therapeutic procedures, along with the rise in the standard of living, are all major factors in the continuing rise of national health care expenses (Ben Nun, Berlovitz, & Shani, 2005; Maccabi, 2008). Demand for health services is growing at a greater rate than the economy of the western countries, creating a disparity between the potential capabilities of medicine to heal and its availability to do so for everyone.

Beginning in the 1970s, the phenomenon of "shortage" took hold and applied to health services as well as to other areas in the economy. The concern for saving a life, or the more common issue of prolonging life and improving a person's quality of life, was becoming a matter dealt with in terms of cost, expense, and percentage of GDP spent on health.

In this new reality, the health services had to compete for resources with educational services, social services, defense and security spending, industry and trade, and immigration services. None of the richest economies could cope for long with the ever-increasing rise in demands. It became impossible to provide all citizens, from public coffers, with everything that medical science could offer. The idealistic romantic perception of medicine ("everything for everybody") that was prevalent in the previous decades had reached the end of its path.

The Post-Romantic Era in Medicine

With the end of the Romantic era and the decline of the idealistic notion of giving "everything for everyone", there remained two possible strategic solutions to devising a health care policy: "everything for some" or "some for everyone" (National Institute, 2003):

"Everything for some": The Liberal Approach to Social Welfare and Health The Liberal approach to social welfare and health advocates giving everyone equal chances and opportunities to develop their potential, and contribute and/or acquire material wealth as they choose. The State maintains its involvement to the necessary minimum, extending a security net only as the last line of protection for those who are unable to attain minimal medical services for themselves. The Liberal world view negates universal rights to medical care and prefers to do the minimum in caring for the weak. The leading example of the implementation of this approach is the liberal funding of the health system in the United States, where there are no universal health care rights, and the State provides health coverage only for the weakest populations (Medicaid and Medicare, which cover the poor and the elderly). American citizens purchase their own commercial medical insurance through their employer, who provides collective coverage policies, which are annulled when the employee is terminated or changes jobs. The Liberal approach to health care policy believes in the ability of market forces to provide all possible medical services available to the segments of the population that is able and willing to pay for it ("everything to some"). The price of excellence in medical knowledge and technology erode solidarity and raise expenditure levels: The dependence between the individual's financial resources and the delivery of health services in the U.S. health system is tight. Some of this population finds it difficult to pay, from their own pockets, the price of medical treatments in the United States, which can cost hundreds of thousands of dollars. On a national level, the United States spends more on health care than any other country in the world, both relative to the rate of national GDP expenditure (16%), and in the rate of health care spending per capita (signified in dollars by the term used to denote the strength of purchasing power: Purchasing Power Parity - PPP) 6,714$ in the United States compared to 1,943$ in Israel, and less than 4,000$ in countries such as Canada, Australia, Belgium, France, Holland, Germany, Denmark, Sweden, Britain, and Japan). Despite the higher rate of spending on health, the overall level of health for most of the U.S. population is less when measured by standards such as life expectancy, infant mortality, or immunization rates, than those of citizens in countries who participate in the Organization for Economic Cooperation and Development (OECD).

“Something for Everyone”: The Social-Democratic Approach to the Health and Welfare State

The second method of solving the wide disparity between the capabilities of medical services and the possibility of financing those capabilities to reach everyone, is the Social-Democratic approach. This approach guarantees a reasonable, publicly funded basket of defined and limited health services to the entire population. The Social Democratic approach emphasizes not only equality of opportunities, but equality of access and outcomes, while guaranteeing universal rights in a defined basket of health services. In most western countries, including Israel, the Social-Democratic view of public welfare, “something for everyone”, prevails. In these countries there is a basket of health services that represents only a partial range of medical services (“some” or “part of”), which is provided to the entire population (“to everybody”). The services are utilized according to an individual’s own health needs and not according to the financial resources at his command. Israel’s National Health Insurance Act of 1994 (www.health.gov.il) illustrated the “something for everybody” ideology. The legislation was based on fairness, equality, and social solidarity, to guarantee provision of medical care to all citizens by health maintenance organizations (HMOs) with a defined, publicly funded, reasonable basket of health care services. There is a division between the ability to pay (health care tax and income tax, which are based on and deducted from wages), and the right to receive medical care. These principles apply in most of the western countries - by way of the national health care services in Britain, Denmark, Sweden, and Norway (European Observatory, 1999, 2004-2007), or by way of public health insurance systems (e.g., Germany, France) The guiding principle for the majority of health systems in western countries is the need to define the basket of services based on the national economic resources of each country.

