Chapter

DETERMINANTS OF SUBJECTIVE WELL-BEING OF CHRONICALLY ILL PATIENTS: THEORETICAL CONSIDERATIONS AND SOME EMPIRICAL RESULTS

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ABSTRACT

This paper suggests a framework for multidisciplinary evaluation of clinical and psychological determinants of well-being of the patients who suffer from chronic diseases, using Multiple Sclerosis (MS) as an exemplar case. Using insights from the recent literature in cognitive psychology, we argue that patients' experience with the disease may be distorted by the internal image of disease, resulting in coping strategies which are suboptimal and detrimental for one's own health state in the long run. We elicit various coping strategies of the patients (CS), and evaluate their effects on disease progression. Our results confirm this hypothesis: patients who actively resist the disease and continue normal life to the extent they can have lower rates of deficit accumulation than obsessive and abstinent patients.

1. INTRODUCTION

Interdisciplinary studies in social sciences and beyond are not anymore a matter of pure intellectual curiosity. In recent years, it gradually becomes an important practical way to improve everyday life. This consideration was the major driving force behind the present paper, where we set up and develop a multidisciplinary framework for assessment of clinical, psychological and social determinants of well-being of the patients suffering from chronic diseases, using a specific case of Multiple Sclerosis (MS).

In fact, any disease causes stress, hence psychological components of patients' well-being are important almost by definition. Yet there is another, perhaps even more important reason behind psychological approach to well-being, which is peculiar to chronic patients. Patients with long-lasting disease have enough reasons, remaining health resources, and time to form their own, subjective perception, or internal image of disease (IID), which is an interesting object of study on its own. Formation of IID has profound implications for disease development in combination with clinical, socio-economic, and cognitive factors.

We compare and analyze these determinants of patient's health in a unified framework, which draws on a distinction between the various measures of subjective well-being, as developed by Daniel Kahneman and his co-authors (see e.g. Kahneman e.a., 1997; Kahneman, 2003; Kahneman and Riis, 2005; Kahneman, 2011). Their research convincingly shows that individual perception of a particular episode in life (instant, or experienced utility) is not identical with this experience evaluated in other moments of time, including those moments when the same individual has to make a decision based on this experience. Inasmuch as this conjecture is true of healthy people, it should be even more valid for individuals caught by a serious illness, which affects not only their health state, but also one's *perceptions* of that state. Consequently, the patient who forms an IID which appears devastating for one's life prospects, would untimely classify herself as fatally ill, whereas according to clinical indicators this fate might in fact be very distant - e.g. would not have occurred earlier than in a decade or more years of relatively normal life. The problem is that this evaluation of one's health tends to spread over individual decisions, including those which *do* affect their health state in the medium and long run – such as whether to continue normal life whenever she can, whether to quit job, ask assistance of other people and, not least, whether or not to fulfill prescriptions and recommendations of the doctors. If these questions are answered in the negative, this might indeed affect objective conditions of the patient in the medium run,

confirming one's anticipations as ex post `rational', and speeding up worsening of her health conditions. This outcome is clearly bad for the individual, because *ex ante* the moment of disability could have been relegated by years and decades had she adopted a different attitude or *coping strategy* towards one's disease. It is also undesirable from social viewpoint, because more heavily ill patient will attract more resources of the caretakers, be it government subsidies or attention of patient's "significant others".

As a specific sample, we use patients with Multiple Sclerosis (MS), commonly acknowledged as one of the most severe chronic diseases, which in most countries entitles its patients for lifetime medical treatment covered by the government. Thus far, however, this treatment is typically focused on and conditioned by the clinical indicators, while their interaction with the psychological state of the patient, and especially self-perception of one's illness receives much less attention, or is downright ignored. In most countries, medical assistance based on clinical indications is at best supplemented with psychological testing and the professional counseling of a psychologist aimed to persuade the patient to adhere to the prescribed treatment. This approach, however, ignores the reverse causality of clinical diagnoses on the psychological status and the perceived well-being, which, in turn, are all important determinants of the actual coping strategy adopted by the patient in the medium-to-long run (Aikens e.a, 1997; Arnett e.a., 2002; Korostil and Feinstein, 2007). Existing studies have shown that elevated quality of life improves the clinical features of the disease (Ebrecht *et al*., 2004; 2008; Stanton e.a., 2007; Grant *et al*., 2009; Hamer *et al*., 2009). Conversely, feelings of anxiety and insecurity correlate with deterioration of life quality and poor adaptation to the disease (McNulty, *et al*., 2004; Rumrill e.a., 2004; Wineman *et al*., 1994). Further, the state of patient's health at the various stages of the disease has an impact on the quality of her life as well on the colleagues and relatives (Oswald and Powdthavee, 2007a,b). Affected by all these feelings and pressures superimposed on the clinical picture of disease, the patient forms an *internal image of disorder* (IID), which shapes her further attitude to the disease, including perception of oneself as of a `normal' or `handicapped' individual at early stages of the disease, willingness to resist to its adverse dynamics, or compliance with the doctors' prescriptions. In turn, these mental attitudes greatly affect the course of treatment, and thus the progression of disease and the possibilities to affect it with clinical methods supplemented by a variety of psychological and social assistance. Understanding the mechanisms of IID formation would thus facilitate the development of the treatment strategy aimed to alleviate progression and/or stabilize the clinical state of the patient, as well as serve

to optimize social policy in public healthcare in relation to MS patients and, subject to the appropriate corrections, to patients suffering from chronic illnesses in general.

