Agents of their health? How the Swedish welfare state introduces expectations of individual responsibility

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Abstract

In recent years, the notion of individual responsibility for one’s health has been introduced into Swedish medico-political debate. Formerly expressed as a recommendation, it has now taken on the form of expectations. In a Swedish context, this shift from collective to individual responsibility is novel because it implies a break with well-established welfare state practice of comprehensive care for their citizens. Using a systems-theoretical approach, we interpret this shift of expectations as a political solution to the problem of legitimate allocation of scarce resources. A more inclusive medical conception of illness has facilitated the introduction of many new diagnoses that, in turn, have lead to a strong increase in claims for medical treatment and for compensation. This semantic change in medicine aggravates the budgetary situation of the welfare state. The political solution lies in a reorientation of the expectations the medical system can have on citizens as well as a shift of the expectations regarding the rights and obligations citizens can have on the medical system. Individuals are increasingly expected to live healthy lifestyles and to avoid hazardous habits. If they do not live up to these expectations, they have to face low prioritisation or denial of treatment.

Keywords: illness, responsibility, healthcare policy, systems theory, sick role

Introduction

...if one has to start somewhere then it is with trying to turn the Swedish culture of caretaking into its opposite, more toward individual responsibilty. We must stop sitting cross-armed and waiting for others to solve our problems. […] Healthcare has to be clear about putting responsibility where it belongs: with the individual. (Dagens Nyheter 2008-02-25)\(^1\)

[Twenty-six] years old and healthy – but [the insurance company] does not want to insure her. Anna is too fat to get insurance. […] ‘You should have lost weight by now’, the risk analyst said to me. […] ‘All research shows a correlation between overweight and serious illnesses’, says the press chief of [the company]. […] We have a future responsibility when we sign insurances. Even if you are not ill today you might become ill in the future. (Metro 2009-05-13)
In 1997, the Swedish parliament adopted an ‘ethical platform’ that would provide rules of priority setting in healthcare. An investigation conducted by the Swedish National Board of Health [Socialstyrelsen] seven years later showed that the platform’s rules were hardly suitable to give clear directives for the physicians involved in decision-making processes on prioritisation. As a consequence, the Board considered a proposal from the National Centre for Priority Setting in Health Care [Prioriteringscentrum. Nationell kunskapscentrum för prioritering inom vård och omsorg] (2007) that explicitly suggests the down-prioritising of those who neglect their health and/or choose risky lifestyles. The proposal is intended to amend the existing rules with a ‘responsibility principle’ according to which individuals should be held responsible for their health.

The connection of health and individual responsibility as such is not new. For several decades, there has been advice to exercise, to reduce weight, to drink less alcohol, and not to consume tobacco products. Authorities and professionals have been giving advice on how to achieve better health by preventive behavioural changes. These medico-political messages were only meant as recommendations for healthy lifestyles or warnings against risky behaviour.

In the last decade, though, the tone in official reports, newspapers, TV programmes and political speeches has changed, as the quotes above show. Individuals are no longer only recommended to live a healthy life; they are expected to do so. Whether they qualify for desired but expensive medical services and whether they get reasonable conditions for insurance is coupled with their chosen way of living and their attitude toward their health (Riksrevisionen 2004: 9, Rosén 2006, Ågren 2003). According to this logic, people guilty of excessive drinking, lack of regular exercise or practising extreme sports must take the consequences of their choices if they fall ill or become injured (2007/08, 110, 23). Conversely, healthcare providers should spend fewer resources on these patients than on people more attentive to and careful of their health (Kjellström 2006, Furberg 2007). There is an abundance of examples that illustrate that the shift in policy is already in practice with palpable consequences for the patients (see later).

This marks a shift from a collective responsibility of the welfare state towards individual responsibility. At least in a Swedish context, this development is novel. State responsibility has always been one of the main characteristics of social-democratic welfare regimes of Scandinavian type (Esping-Andersen 1990), in healthcare as well as in other social matters (Kosotieti 1987, Svalflor and Taylor-Goody 2002, Svalflor 2007). The individual has been regarded as the victim of various social conditions and therefore, rightfully, the receiver of benefits when in need of services, care and help.

Sociologists have attempted to explain responsibility shifts in healthcare from several starting points and approaches. Marxist approaches mention neo-liberal economic deregulation and cutback policies as the main causes (Turner 2004: 300, see also Donahue and McGuire 1995). Research inspired by Foucault focuses on how the contradictory meanings of health are substantiated or refuted. Individual responsibility for one’s health is viewed as a method of discipline and bio-power (Jolanki 2008, Minkler 1999, Light and Hughes 2001, Beck-Gernsheim 2000).

In this study, we want to offer an analysis with a different approach. We do not focus on concrete practices in healthcare. Neither are we here interested in answering the certainly important question if (in an empirically significant number of cases) and to what extent persons are already held accountable and as a consequence are attributed responsibility for their health. Applying Niklas Luhmann’s theory of social systems (Luhmann 1995), we shift the focus of the research problem towards the communicative structures that enable politicians, physicians and other authorised decision makers in healthcare to legitimately
make use of the semantics of individual responsibility. In this light, the shift from collective to individual responsibility in healthcare appears as a direction of expectations towards the individual. We are interested in the communicative structures recently established that legitimise the attribution of individual accountability and make normal the expectation of individual responsibility regarding health to which these practices might be applied.