In summary, the “post-Romantic” era requires confronting the disparity between necessity and capability. There are two world views that can cope with this disparity: the first (“something for everybody”) sees health as a basic right of a country’s citizens and promises to advance equality, solidarity, and active involvement of the state. The second, (“Everything for some”) views medicine more as a purchasable product (Privilege) and not as a right, deferring to market forces and competition to also delineate the economic mechanisms of the health system.

The reform that President Obama is presiding over is meant to contend with the inequalities, increase the number of insured, and put the brakes on spiraling health care costs. There will still remain uninsured people and large discrepancies among the population that will likely be difficult to reduce.

Ethical Dilemmas Arising from the Social Democratic Approach

Theoretically, the Social Democratic approach is the fairest and most equal way to distribute resources. However, when taking a second look, several ethical dilemmas arise:

1. Who will decide what is included in the public “basket”? Will it be physicians’ representatives? The patients? The Ministry of Health? Health professionals? Or, perhaps, the courts, who do not hesitate to rule on purely medical issues?

   In Israel, a committee for the upgrading of the health basket is assigned the task, annually, to assess new technologies and medicines, and decide, based on their costs and the government budget allotments for the given year, what can be added to the health basket (Shemer, 2006).

   The committee is appointed by the Ministry of Health (MOH) and includes representatives of the MOH as well as independent medical professionals and representatives from the public. In 2008 the committee's appointment triggered a conflict between the Ministry of Health and the Israel Medical Association (IMA) because half of the committee members were government employees compared to 15% in the previous year. The essence of the argument centered on the ability of the committee to retain its independence from government influence, preserve an unbiased atmosphere and decision-making process.

In 2003 Prof. Mordechai Shani, former Director of Sheba Medical Center and Director of the Gertner Institute, and Dr. Boaz Lev, Director General of the Ministry of Health, initiated the establishment of a "Health Parliament" that consisted of 500 people from the public, chosen as a representative sample of the population, who agreed to take part in the project (Health Parliament, 2003). Within the framework of the project they attended lectures on health topics, held discussions among themselves and with various experts, and agreed upon central issues in a position paper, including fairness and distribution of resources. Among their recommendations, were not to fund expensive medical treatment for a small group of patients (such as patients with malignancies who need life saving expensive drugs), and not to fund inexpensive treatment for the entire population, but instead focus on the middle range, relatively expensive treatments for a large segment of the population. The significance of this for those few that are dependent on the very expensive treatments is clear.

2. The second ethical dilemma is what will be included, and what not, in the public health basket. The significance of this is all too clear for a patient whose life depends on a particular drug that he cannot afford to pay for. Such was the case in 2008 when the battle to include Revlimid, a 2nd line myeloma drug ended in a court ruling not to intervene (Ha'aretz, 2010). A year later year the drug was introduced into the basket, too late for many of the patients who could have benefited from it. Another, current, controversy being played out in the media, over including children's dental treatment in the health basket at the expense of adding new technology, is an example of the problems and emotions associated with the decision making (ynet, 2010).

3. Feasibility: The control of health care expenditure in the Social Democratic approach is made possible by the functional distribution of the pay outs made among the patient population: 70% of the spending is disbursed on 30% of the population, while only 1% of the population, those who are the most critically ill, absorb 30% of the spending. It is feasible, therefore, to control expenses by administrative measures according to the Pareto principle. However, despite its being feasible, does not mean it is ethical.

In summary, the Social Democratic worldview raises ethical dilemmas that ensue from the need to fund health insurance to everyone along with the necessity to choose what is included in the public basket. The significance can mean life or death for those unable to pay by themselves, or who do not have additional private insurance.

The Physician-Patient Relationship

In 1996, the Knesset enacted the Patient's Rights Law. This law defined a patient's right to receive quality medical treatment and his right to a full explanation and understanding of the various options available to him.

The law emphasizes the rights of the patients and the obligations of the medical provider towards the patient. The medical provider's obligations are considerable and include the need to present treatment options even if they are not included in the health basket, and even if he knows them to be beyond the patient's ability to obtain. The provider's rights are, likewise, anchored in the Patient's Rights Law.