The paper has the following structure. Next section summarizes characteristics of MS as the disease. Section 3 briefly outlines concepts of subjective well-being and suggests a simple theoretical framework to explore their interconnections. Section 4 describes our research design, including patients' sample and survey measures. Section 5 contains the analysis of our results, and section 6 discusses the implications and concludes.

2. MULTIPLE SCLEROSIS AS A CHRONIC DISEASE

Multiple Sclerosis (MS) is one of the most severe chronic diseases, which cannot be cured at present state of medical knowledge, and whose origins are not well understood. It is a chronic autoimmune disease in which protein myelin is destroyed throughout the brain and the spinal cord. Myelin is a dielectric covering an axon (appendix of a nerve cell) which allows electricity transfer from one nerve to another.
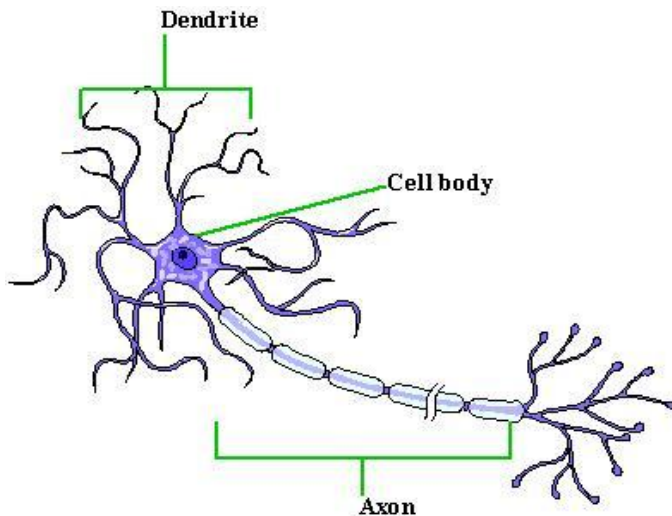
Figure 1. Neuron and myelin covering of axons

As electricity (beginning of any activity in the body) is crucial for any data transfer from one nerve cell to another, the case of myelin destruction means cessation of nerves communication, which results in loss of a body function associated with these damaged neurons. In MS the immune cells of the body destroy myelin layer around the axon in random

places (hence the characteristic `multiple'), therefore it is currently impossible to predict the future organ or function of a body which is going to be eventually 'turned off'. With illness' progression, the patient becomes disabled, albeit at unknown speed. Some authors claim that MS does not reduce the general life expectancy, while others (Bronnum-Hansen et al. 1994, 2004) believe that this disease makes life up to 13 years shorter.

Usually the first signs of illness are noticed at the age of 20-30 years, yet, like many other chronic diseases, MS cannot be reliably diagnosed with its first manifestations. At the early stage of disease, the commonly occurring symptoms include loss of some of the visual fields or of the entire vision, blurred or double vision, muscle weakness, loss of balance, fatigue, memory disorders, and/or urinary incontinence. These symptoms per se do not necessarily imply MS, because they can be transient or indicate other disease. Definite diagnosis requires at least two clinical relapses with substantive time gap between them or MRI findings, showing "dissemination in time". At the same time, early diagnosis is instrumental for timely start of the treatment, as the earlier it starts, the better are patient's long term prospects.

In most countries of the world, MS patients are entitled for State Life Support. In 2010 government of Russia spent around 59 mln. euro providing about 30 000 patients with treatment according to official statistics (Ministry of Health and Social Development report 2010). This help is instrumental for most people, as typical treatment consists of drugs taken constantly and regularly, worth 15 to 20 thousand euro per annum. Currently available medicine at best significantly slows down the progression of the disease, but cannot prevent eventual aggravation and degradation of health later in patient's life.

Medical assistance based on clinical indications is at best supplemented with psychological testing and the professional counseling of a psychologist aimed to persuade the patient to adhere to the prescribed treatment.

Like many other chronic diseases, MS cannot be reliably diagnosed with its first manifestations. Once alerted about the possible MS diagnosis by a local neurologist, or simply after self-assessment of the symptoms, a typical patient feels a shock, which often pushes him or her to react to the news in an unreasonable manner. For example, when asked by a doctor about what kind of health concerns does the patient experience, a typical answer sounds like 'There is a clouding in MRI image', instead of spelling out physical problems, if there are any. Some patients would collect information about this diagnosis asking relatives and friends with similar symptoms or medical background, and/or surf the Internet for the patients' and

doctors' forums, the sites of pharmacological firms, etc. Having collected these (often unreliable) data, the patient has at her disposal a set of clichés to be used to construct the IID which, at this stage, will usually be affected by the shock, neglecting one's capabilities to cope with the new circumstances of life. Thus, at the initial stage, the patient confronts mostly not clinical, but psychological problems – e.g., believing that this diagnosis implies one's life approaching its end, and readily surrendering to the disease, whereas in fact she might still face many years of active and productive life (de Ridder e.a, 2000; Fournier e.a., 2002; Dennison e.a., 2009). Hence, it is instrumental that the patient takes an active side in her fight against MS, rather than giving up straight away (McCabe, 2002; McCabe and De Judicibus, 2005). This is especially important at the early stage of the disease, where proper treatment and strict fulfillment of doctors' recommendations might be instrumental in relegating the late stages of MS to years and even decades (Kroencke e.a., 2001; Lynch e.a., 2001).