The systems-theoretical method of equivalence functionalism (Luhmann 2005[1964], Christis 2001) allows us to interpret the shift to individual responsibility as a solution to a specific problem. Unlike Marxist approaches, we do not locate the problem in the economic sphere (Signal 1998, Navarro 2002) and unlike Foucauldian approaches, we do not regard it as a problem of the medical system (Martin et al. 1988, Turner 1992). Instead, we consider both the problem and its solution as a matter of the political system of society (Luhmann 1990b, Schirmer and Hadamek 2007). By shifting attributions of responsibility from the collective to the individual, the political system provides a political solution to the problem of scarce resources in the provision of medical care. The political system re-organises the distribution of medical resources by rearranging the rights and obligations of people considered as ill. This rearrangement is legitimised by means of changed expectations towards individual responsibility that are made possible by current social semantics. The (shifting) attribution of responsibility is a communicative steering device the political system can make use of in order to keep control over increasing claims for medical treatment.

The outline of the article is as follows. We start with the distinction between two different observations of illness, connected to the medical and the political system, respectively. With the focus on diagnoses and symptoms (Michailakis 2008: 66-84), the medical system can only account for whether somebody is diagnosed ill or not. Observed from a medical perspective, illness is a matter of causes and therapies. Social, political and economic consequences are beyond the range of medical scope. In contrast, the political system, lacking medical expertise, can only settle whether one can be considered as ill or not. Political observations regard illness as a matter of socio-political consequences. The political observation of being considered as ill is linked to certain rights and obligations mediated by the ‘sick role’. In the section thereafter, we deepen our analysis of political observations of illness and connect the rights and obligations as formalised in the sick-role to the attributed causal effect a person’s lifestyle has for their health condition when observed as a responsible agent (and not as a victim). The next section describes a semantic change in the medical system (the introduction of a biopsychosocial illness concept) that enables many new diagnoses and triggers many new claims that, finally, lead to an overburdening of the welfare state. That way, an increased number of diagnoses and of people diagnosed as ill raising claims for treatment gain political relevance, and thus necessitate political reactions. Due to its societal function and its self-description, the welfare state finds itself in the unfortunate position of being in charge of finding solutions. We analyse the shift in expectations from collective to individual responsibility for one’s health as a political response aiming at a legitimate way to restrict the number of people that are ‘considered as ill’. The shift to individual responsibility is, according to our analysis, a functional solution to the political problems the rising claims to treatment creates. The article ends with a conclusion of the theoretical explanation and framework to observe changes in the communicative structures that are provided in the previous chapters.

Medical and political observations of illness

In line with the theory of functional differentiation as developed by Luhmann (Luhmann 1982, 1989, 1990a, 1995, 1997a) and in line with the operative difference between function
systems and organisation systems (Luhmann 2005[1975]), we argue that only the medical system has the technological and semantic tools to observe the nature of illness. Only within medical communication (i.e. medical theories and diagnostic methods) can somebody be diagnosed as ill. Other function systems and organisations (politics, education, law, and business companies, etc.) can observe illness only in relation to its social consequences. They cannot observe whether people (really) are ill, but only consider them as ill. Somebody who is considered as ill is granted specific rights and is freed from specific obligations in some contexts (while possibly denied opportunities in other systems).

In this section, we will explain the distinction of being ‘diagnosed as ill/considered as ill’. The first subsection deals with medical observations of illness in terms of diagnoses and symptoms. The second subsection addresses illness as a matter for the political system and for organisation systems. Being considered as ill implies that people are observed in terms of rights and obligations as specified in the relation of the individual and the state (or other organisations).

**Being diagnosed as ill**

What does it mean – sociologically speaking – to be ill? Medical observations of illness represent human beings in regard to how and whether their organisms are affected by pathogens or constrained in their functionality. In modern society, the medical system has taken over the function of defining the nature, causes and cures of illnesses. Like other function systems, it has developed a specific communication code and has built up a huge semantic stock of information by selectively processing specific distinctions (Luhmann 2005[1990]). The most important of these is the distinction diagnosis/symptom (Michailakis 2008) with which the medical system marks consistently observed pathological deviations in the functioning of human bodies as either medically relevant or irrelevant (see Carleheden 2007: 96).

Human phenotypes are characterised by an enormous variation. In principle, there is an infinite number of pathological deviations from the average, such as fatigue, concentration difficulties, pain, dizziness, sensory disturbances, balance problems, dry skin, nausea, sleeping disorders, urinary narrowing, weight loss, muscular weakness, twinkling eyes. Many of these are recognised as symptoms for physical as well as psychiatric diagnoses (see F- and Z-codes in ICF, WHO 2003). When defined as a symptom, a deviation is accepted as a valid indicator for a certain medical diagnosis. However, some deviations do not qualify as symptoms for diseases but rather as non-symptoms that are considered as medically irrelevant. Whether a biological, physiological, psychological or behavioural deviation can make a difference of medical relevance depends on currently available and accepted medical theories. In other words, it depends on current semantics of the system (Luhmann 1980). The distinction diagnosis/symptom allows the medical system to describe complex deviations and find the reasons behind (aetiology) in a relatively direct way. The identification of relationships between the observed deviations or the reassessment of existing relationships between symptoms opens up the way for many new diagnoses or the revision of old ones. If people’s physical, intellectual or behavioural conditions are classified as deviant and these deviations are recognised as symptoms for a disease by medical communication, they are ill (at least in a sociological sense). If their deviations are not recognised as symptoms for a disease (either by professionals or laypeople), they are not ill.