At the other extreme, a medical provider must still extend non-urgent medical assistance to those who behave aggressively or violently towards him. A law proposed in 2006 which whose purpose is to protect workers in the health service sector who are exposed to violence has been enacted only recently (Knesset, 2009).

It is reasonable, therefore, to change the approach and create balance in the system. It is up to the patient to take personal responsibility for his or her own health and to maintain it by abiding instructions, performing tests, taking medications, and following recommendations, as prescribed by the treating physicians.

The central point behind the idea of personal responsibility is that it is a mutual pact between patient and medical provider: for example, the patient is obligated to follow doctor's recommendations regarding a particular issue or perform diagnostic testing, (e.g., fecal occult blood or colonoscopy after age 50 for the early diagnosis of colon cancer, or a PAP smear to diagnose cancer of the cervix). To the extent that patients are fully compliant with their physician's recommendations and instructions, the responsibility extends to the health system.

On the other hand, in the event the patient should develop colon cancer or cervical cancer and did not perform the recommended diagnostic tests, it would be reasonable to ask him or her to bear at least part of the cost. The cost of a liver transplant can reach hundreds of thousands of shekels in Israel and over a million dollars in the United States. Part of the transplant cost will be imposed on those patients who need it and who did not heed the Ministry of Health's recommendation for immunization against Hepatitis.

In summary, the idea of personal responsibility implies a bilateral relationship between patients and healthcare providers. It would, seemingly, improve compliance and health outcomes.

The New Era of Sharing Responsibilities

The concept of exhibiting personal responsibility in our own health care, as defined by Steinbrook (2006), implies that if we follow a healthy lifestyle (by exercising, maintaining a healthy weight, refrain from smoking, etc.) and are compliant patients (by keeping our medical appointments, heeding our physician's advice, etc.), and using hospital ER facilities only for true emergencies, we will be rewarded by feeling better and spending less money on health.

As already described, the refusal to take preventive measures such as the Hepatitis B virus vaccination, or a colonoscopy screening for colon cancer could end up resulting in tremendous costs if there were to be a need for a liver transplant or a diagnosis of carcinoma of the colon. The patient who opted to disregard his physician's recommendations (in this case, regarding vaccinations or screening) should pay at least part of the costs of procedures that are a consequence of non-compliant behavior.

The current equation should change; with the physician still retaining medical responsibility, and the patient accepting responsibility for compliance. Although the sharing of responsibilities between physician and patient seems both logical and just, there are ethical issues which must first be addressed.

Ethical Considerations

Feasibility

The largest proportion of medical spending, as already described, is spent on a limited fraction of the population – 70% of health care expenditure is used for 30% of the patients and 30% on 1% of the patients. It is, therefore, feasible to control treatment expenses by administrative measures. On the other hand, recommendations for preventive measures are largely directed towards a considerable percentage of the population, who are healthy and are not familiar with the healthcare system. Some of these healthy people rarely visit physicians or nurses so that reaching them to explain the importance of prevention is problematic. How can the health care system then ask them to pay for the consequences of not having taken preventive tests or measures if the importance of doing so has not been explained to them?

Preventive measures in the pediatric population are even more complicated. Dental care for children is hopefully soon to become part of the public health care basket in Israel. A child who does not go regularly to the oral hygienist or undergo timely dental treatment when needed and then later in life needs expensive treatment may (justifiably) refuse to pay his share on the grounds that it was his parents' responsibility to make sure he received dental treatment as a child.

The target population is, therefore, very large and diverse. Yet, even though the healthcare system should be doing its utmost to create an outreach program that will reach everyone, in order to diagnose early cases and prevent disease, it is just not realistically feasible to think that each group can be reached and that the importance of health recommendations be relayed. Still, the ethical justification of demanding that a person pay for the consequences of not having adhered to medical recommendations that were not explained to him is very problematic.