It is no less important to consider individual differences in attitudes towards the disease. To provide better assistance to all kinds of patients, it is important not to reduce the disease to its objective manifestations, but take into account the attitude of MS patients to this disease, which is shaped under the stress of clinical symptoms and social environment including the relatives, colleagues, and acquaintances (Patten e.a, 2000; Schwartz and Frohner, 2005). All these conditions are perceived and transformed by the patient, which reacts to the MS symptoms and develops the attitude towards the disease referred to as IID.
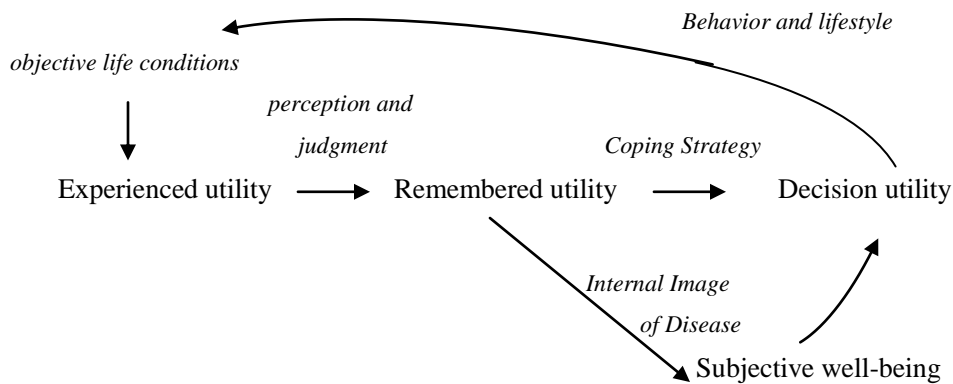
Clearly, IID formation is not a panacea that can treat MS. However – and this is our working hypothesis – individual attitudes towards one's illness affect quality of treatment, and hence progression of the disease itself. Hence, we aim at development of a system of assessment of clinical and psychological state of patients suffering from chronic diseases, leading to the classification of patients' IID conditional on observable clinical, socio-economic and psychological factors. To understand their interactions and effects (either real or imagined) on subjective well-being, let us look more closely at the problem of its measurement.

3. MEASUREMENTS OF SUBJECTIVE WELL-BEING

Attempts to measure individual utility (or well-being) comes back to at least Jeremy Bentham in late XVIII century; yet only recently these attempts have been put on satisfactory theoretical and empirical footings. The key role in this process has been played by Daniel Kahneman, Nobel laureate, with his numerous co-authors over the last 15 years (Kahneman

e.a., 1997; Kahneman e.a., 2004a,b; Kahneman and Sugden, 2005; Kahneman e.a., 2006). In these works, theoretical and empirical distinction has been drawn between instant perception of well-being in a momentary state, or *experienced utility*, and evaluation of one's satisfaction from a particular sequence of momentary experiences, or *evaluated utility*. The former «is best understood as the strength of disposition to continue or to interrupt the current experience" (Kahneman, 1999, p.4). The later can be thought of as a subjectively taken integral measure of a sequence of instant utilities over time, but possibly distorted due to various psychological biases in perception and judgment, such as violations of temporal monotonicity (Kahneman, 1999; Kahneman e.a., 2006). This utility, in turn, serves as a basis (perhaps further distorted) for *remembered utility*, which «is the global evaluation that is retrospectively assigned to a particular past episode or a situation in which similar experiences occur" (Kahneman, ibid.) or "a gestalt impression constructed from only a small and often biased sample of experience» (Reid, 2004, p.6-7). A sequence of these utilities may be integrated further to form subjective assessment of quality of one's life, or well-being across all dimensions of human life. At the same time, remembered utilities play an active role when they serve as inputs to utilities anticipated at the moment of decision from particular courses of action in similar situations. These are weighted and balanced against each other in calculation of *decision utility*, which is reflected in choices, actions or otherwise revealed preferences, which bring another sequence of experiences, etc.

Differences between many of these utilities are rather subtle both empirically and as a theoretical construct, which seems to be one of the reasons why these notions are not linked to a rigid formal theory. However, an important insight from this taxonomy is that experienced utilities (perceptions of instantaneous feelings and sensations) do affect remembered utility (Internal Image of Disease), which, on the one hand, crucially determines perception of one's health state (subjective well-being) and, on the other, is instrumental in reaching decisions affecting one's behavior towards the disease (coping strategy). These connections are illustrated in Figure 2.

Behavior and lifestyle

objective life conditions

perception and
judgment

Coping Strategy

Experienced utility ⟶ Remembered utility ⟶ Decision utility

Internal Image
of Disease

Subjective well-being

Figure 2. Interdependence between various types of utility and behaviour.