In recent decades medical communication – both with respect to diagnosis and treatment – has started to connect consistently observed deviations (such as obesity, anorexia, insomnia, cardiac arrhythmia, or tremor) with social problems such as unemployment, high divorce rates, performance pressure in school, and loneliness. These deviations may account for

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many people’s temporary inability to work and perform as usual, for premature deaths, or for their distress in general. Medical communication can define these deviations as symptoms for diseases and, thereby, diagnose people as ill. No social system other than the medical one has the ability and the technology to do so (Färdow 2003: 248).

**Being considered as ill**

Other social systems can only determine whether people – under their own observation schemes – can be considered as ill. What that means will be the issue in this section. Let us look at two examples about a fictitious person who is working as a secretary for a company; in her leisure time she sings in a choir, which is committed to perform regularly in a local music club. In the first example, she suffers from a fractured metacarpal bone on the side she writes with, in the second example she has a minor cold. In both cases, she is diagnosed as ill (respectively, as injured). However, that does not mean that she is automatically considered as ill (injured). The broken writing hand may constrain her severely in executing her job as a secretary, but her ability to sing in the choir is not affected. Therefore, she will be (partially) freed from work and be granted sick-leave while she still is expected to participate at the performances of her choir. The reverse is true when she has a cold. Since she can fulfil her tasks at work without bigger problems, she will be denied sick-leave. But she will be freed from her duty of singing in the choir because her voice is not at full capacity. The very same medical diagnosis (broken hand; cold) can lead to exemption from duties in some contexts, while not in others. The very same diagnosis can lead to a grant of rights in some systems and to a denial of rights or to a reduction of possibilities in others.

A medical event (the communication of a diagnosis) becomes politically (and organizationally) relevant as soon as social expectations cannot be met as normal due to the illness. The question from this perspective is not how to treat or cure the disease but whether the disease (based on medical diagnoses) can be considered sufficiently bad to grant the right to sick-leave or other extra-treatment as well as to free one from the obligations one is committed to due to contract commitments. Illness then becomes a matter of rights and obligations, not so much in a formal legal sense but rather mediated by a social role as reasonable, reciprocal expectations substantiated by social semantics with real and tangible consequences for the sick and for the bearers of complimentary roles.

The connection between illness and rights/obligations was already pointed out by Talcott Parsons in his classical conception of the ‘sick role’ (Parsons 1951a: chapter 10, 1951b). This concept has been criticised and re-visited widely in the sociology of health and illness – e.g. it does not fit in with impairment (Barnes and Mercer 1996, Oliver 1996), with chronic illness (Gallagher 1976, Crossley 1998, Turner 2004: 141), and is misleading when studying mental illness (Szasz 1972). Moreover, it implies a hierarchical relationship between doctor and patient (Freidson 1970) that is rather more characterised by conflict than consensus (Turner 2004: 131) and, finally, it neglects the patients’ perspectives (Conrad 2007, Bury 1997: 374). While respecting these critics, we must acknowledge that Parsons’ concept of the sick role is of lasting value in at least two aspects. On the one hand, the sick role made the sociological relevance of sickness (and the necessity of medical sociology as a whole) visible and understandable (see Turner 2004: XV). On the other hand – and more importantly for our purposes – we can with Parsons understand the sick role as a political (rather than as a medical) concept that aims at specifying the consequences for social systems and how they are handled when people are considered as ill. Being led by the question on how social order is possible, Parsons saw the sick role as a steering mechanism with which the political system could maintain social order when too many individuals in society became diagnosed as ill,
considered and experienced themselves as unable to work and thereby dependent on society for their living (Crossley 1998: 527, Kelly 2001).

For Parsons, the sick role is associated with two obligations and two rights. When feeling sick, the person is obliged to seek medical examination and get her condition confirmed. Furthermore, the sick person is obliged to consider her illness as an unwanted condition, and therefore, she is expected to follow medical advice in order to recover from the illness as soon as possible. On the other hand, the sick role implies the right to be freed from (some) expectations and obligations that she has to face when in a healthy condition. Secondly, the sick role in Parsons’ version also exempts a person from being responsible for her illness (see next section).

It must be stressed here that while we draw on the sick role’s basic Parsonian conception, our commonalities with Parsons are limited when following Luhmann’s systems theory that radically departs from Parsons in at least two crucial aspects. In Luhmann’s theory, communication is more fundamental than action, and function is not determined by structure, as will be shown later.