Cultural and Religious Values

Our beliefs and way of life are not based on logic alone, but, rather on our cultural, religious, and ethical values. Tattoos, for example, are cultural practices of particular ethnic groups, and are often fashionable among youth and other members of the general population, yet can be dangerous if not done aseptically. Vaccinations are opposed by certain (religious) groups based on personal beliefs and, often, misconceptions. Abortions are certainly controversial. Religious groups and political parties are known to oppose abortion even in cases of proven malformations. Among some groups even prenatal diagnosis is unheard of. The care of a person born with Down syndrome, for example, can mount to 300,000$ per year. Should the public pay the bill for people's beliefs even if pre-natal screening was offered in the healthcare basket free of charge and not done?

The healthcare system does take into account religious, cultural, and ethical values such as - for example - the right to bear children. The public health basket finances IVF for up to two children, and supplementary insurance even finances additional IVF treatments. Any effort made to limit the number of attempts at IVF in the health basket, although logical from a medical standpoint since chances of success diminish, has met with resistance in Israel's legislative body.

Religious and cultural issues govern our lives and influence the decisions we make. It would seem, therefore, that a decision that imposes financial burden on people as a result of their beliefs is not practical, at least not in Israel.

Personal Freedom and Choice

Pluralism and the right to hold individual beliefs are fundamental to democratic societies. Many believe that health-relevant behavior belongs to the private sphere, with individuals having the right to make their own choices about diet, alcohol consumption, or their professional and recreational activities. This autonomy, they believe, is a central liberty. Discrimination, based on religion, race, or gender is unacceptable, so why should discrimination based on body morphism such as obesity be acceptable? The private insurance sector also bases their policies on BMI. Should the public healthcare system do the same? Weight reduction is almost unfeasible, as more than 90% of those who lose weight regain it. Our genetic make up must not be a basis for discrimination in the same way that religion, race, or skin color should not. Hence, even indirect intervention by withholding resources or services needs to be justified.

Inequity

In Israel, the most troubling issue raised by the concept of personal responsibility is the matter of inequity in health care delivery. As in other parts of the world, there is an association between low socio-economic status (SES) and inequities in health care delivery and outcome. Infant mortality, for example, depends on the mother's education; 2.8% in mothers with 16 or more years of education versus 4.6 times higher in women with 4 years or less. Occult fecal blood screening in Israel's population aged 69-74 in low SES versus the rest of the population is significantly lower. Breast mammography screening every two years as recommended in Israel was performed by 25% of the low SES population versus 21% of the other group. There is also a marked difference in mammography screening among women; up to 80% of those living in kibbutzim or villages inhabited by high SES populations take the test. In contrast, among the Jewish religious community and Arab Muslim Israelis, there is a low rate of mammography screening, probably due to cultural, religious, and SES factors. New immigrants such as Ethiopian women use fewer bone density check-ups and do not go for routine gynecological examinations in comparison to the other Israelis.

These health disparities between high SES segments of the population and underprivileged people are striking and are a disgrace to our society. These people already suffer from poorer health status and frequently avoid buying recommended drugs as they cannot afford co-payments. Is it ethical to make these people pay for not following medical recommendations? We believe that the answer is NO in capital letters.

Evidence-based Medicine (EBM)

Another problem is the long-term validity of medical recommendations. For example, recommendations for mammography screening changed as researchers discovered that many small lesions had questionable significance. Though making women perform an exam that might find a tumor of questionable significance, it could cause a lot of concern. Such a finding may or may not change a life; therefore, recommendations can carry heavy responsibility on the part of the physician who issues it.

It is ethically unreasonable to demand that a person pay for not adhering to a physician's recommendations that may not be based on facts. As evidence-based medicine changes and new things are learned, what becomes the scientific justification for our recommendations? Take for example a procedure such as frontal lobectomy, which was performed for mental illness such as depression much less than 100 years ago. Would it be ethical to make families pay for the long-term hospitalization of their family members who had refused this treatment? We perform ECT for depression; do we really know what the consequences of this treatment are?

It is not ethical, therefore, to make people pay for not following medical advice that might yet be proven in the future as either dangerous or based on erroneous interpretation of scientific evidence.

Conclusion

In summary, what looks logical, simple and right is not that simple. Ethical issues that exist, including feasibility, cultural values, personal freedom, an ideology of pluralism, inequity, and validity, must become part of our method of action.

The basic rule – "primum non nocere" – "first do no harm" – is as relevant as ever. Although budget restrictions and the need to balance between patients and physician duties are important, the implementation of a patient's personal responsibility must be done sensitively and carefully for the future benefit of healthcare.

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