As individual perceptions and feelings are largely outside of control, little can be done to affect perceptions of different states, as well as rememberances of one's experience flows without substantial interference into individual psyche. This option we leave for the future; a first approach to this would require substantial utilization of methods of measurement of individual well-being, either as instantaneous intakes via Experience Sampling Method (Csikszemtmihalyi, 1994), or as measures of recent past experiences aggregated over the last day via Day Reconstruction Method (Kahneman e.a., 2006).

The former, ESM, assumes that subjective representations reflect different psychological reality: experienced utility is based on psychophysiology of perception, whereas in evaluated utility, these perceptions are intermediated by memory, individual background, mood, contextual conditions, and sequencing of experience flows (the peak-end rule). These differences manifest in IID representation: for example, if the perceived health state (instant utility) is rather good during a day (say, 5 of 10 according to subjective scale) but the background belief on fatality of the illness is high, the patient's feelings and IID will be inadequate for decision making (say, 2 of 10 in the same scale) provoking non-cooperation with the active therapy. That is, if the doctor could persuade the patient that her health state is really not that bad, recalling back the 'experienced utility' of the patient at the early stage of

disease, instead of self-invoking IID of evaluated utility, the patient is likely to take a more active role in her own treatment strategy. There is a number of ways to drive the patient to such reasoning (Hoeffler e.a, 2006): for example, one can solicit patient's self-assessment of health status only following a sequence of specific questions concerning her feelings and her life (memory, general condition, ability to self-care, etc.) which are likely to be positively answered, etc.

The second tool to evaluate experienced utility is the Day Reconstruction Method (DRM) introduced by D. Kahneman and co-workers, which is now widely used in psychology. Recently, A. Knabe, S. Rätzel, R. Schöb, and J. Weimann used this method to compare well-being of the employed and unemployed persons in Germany. DRM is based on self-assessment by the respondent of utility of various events during their previous day, which are made in convenient (for the respondent) moment. Every event is assessed with several criteria (fatigue, enjoyment, tedium, relaxation, happiness, *etc.* – overall, 8 to 12 categories). The respondent should evaluate each category according to subjective perception with the help of 6- or 10-point scales ranging from 'not at all' to 'very much'. It was found that unemployment indeed affects instantaneous well-being.

At present, however, we do not have the resources to investigate connections between instantaneous perceptions and remembered utility. By contrast, dependencies between given perceptions, individual decisions and subjective well-being are relatively simple, and can be captured by the following theoretical framework.

4. THEORETICAL FRAMEWORK

For the sake of transparency, we start by describing the connections between individual lifestyle (actions), subjective well-being, chronic disease and IID by means of a highly stylized model, which is nevertheless set up without loss of generality. The model describes an individual in three time period: in $t=0$ she is in healthy state (without chronic disease, which is also the benchmark case of healthy subject). In $t=1$ she is at early stage of the disease (say, after diagnosis under MS, but before robust accumulation of cognitive deficit). Finally, in $t=2$ she is at late stage of disease, with accumulated deficit. Impact of disease is captured by disease function d, which is normalized for three stages as $d_0=0$, $d_1=1$ and $d_2>1$, depending on natural factors and individual behaviour as described later.