Whereas observations of illness in terms of ‘being diagnosed as ill’ are exclusively the concern of the medical system, there are manifold observations on the basis of ‘being considered as ill’. Not only the political system and its organisations but also almost every other organisation (e.g. companies, military, sports clubs, etc.) proceed from specific expectations and the attendant rights and obligations when observing people’s health status. All systems, other than the medical system, build their own rules regarding who can be considered as an authorised/unauthorised holder of the sick role, depending on whether it is about the eligibility of job candidates, the legal capacity of a convict or the mental capacity of a student. Being considered ill in the context of one system does not automatically oblige another system to come to the same conclusion. Due to differing rationalities, interests and communicative codes, different systems can count the very same person as ill/not ill in a legitimate indifference to decisions made in other systems.

**Responsibility and the sick role**

In a medical context, human beings are first and foremost considered as bodies (Saake 2003). Political and organisational observations of illness, by contrast, focus on social attributes (e.g. employability, efficiency) of human beings who are considered as ill or not ill. Being bearers of specific roles, sick persons find themselves in a web of social relations, expectations and demands vis a vis their doctors, their employers, and the welfare state and/or their insurance company. Within this web, responsibilities are negotiated. Whether the individual, the collectivity or the external environment are held responsible for the individual’s health condition is a matter of contingent attribution depending on three theoretical prerequisites: (a) there is a mutually constitutional relationship between rights and obligations; (b) the sick role – just like social roles in general – is strongly connected with agency; and (c) agency, in turn, is linked to responsibility as responsibility is attributed along the distinction action/experience.

(a) Roles such as the sick role or the physician’s role clarify what its bearer is supposed to do with whom, when and how. They determine the rights and obligations the bearer has towards others. Rights and obligations form a mutually constitutional relationship. One party’s right is somebody else’s obligation. When a sick person has the right to sick-leave, it is somebody else’s obligation to finance this sick-leave. When a patient has the right to treatment, somebody else has the obligation to treat her and somebody has the obligation to
finance this treatment. The doctor has the right to instruct the sick person what to do in order to improve her health condition; for example, to take drugs as prescribed. The employer has the right to get the sick person’s health condition confirmed by medical diagnoses. When a sick person does not meet obligations properly, the other party—be it the doctor, health insurance company or employer—has the right to deny benefits or claim compensations carried out by the sick person.

(b) In order to be a receiver of benefits, expectations and demands, the sick person has to be considered as more than merely a body in need of treatment. She needs to be an agent capable of actions.3 Being an agent, the sick person can raise claims to treatment (or refrain from doing so) and can fulfill obligations (or refrain from doing so). Agency is inseparably interwoven with the principle of responsibility. According to an old Aristotelian notion, ‘a person is responsible only for those acts that he or she freely and voluntarily chooses. Thus, people who act involuntarily, either through coercion or unavoidable ignorance, should not be held responsible or blamed for their actions’ (Leichter 2003: 609, see also Minkler 1999: 121). At the core of this notion lies the assumption that she can be held responsible if she has scope to avoid the outcome; if not, she is freed from responsibility. Being an agent implies being capable of choosing actions or abstaining from choosing actions. Only people with agential capabilities can be held responsible for outcomes of their behaviour.

(c) Hence, responsibility presupposes causality. The action (or omission of that action) is regarded as the cause of the outcome. If the sick person does not make a claim for treatment, she will not be treated, cannot get a medical diagnosis and cannot call for sick-leave or other benefits. If she does not live up to obligations, she will lose previous rights granted by being considered as ill or will have to pay fines. However, it is not as easy to pinpoint responsibility as action-theoretical approaches such as Rational Choice (Coleman 1994, Boudon 2003) and Behaviorism (Homans 1961) might suggest. Neither is active choice always detectable, nor outcomes of actions (Fuchs 2002). Among the novelties in Luhmann’s communication-based approach is the understanding of actions and their outcomes from an observer’s point of view, not from that of the agent herself. Crucial in Luhmann’s approach is the distinction action/experience (Luhmann 1995, chapter 4). It is up to an observer to decide whether illness results from an agent’s actions; that is, her choices or whether it is something the agent only experiences without having options to act against. Any attempt to answer why a person has become ill, then, is necessarily bound to contingent attributions made by a particular observer, either to the person’s (neglect of) actions or to environmental factors beyond her control: because of genetic or psychic dispositions, because she was too close to infected people, because she did not dress warmly enough and overburdened her immune system. Different observers (with different perspectives, interests, knowledge etc.) might attribute causality, and thus responsibility, differently from others. There is neither a common standard nor an observer-independent position to determine whose attribution of causality is closer to the truth. Within the limits of evidence and plausibility established by science, there are always several options that observers can choose (see Luhmann 1990c, chapter 2).

What one can be held responsible for, as well as who can be held responsible for what, depends not only on contingent observational routines, i.e. implicit assumptions, theoretical presuppositions, etc. Responsibilities are also defined by the specific reciprocal expectations of complimentary role relations like doctor-patient or legislator-taxpayer. The sick role—as defined in Parsons’ times—frees the individual from the responsibility for becoming ill (experience, i.e. the individual is considered as a victim of becoming ill), but not for the responsibility of remaining ill due to defection of medical advice (action, i.e. the individual is considered making an active choice by following/not following medical advice). It is part of the role expectations to follow a doctor’s instructions or take the consequences.

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Semantic changes due to advances in medical theory, a new political ideology, a recessive economic climate, or a new Zeitgeist might lead to a shift of expectations towards bearers of certain roles. Changing expectations might imply (or make necessary) redefinitions of rights and obligations. Whether undesired outcomes can be attributed to action or to experience (i.e., who can be held responsible), consequentially, has to be (re)negotiated. In order to understand the current shift towards attribution of individual responsibility for one’s health (expectations attached to the sick-role) one has to examine the changes in semantics and the accompanying changes in the role expectations; that is, rights and obligations that are compatible with and sustain these new semantics. In the next section, we concentrate on semantic changes in the medical system, namely the expansion from a biomedical to a bio-psycho-social concept of illness.

A new concept of illness

In recent years, a profound change in the semantic content of the sickness concept has taken place. The formerly dominating biomedical definition of illness has been replaced by a bio-psycho-social concept of illness (WHO 2003: 192, Checkland et al. 2008, Donahue 1995, Lawton et al. 2007, McClean 2005). The biomedical concept is restricted to scientifically measurable parameters such as genetic defects, bacterial or viral infections, but it hardly leaves any room to attribute illnesses to causes beyond the body. Many new diagnoses would not be possible with this conception of illness because they fall outside the limited scope of biomedical observations.

By contrast, the bio-psycho-social view includes in its definition of illness parameters such as socio-economic conditions, working environment and lifestyle as possible factors that in combination with biological factors can account for the occurrence of illness. The concept has its origins in the World Health Organization’s definition of health as ‘a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity’, as used since 1948 (see White 2005). The bio-psycho-social view extends the observational range of the medical system and increases the number of deviations that are recognised as medically relevant symptoms. This implies an enormous expansion of the medical system’s capacity to detect illnesses and to develop methods to cure them (Michailakis 2008, chapter 3). As a consequence, the number of people diagnosed as ill increased, too. If there is a medically possible way to treat more and more illnesses, there is no (medical) reason why patients should not claim to be treated. Like other function systems, the medical system lacks an in-built stop-mechanism that could set a limit to medical diagnoses and efforts at treatment. Not only the Hippocratic oath and normative medical theories, but already the operative mode of medical communication, ensure the continuing autopoiesis of the medical system.

The incentive for patients lies at hand: if there are more medically approved and acknowledged causes for why one might be ill (and, for that matter, could be considered as ill), wouldn’t it, ceteris paribus, be rational to claim sick-leave? And furthermore, if there are more and more technological possibilities to successfully cure more and more illnesses, impairments or divergences from what is considered a normal condition, why not raise the claim for treatment or assistive technology despite their high prices? In addition to financially disadvantageous demographic changes, this situation forces the welfare state gradually to take into account the fact that resources will be insufficient for approving the claims that taxpayers raise when medical developments give prospect for successful treatments. We argue that prioritisation and rationing in the provision of healthcare due to lack of funding and
lack of capacities can be regarded as an indirect consequence of semantic changes in the medical system.

(Too much) Illness as a political problem

In contrast to most of mainstream sociology, Luhmann considers communication and not human beings as the primary element of sociality. Instead of class structures or other hierarchical order principles in different shadings, as Bourdieuan (Bourdieu 1984) or intersectionalist approaches (Crenshaw 1991) assume, Luhmann can focus on a horizontal, functional differentiation of society along incongruent communication systems, each fulfilling a distinctive function for society. At first sight, this may appear as a continuation of the functionalist tradition from Durkheim via Parsons to Habermas but, in fact, it is also developed in sharp contrast to it. Informed by neurobiological (Varela et al. 1974) and cybernetic insights (von Foerster 1996, Bertalanffy 2009 [1969]) of modern systems theory, the Luhmannian perspective observes society and its subsystems as operatively closed, self-referential systems of coded communication (Luhmann 1995). These systems can register events in their environment only through system-internal operations i.e. they redefine external events in their own terms (Luhmann 1990a, 1997a). For example, the political system operates only politically just as the medical system operates only medically, and the economic system can only operate economically. Because each of these (and other) function systems fulfils a specific, indispensable function for society, systems are neither substitutable by one another nor can one of them dominate or rule over the others. Note the difference in a Marxist understanding of society as characterised by an economic domination over politics and other social realms, or the Foucauldian assertion of medical discourses of biopower and disciplinary mechanisms propelling an increasing medicalisation of society.

As shown earlier, medical communication centres on the production of diagnoses concerning human organisms. Events in the environment of the medical system can only become relevant for the system as they can be observed in terms of symptoms and diagnoses. For example, the inordinate occurrence of exhaust fumes, resistant bacteria or mass unemployment become medically relevant if, and only if, they can be connected causally to symptoms of diseases (Michailakis 2008).

In the political system, in contrast, disease emerges as a political problem and demands political solutions. Hence, the political meaning of the occurrence of exhaust fumes, resistant bacteria or mass unemployment lies not (immediately) in being causes of disease but causes of social problems that require counter-steering measures (Schirmer and Hadamek 2007). Political communication centres on the provision of collectively binding decisions (e.g. legislation) that are carried out through the medium of power (Luhmann 2000a, chapter 2). Especially in its late-modern appearance as a welfare state, the political system cannot simply produce arbitrary decisions in line with the will of its governmental executors, but it is dependent on the support of a collectivity – generally referred to as the ‘people’ or the ‘public’. Of course, the public is not included in decision-making processes in healthcare politics, but in the form of patients, associations, taxpayers and voters, it plays an important part in legitimising (or delegitimising) decision makers and their decisions. The reference problem for the political system is, therefore, to be found in the ‘production of societal visibility and accountability’ (Nassehi 2002: 45).