In normal case, our individual performs some tasks whose variety and complexity is represented by a single real variable x called `effort', which is interpreted as an aggregate measure of quantity and quality of activities, including paid and unpaid work, housekeeping, childcare etc. Activities in the list are associated with increasing disutility which is captured by an increasing convex function $C(x)$, $C'>0$, $C''>0$. Cost function will also depends (is conditional upon) disease, whenever $d>0$. Efforts serve to produce output given by a production function $Y=Y(x)$, which we assume linear for the sake of simplicity, but again without loss of generality. Finally, the subject has remembered utility (perceived subjective well-being) which is defined on the difference between the two functions, $U=U(Y(x)-C(x))$, which may be best thought as of identity, and in general will be a monotonic transformation of the difference between its arguments; and in either case, it is increasingly convex in efforts, $U'(x)>0$, $U''(x)<0$. The three functions are illustrated on Figure 2; they look analogous to standard production function.
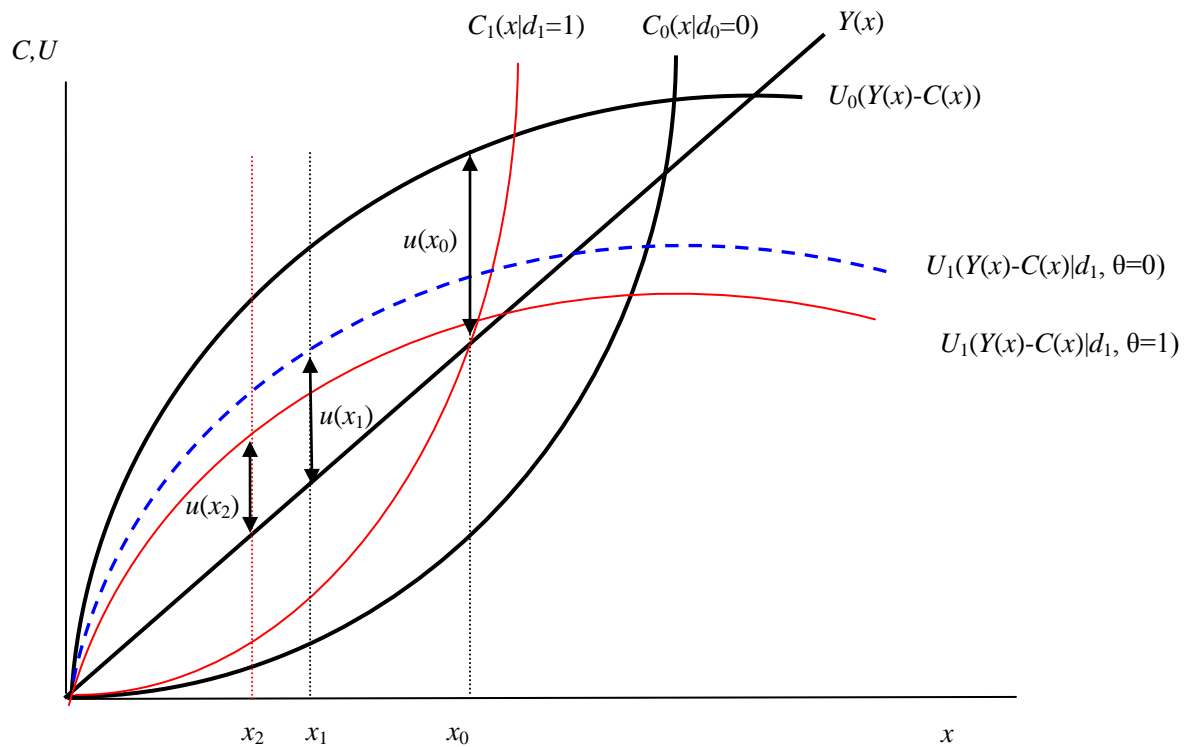

Figure 3. Simple model of chronic disease development.

Initially, the individual is in healthy state, so her functions are drawn in dark bold, and optimal decision will be at a point of maximum difference between $Y(.)$ and costs $C(x)$ of a healthy type with no disease (C_0, conditional on no disease at time 0, as denoted by the disease function $d_0=0$). This utility is maximized at a point $x=x_0$ where $x=C_0'(x)$, and gives the individual utility $u(x_0)$ shown by vertical double arrows.

Suppose now that at time $t=1$, the patient to get trapped by MS, so the disease function $d_1=1$ which causes an inward shift of the cost function, meaning that disease makes completion of the same tasks more difficult (formally, this means that the slope of the $C(x)$ function becomes steeper as d increases, or the cross-derivative $C''_{xd}>0$). Again for simplicity we assume that disease leaves the production function intact, but shifts the cost function to $C_1(x|d_1=1)$ which is shown in thin (red) lines to the left of the former. This shift causes the difference between the two functions, to shift down – the new U_1 function as shifted by d_1 alone is shown in the blue line. The new individual solution for the optimal efforts is given by the condition $x=C_1'(x)$, with solution $x=x_1$ to the left of x_0, because of the properties of the functions. This solution stipulates less efforts and lower utility $u(x_1)$, again shown by a double arrow.

This solution, however, would have been valid only if disease affected the costs and utility only directly, via worsening health conditions, i.e. if remembered utility would have been identically equal to the integral of the experienced one. In general, however, they are different depending on psychological types of the individuals (for short, types), which we denote by θ. For illustrative purposes, we confine attention to two types: `optimistic' with undistorted perceptions, and remembered utility identical to the (integral of) experienced one, and labelled $\theta=0$; and `pessimistic', with remembered utilities affected and depressed by the experience of disease, and $\theta=1$, so that the first period utility decreases in θ, $U_1'(\theta)<0$. (In reality, types shall be located in-between these two extremes, but the idea would remain the same.) As a result, optimistic type has utility $U_1(x|d_1, \theta=0)$ undistorted by the disease (the dashed line described above), while utility of the pessimistic type will still depend on the difference $Y(x)-C_1(x)$, but will be further downscaled to $U_1(x,|d_1, \theta=1)$, which is shown in the thin line. Maximizing these functions, optimistic type will keep the solution at $x=x_1$ and enjoy utility $u(x_1)$, while pessimistic type (again by construction of the utilities) will have lower efforts $x=x_2 < x_1$, and lower utility $u(x_2)$, not anymore equal to $Y(x)-C_1(x)$ in case of identity U_1 function. Here again, just for simplicity and without loss of generality, we assume that types of the patient affect only utility, but neither cost nor productivity.

Finally, in stage 3, disease will further aggravate, resulting in worse clinical indicators (accumulated deficit). As implied by the medical evidence discussed above, we conjecture that this deficit accumulation is inversely proportional to efforts x (which include, at least, efforts to fulfil all doctors' prescriptions) – formally, $d=d(x)$ and $d'(x)<0$ at $d>1$. This means that higher values of x slow down accumulation of deficit. In other words, even though $C_2(x|d_2)< C_1(x|d_1)$ because of natural progression of the disease, patient who adopted strategy x_1 instead of x_2 at stage 1 will be exposed to smaller inward shift in the cost function in period 2 because $C''_{x\theta}<0$ at any level of $d>1$. This mechanism may be extended to future periods, revealing the same tendency: optimistic individuals will choose higher efforts resulting in lowering the rate of progression of their disease, and as a result, would enjoy higher cumulative lifetime utility not only because of their type, but as a result of their sequential decisions (coping strategy). A stylized pattern for well-being of a healthy individual and of an individual who got caught by MS at the same moment of lifetime (at the origin) is illustrated on Figure 3. Perturbed line without trend shows subjective well-being of an `ideal' healthy patient, whose life experiences are affected only by random day-to-day fluctuations. Similar fluctuations are superimposed on the subjective well-being of an individual caught by MS, where uprising trends corresponds to secondary progressive MS type, which is initially relapsing-remitting, but progressive later on; but the same idea generalizes to the other types of MS. Both individuals were ex ante identical, so had the MS patient been healthy, her profile would have been given by the bottom line - exactly that of a healthy person.
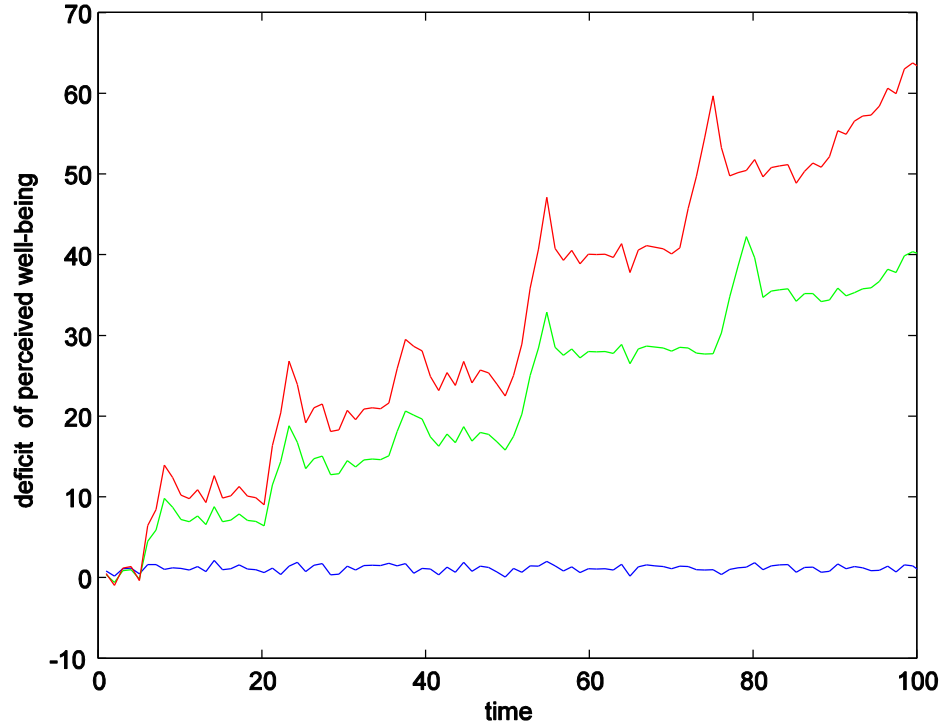
Figure 4. Accumulation of deficit and subjective well-being of a healthy person (blue, bottom), optimal (green, middle) and downward-biased (red, top) MS patient

Red (top) line corresponds to the accumulation of deficit of a suboptimal patient who exaggerates own disability at early stages of the disease. Green (middle) line is an optimal strategy of a patient, who suffers from relapses, accumulates deficits and ultimately lives less happy life than healthy person. However, this person still lives longer and healthier life than the suboptimal (`red') patient, both because of premature exclusion of this latter from active life in the early stage of disease, and because of systematic abstinence from fighting the disease, resulting in earlier decay. As a result, optimal progression of the disease is lower, and accumulation of deficit could have take place at later points in time.

This model naturally leads to an empirical estimation strategy. Interpreting the x's as an aggregate decision strategy, we obtain utility as a continuous mapping from that strategy as well as from objective conditions of disease development, and patient's type, including her IID. We define and estimate this model in the next section.

5. EMPIRICAL STUDY

To conduct and empirical test for our hypotheses, we conduct an empirical study consisting of two parts. The first of these, conducted in March 2011, has been qualitative, and was aimed at revelation of coping strategies using text analysis of several Internet-communities of Russian MS-patients. As a result, we uncover 7 substantially different strategies of the patients, depending on their orientation at work and colleagues, family, recovery, ignorance of the disease, etc. Based on these, we proceeded with the second part: a socio-demographic and psychological questionnaire distributed in April-July 2012 to a sample of MS patients of the hospital of the Research Institute for Neurology. Design and results of this study are presented and discussed in what follows; the study complied with the international ethical standards of research involving human subjects, as has been confirmed by the professional IRB of the Institute for Neurology in March 2012.

5.1. Qualitative study

For this study we have investigated over 500 posts and messages found on Russian internet forums, which have been analyzed using qualitative methods. As a result of our analysis, we have identified several coping strategies in accordance with the basic life values of patients as revealed in their electronic communications.