Because of its own self-description, and as a debt to the support from a large collectivity, the political system is in charge of social needs and takes responsibility for
citizens’ claims (Schirmer and Hadamek 2007). It is virtually impossible (or at least hazardous) for political decision makers to dismiss claims or to refuse to tackle social problems by declaring them politically irrelevant. Once claims are raised, any event in the environment can potentially become an urgent matter for the political system. The government may show ignorance but oppositional parties and movements will not. Especially during economic crises and during election campaigns, downright outbidding competitions between opposing camps for a better tackling of the respective problems take place. Like the medical system, the political system lacks internal stop-mechanisms to limit a potentially ever-growing number of new claims (Luhmann 1990b: 50, 1997b, 2005 [1984]: 98) which finally leads to an overload of a welfare-state's capacity of decision making (and legitimising).

The described semantic changes in the medical system (Socialstyrelsen 2003: 62, Fredin 2004, Johannisson 2006) have an enormous impact in Swedish healthcare policy and medical practice. Amounts of new claims cannot be handled by healthcare providers and cannot be financed by the welfare state. The public gets annoyed by long waiting lists, stressed personnel and poor quality, and in the end, a too-great number of people who are diagnosed as ill become a political (not a medical) problem.

The political solution

Being a political organisation, the government cannot interfere in medical diagnosing, *i.e.* it can neither decide on which diagnoses are medically valid nor on who is diagnosed as ill because of which symptoms. Instead, the government can reform health insurance regulations. It can set frames and thresholds for determining who can be considered as ill, and secondly, it can alter the meaning of the sick role by determining the rights granted to, and the obligations demanded of, those persons who are considered as ill.

However, any such measures have to be pursued with care. They must be anchored in public opinion and – at the same time – go in line with the long time prevailing expectation of a welfare state taking care of its citizens. A simple cutback of healthcare expenses might reduce economic costs, but could imply high political costs because it might be understood as a desperate or arbitrary measure. Discord and conflicts among those whose claims are going to be rejected, could become enormous. The self-description of the welfare state would get damaged by a loss of credibility among the public.

In order to solve the problem of rising claims for healthcare while neither blowing the budget nor damaging the trust in the welfare state, more subtle measures have to be found. Ironically, one step towards a solution is provided by the very generator of the problem, namely the medical system. As argued, the bio-psycho-social illness concept extends the scope of possible symptoms and enables many new diagnoses. At the same time, however, medical research building on the extended illness concept (particularly preventive medicine, see Ramel 2002: 2764, Terry *et al.* 2000: 5677) opens up for causal attributions beyond biological parameters in two possible directions. On the one hand, individual lifestyle, habits and behaviours are considered to be an important factor for illness; on the other hand, the social environment in which the individual lives has – at least until recently – been considered a crucial source of causes of illness, too.

Medical observers study how individual organisms react to poisonous effects of tobacco consumption, work overload in a stressful work milieu, or toxic substances in the air. They might find correlations between the occurrence of a particular disease and the existence of some of those factors. From these findings, they might conclude that certain lifestyles and
environments are potential triggers or promoters of a disease and that the avoidance of the respective lifestyle/environment will decrease the likelihood of suffering from the disease. In this regard, the medical system attributes causality. Either lifestyle (individual) or physical and social living conditions (collectivity) or both account for illness (Michailakis 2008: 194ff).

Attribution of causality imposes the question of responsibility. However, as mentioned above, it is not the concern of the medical system. Neither is it a concern for the medical system to prohibit risky behaviour and substances. Both fall into the realm of politics, because responsibilities are connected to rights and obligations as defined in reciprocal role expectations. Therefore, the political system reformulates medical discoveries in terms of changed expectations on health promotion and prevention of illness – both concerning the threshold to be eligible for being considered as ill and the rights/obligations of the sick role. In the end, some rights are limited and new obligations are imposed on patients in order to qualify for the sick role. We have to remind ourselves that the specific role expectations the bearer of the sick role has to meet only come into effect in relation to the concrete diagnosis and the social context. Rights and obligations are not generally the same for every diagnosis and every context, as pointed out earlier.

The change of the sick role does not take place in an immediate and direct way. Medical recommendations for health-related habits/behaviour are transformed into social expectations and into demands. Expectations are voiced by the National Board of Health, the Swedish National Institute of Public Health, Läkartidningen (Swedish Physician’s Journal), in Government Official Reports [Statens Offentliga Utredningar SOU] and not least in the daily press.

The emerging trend is that an individual gets less financial aid, becomes down-prioritised or even denied treatment if she fails to live up to the expectations and demands of preventive care. A 73-year-old patient was denied a surgical operation at Eskilstuna hospital (a small hospital in the middle of Sweden) on the grounds that he was a regular smoker (Dagens Samhälle 2009-06-10). One clinic at Umeå University hospital has adopted a similar policy: if the disease or injury is not life-threatening, patients are instructed to quit smoking at least two months prior to their operation – else they are not eligible for the operation (Jonsson 2009). Obese persons and alcohol-addicts were placed at the bottom of the waiting list with similar reasoning (Söderhjelm 2003). A big Swedish insurance company has started charging 25-50 per cent extra to smokers in health insurance premiums. The core of the reasoning is the same: those who take higher risks with their health should wait or pay more (Göteborgs Posten 2009-06-15). The melody in the Government Bill ‘A renewed public health policy’ is in the same key, although disguised in a camouflaged tone when stating that ‘big improvements of public health can be achieved when the individual has the possibility to take, and takes more responsibility for her/his health’ (Swedish Government 2008: 7). The Swedish National Institute of Public Health states in one of its official reports that factors based on individual choice such as ‘lack of physical activity, unhealthy dietary habits, tobacco consumption and risky consumption of alcohol still are our biggest causes of disease and death. Lifestyle-related ill-health is a great strain on healthcare and, therefore, leads to enormous costs’ (Swedish National Institute of Public Health [Statens folkhälsoinstitut] 2009: 5). The view expressed by the National Institute has been reiterated in reports from several county councils.

Importantly, these examples should not be seen as systematic empirical evidence of changed medical practice. Instead, they are meant to illustrate how the expectations of individual responsibility are communicated and increasingly anchored in the public debates in healthcare politics.5 Many more cases are reported in the media, and – whether they are true or the product of mass-media exaggerations – the reports contribute to the anchoring of the
new expectations. Several survey investigations on this issue indicate that there is a vast agreement among the general public and medical personnel that patients have to take over more individual responsibility (Ågren 2004, Socialdepartementet 2001: 29). Also, the proclamation of such studies contributes its part to the anchoring of the semantics of individual responsibility for their own health in society. However, there is still no clearly accepted yardstick for common policies. A shared standpoint and a generally acknowledged code of practice have yet to be settled and established.

From a sociological viewpoint, it is crucial to see that responsibility, like causality, can be attributed in one or an opposing way. An individual can be seen as rational or driven by subconscious forces; that is, an active agent of her life or a passive victim of her living conditions. Whether a consumerist lifestyle, for instance, is seen as a product of the capitalist economy, suppressed childhood experiences or the outcome of a choice the individual made in accordance with her interests, preferences and character, also depends on the observer’s interests, preferences, character and on prevailing semantics – in a cybernetic sense, the viewpoint is principally selected arbitrarily (Luhmann 2000b, chapter 4).

For many decades, the Swedish welfare state chose a collectivist viewpoint and considered itself as the caring hand for its population. The state saw itself as the agent, while the population was seen as the experiencing part. However, in light of the overburdening by too many claims for treatment (or for better life conditions) that medical advances made possible, this political self-description is no longer appropriate. Collective responsibility is no longer considered as a realistic way to meet citizens’ claims. Standing at the crossroads between collective and individual responsibility for health, the only manageable option is the second one.

At this point, the above-described findings by medical research are suitable when looking for a legitimate basis to restrict the amount of claims in order to save resources. Medical research provides the external validation and source of non-arbitrariness because it is considered free from political interests and biases, while politics by definition is not. A medical diagnosis can be treated as an external fact that cannot be surpassed by political or economic arguments. But it can be utilised for political purposes to justify unpopular policy measures. The government can – paradoxically – promote itself as acting and experiencing. As part of its self-description as a functioning welfare state, it has to present an achievable solution that underscores political capability to act (action). At the same time, the government can present itself as experiencing events (experience) in other realms of society that are beyond its scope. Thereby, whatever measures are taken, they can be justified as necessary due to causes the welfare state cannot be held responsible for. The political system accounts only for the effects of events in other systems, not for the causes.

Moreover, this legitimising strategy can easily be combined with moral arguments in the name of social justice. By attributing responsibility for their health to individuals, the political system promotes them from being simple victims (experience) to accountable co-helpers (action) for successfully mastering efficient and just healthcare. If some individual habits and behaviour (action) lead to increased illness and thereby burdening public resources, why should other patients pay for this by reduced treatment? According to this reasoning, individuals who conduct a hazardous lifestyle put not only their own health at risk but they become responsible for scarce resources and scarce capacities that could be used for people in need of treatment despite healthy lifestyle. The shift from collective to individual responsibility can then be presented as a move towards more justice (Prioriteringscentrum 2007: 03).
Conclusion

This article started with the observation that a former taboo in the context of the Swedish welfare state – the idea of individual responsibility for one’s health – had recently become more and more acceptable. Our aim has not been to provide a systematic empirical examination of how and to what extent this semantic shift has replaced the welfare state as health-provider. Instead, our study has been guided by a theoretical approach. We aimed at an understanding of the communicative structures that made the shift to individual responsibility possible as well as necessary. With the help of systems-theoretical analytical tools, we have tried to map the complex interplay of different function systems, which each operate with their own modes of observation, and process their own reference problems. Seen in this light, the shift towards individual responsibility for one’s health is not interpreted as the result of neoliberal deregulation policies, as Marxist approaches would assume, or as disciplining bio-power, as post-structuralist schools state. Instead, we interpret it as a political solution to a political problem created by changes in the environment of the political system, namely a change in medical semantics towards a more inclusive concept of illness.