1. **Family** as a strategy characterized with responsibility, presence of an idea about certain obligations (family duties) which gives patient an incentive to live.

"Most of all support and respect from family and a sense of 'cannot fall apart' helped. And you cannot fall apart, because a baby was born and care for him cannot be delegated to anyone (at least at such an early age). This is how I am living now"
http://community.livejournal.com/vmesters/10888.html, assessed March 2011

2. **Work** is a similar attitude, but centered around an idea of duty at work rather than servicing the family.

3. **Recovery** refers to behavioral goal that at present appears unattainable: overcome the disease completely. This can be exemplified with the type of behavior when a patient is constantly trying new treatment options, does not believe in the incurability of the disease, or hopes for a breakthrough in medicine which will help her becoming healthy again:

"Is it possible to cure multiple sclerosis with a diet? An affirmative answer (with an exclamation point!) occasionally appears in bold and capital letters on pages of a newspaper

or the confession book." http://www.antisclerosis.ru/forum/topic22.html, assessed March 2011

4. Some people caught by the disease come to the conclusion that the only reason to live is for the sake of positive emotions. We label this kind of attitude '**Hedonism**': a patient of this type lives under the motto "take everything from your life here and now", fills the life with risks, relying on the fact that life is short anyway:

"I am even too active now. Don't take any pills. Proposed to some people to try what I did, but they rely on medicine. Well, that's their business, though, quite sad of course."

http://community.livejournal.com/vmesters/18060.html, assessed March 2011

5. A somewhat similar strategy '**Denial**' is applicable to persons who, having been reported to have diagnosed MS, do not believe in it, hoping that the doctor was wrong, and continue living as they lived before ("If the facts are against me, the worse for the facts.")

"So we took this a mistake from the beginning. I took PK_MERTS in appointed doses. This medicine did not help me at all as one would have expected! Note that NO ONE ANNOUNCED AN ACCURATE DIAGNOSIS YET! Began to doubt the description of MRI images (which were made in Yakutsk, Republic of Sakha (Yakutia). We did not do any diagnostics except the one in Yakutsk)) and then, consequently, in the relevance of diagnostic procedures performed." http://www.antisclerosis.ru/forum/topic95.html,

assessed March 2011

6. '**Dependence**' is a strategy elaborated by people who believe that disease makes them eligible for virtually unlimited assistance and help from the others. For such people, support from others is overly important, even though it may not be necessitated by the present state of patient's health. It seems that adopters of this strategy are characterized by rather complex psychological problems whose origins are beyond MS.

7. Finally, strategy `**Depression**' is reserved for people who, unfortunately, have neither physical nor mental or financial abilities to cope with the disease. They cannot accept the possibility of death. They have no power or will to fight for their life, and express preference for decease as soon as possible.

Our analysis of internet forums suggest that these 7 strategies – *Recovery, Depression, Hedonism, Dependence, Family, Denial* and *Work* – can probably be traced over to general population. However, some of them are very unlikely to be well-represented in any quantitative study, including our own, which we discuss in the next subsection. Specifically,

strategies 'Depression' and, to a lower extent, 'Denial', are more likely to be under-present among the patients of the Institute of Neurology, as many depressed people might never come to the clinic. In view of that, we restrict attention to a subsample of strategies Finally, strategies like `hedonism' or `consumerism' might be less common.

5.2. Quantitative study

Our quantitative questionnaire has been partly based on the above qualitative conclusions. It consisted of the following parts:

I. Clinical examination of the patient, including assessments of pharmacotherapeutic efficiency, *duration* of disease and number of relapses. Of special importance of these is the Expanded Disability Status Scale (EDSS – Kutzke, 1983) - a canonical objective characteristic of the degree to which the patient is caught by MS. This measures the extent of disorders in 8 functional systems of the body (visual, cerebral, brainstem etc.) in a scale from 1 (minimal signs of disability in one of the functional systems) to 7.5 (restricted to wheelchair, which is maximum in our sample) and 10 (death due to MS). We use this indicator as our main dependent variable, as it captures well the degree of illness, and is closely correlated with other objective characteristics, such as the duration of MS in months (correlation 0.58), and number of relapses (correlation 0.39, both highly significant).

II. Individual questionnaire from which most of our explanatory variables have been drawn. Its main constituent was a battery of 35 questions aimed at revelation of the 7 CSs outlined above. For example, 5 questions of the kind "I don't believe that I have an incurable disease", "Medical research would soon allow to find an efficient remedy against all serious diseases" and 3 others characterize the strategy of Recovery, and similarly for the other strategies. Subjects have to respond to all 35 questions using the scale from 1 (complete disagreement) to 5 (complete agreement); direct sum of responses to all 5 questions in the strategy category is used as measure of the extent to which the subject endorses it. We use these variables to define CSs as behavioural determinants of MS progression, which is the main explanatory variable of our interest. Maximum correlations between these measures was 0.47, which ensures sufficient variation. On the other hand, our sample size was rather low,

so that for our empirical study we reduced their dimensionality as described below.