First of all, we found it crucial to keep medical and political observations of illness apart. As shown, the medical system is preoccupied with the reference problem of how to detect, treat and cure illnesses. Medical observations circle around the distinctions diagnosis/symptom and ill/healthy. In this regard, medical observations build on scientific causality. How do factor X and behaviour Y raise the likelihood for disease Z or hamper its cure? The reference problem of the political system is very different. It is to be found in the provision of collectively binding decisions, which, when coming into effect, make collectivity and political power visible. Therefore, political observations of illness reformulate medical diagnoses into the social consequences of this illness; that is, the rights and obligations individuals have when they are considered as ill. Medical causal schemes are reformulated into terms of responsibility. This does not concern the question of which germ triggered disease Z but the question of who, first, has to account for person A getting disease Z and, secondly, who has to account for the treatment and its financing, thus transposing it into the centre of political observations of illness.

Responsibility for somebody’s illness is then a political matter, which requires us to further examine the political communication of illness issues in order to get a theoretical grip on the shift towards individual responsibility. In accordance with systems-theoretical reasoning of equivalence functionalism, we interpret this move as a political solution to a specific political reference problem. But in order to grasp the reference problem and its implications, we had to look for possible triggers located in the environment of the political system. As argued above, one such trigger was a semantic change going on in the observational patterns of the medical system. The introduction of a bio-psycho-social conception of illness enabled an enormous amount of new diagnoses. Diagnoses built upon physical (or other) deviances that formerly were ignored or declared irrelevant are now – due to the extended conception of illness – redefined as symptoms for diseases.

This large number of new diagnoses would not create a big problem for society (and hence for politics), were it not to lead to more and more individuals being diagnosed as ill and, in consequence, more and more claims to treatment. A welfare state founded on the principles of inclusion, justice and solidarity like the Swedish one must respond to these demands. As a consequence, a rising number of claims lead to more scarcity of resources and capacities available in healthcare, thereby making restrictions and rejections of claims necessary. Restrictions address both the threshold of who will be considered as sick (and who not), and,
consequently, who will be authorised/unauthorised to receive treatment, compensation and other health insurance benefits. The reference problem for the political system, then, is to find a way to restrict the number of claims that can be anchored to the public domain and fulfill the claim of legitimacy. Seen in this way, the shift from collective to individual responsibility appears as a possible solution for this reference problem.7

We have to stress that the shift from collective to individual responsibility is neither absolute nor exclusive. The welfare state is still in charge of most of the healthcare provision and will probably remain so. What we can observe, however, is a break-up of the monopoly of collective responsibility for health taking place in these times. Recommendations for a healthier life have been with us for a few decades but, more and more, these recommendations are transformed into expectations about individual responsibility for one’s health i.e. into a redefinition of the sick role.

The welfare state and its associated health policy organisations watch their patients with the help of the distinction action/experience. It divides people into agents and victims of their illnesses. Those who live up to the demands on nutrition, motion, habits, and other components of preventive care and still get sick are considered as victims because, logically, their illness is due to factors beyond their control. In contrast, those who fail to meet the expectations are observed as agents responsible for their deeds (and omissions). They are observed as (more or less) active contributors to their bad health condition despite better knowledge and opportunity. If they had lived a better life, they would not have become ill. As a consequence, they will be ‘penalised’ accordingly. New measures are not yet put into practice everywhere at the same time, nor to the same extent. But as our examples should have illustrated, patients who do not follow these new expectations may find themselves increasingly having to take into account punitive measures such as denial of treatment, down-ranking in waiting times, higher insurance fees or the impossibility of getting insurance in the first place.

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Notes

1 This and the following translations from Swedish and German are our own.
2 When we speak of the medical system, we refer to a function system in Luhmannian terms. We emphasise the unity of the system and its external boundaries. The unity of the medical system is maintained by communication that is based on medical observations i.e. observations guided by medical concepts and theories. Although there are organisational, reputational and programmatic differences between medical professionals, practitioners and lay epidemiologists, they share the common denominator of observing by using the medical distinction sick/healthy (and not with political, religious or other distinctions, etc.). We want to thank one of the anonymous reviewers for this hint.
3 As a rule this is the case. However, persons with intellectual impairment are exempted. They are receivers of benefits but the expectations and demands directed to them are different from other role bearers.

4 Therefore, it has been criticised for generating ‘diffuse diagnoses’ (Olin 1999, Andersson and Andersson 2007).

5 Against this background, it is not important whether singular reported stories factually happened or whether they were mass-media exaggerations. Important, however, is that they – just by being reported – contribute to the legitimisation of the new expectations of individual responsibility in Swedish healthcare.

6 The latter has not been discussed in this article.

7 Logically, there are other functionally equivalent solutions possible, for example tax rises or the re-deployment of existing public resources towards healthcare at the cost of other realms of social policy. Although equivalent to solving the common reference problem, they might not be equally suitable to avoid new consequential problems, like discord, lowered tax moral etc. We do not have the space to discuss this here, but see a big potential for future research questions inspired by systems-theoretical thinking.

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