Other explanatory variables include objective determinants of MS progression, including *gender, age,* number of *children*, *marital*, *material* and *employment status*, *general health* status before and after the disease, as well as other self-reported characteristics. Due to sample size restrictions, we do not employ most of them, and characterize below only those which are used in what follows.

III. **Psychological questionnaires** which include the following tests used in the study

1. **SF-36** (www.sf-36.org), which is a widely used and highly validated survey of health and life quality consisting of 36 questions, combined in eight scales which can be then converted to two: physical functioning and mental health. This is the most common measurement of the well-being in general and medical surveys, including MS clinical practice. We complement it by additional tests, such as, FAMS (58 questions) aimed at assessment of quality of life evaluation, and

2. **MSIS-29** (Multiple Sclerosis Impact Scale) developed by the National Hospital for Neurology and Neurosurgery (London, UK) to measure disease experience of MS patients.

3. **HADS** (Hospital Anxiety Depression Scale**)** measuring level of anxiety and depression of a patient during general medical treatment. It consists of 14 questions with 4 answer options. The resulting output consists of concluding levels for two subscales with three value intervals: 0-7 for normal, 8-10 for sub-clinically expressed anxiety/depression, above 11 for clinically significant level of anxiety/depression.

4. **ASS** (Asthenic State Scale) developed by the Russian clinical psychologists L.Maykova and T.Chertkova), which consists of 30 questions answered at fourfold qualitative scale. The resulting value has four interpretation intervals with approximate length of 20 points: from complete absence of asthenia (from 30 to 50) to severe asthenia (from 101 to 120).

5. `**Hardiness**' test developed by a Harvard psychologist Salvatore Maddi as a general measure of individual vitality in difficult life circumstances (Maddi

and Hightower, 1999). It consists of 45 questions combined in three-dimensional attitudes (commitment, control, challenge), which may further be compressed into a single hardiness measure to characterize individual strength to cope with life problems.

6. **EPI** (Eysenk Personality Inventory, www.edits.net/products/54-epi.html) is a standard general test which measures two personal characteristics: level of extraversion/introversion and emotional stability/instability. It consists of 57 seven questions, approximately half of which measuring the first, and another half - the second characteristic; a few remaining questions are used to validate the answers.

We use a battery of these tests (and of some more not reported here) to cover different possible interpretations of IID, and as a mean of calibration of our results.

5.3. Data collection and description

As stated above, we have collected the survey data from 52 hospital patients of the Institute for Neurology of the Russian Academy of Medical Sciences. It should be noticed that this pool is somewhat different from the general population, as it consists of the patients who have pursued their medical treatments at a clinic rather than, e.g., just staying home in full desperation upon learning their diagnosis, which seem to be present in our qualitative study.

Completion of full questionnaire took about 2 hours of patient's time (which was abundant for hospital patients), and has been voluntary, with intervention of the specialist only if explicitly asked for help. Neither the patient nor the interviewer (one of the authors) received any remuneration. Instead, patients were (rightly) told that this study would be part of a research that will help them and similar patients to better understand the mechanisms of MS development; subsequent responses have confirmed that this motivation was quite valuable for the subjects. All patients in the study were in good cognitive state as certified by the MOCA test for cognitive abilities; however, one person was excluded from the sample because of heavy complementary disease (brain cancer). Some more observations were forcedly dropped of the study because of only partially completed questionnaires, which restricts the scale of the empirical model and the set of questions we can use.

Most (about 2/3) of our patients have been either married or had permanent life partner. Other descriptive statistics of our sample, including variables used for the empirical study, are provided in Table 1.

#	Variable	N	mean	med	st.dev.	min	max
1	EDSS	50	4.09	4	1.66	1	7.5
2	Age	51	41.2	42	10.2	24	66
3	Gender (0 – female, 1 – male)	51	.294	0	.46	0	1
4	Children (number)	44	1.14	1	.795	0	3
5	Education (1 – research degree, 5 –secondary)	51	2.39	2	.961	1	5
6	Workload change due to MS (0 – no, 1 – yes)	45	.6	1	.495	0	1
7	Labor productivity change due to MS (2 – some increase, 6 – complete loss)	49	4.24	4	1.09	2	6
8	Homework load decrease (0 – no, 1 – yes)	51	.804	1	.401	0	1
9	Change in MS condition in last year (1 – much worse, 5 – much better)	50	2.16	2	1.04	1	5
10	General health before MS	48	3.44	3	1.15	1	7
11	Recovery	47	18.8	19	3.44	8	25
12	Depression	47	11	10	4.57	5	24
13	Hedonism	46	14.6	14	3.48	8	23.8
14	Dependence	48	16.8	17	3.82	8	25
15	Family	48	20.3	21	2.83	13	25
16	Denial	47	14.1	14	3.54	9	23
17	Work	44	14.2	13.5	3.98	8	24
18	Relapses of MS (number of)	51	5.65	3	5.02	0	20
19	Duration of MS (years)	50	9.9	8.5	7.53	0	30
20	Eysextraversy	50	10.1	10	4.22	2	19
21	Eysneuro	50	14.6	14.5	3.87	4	22

Table 1. Summary statistics of questionnaire data

The first ten variables are self-explanatory. Rows 11 to 17 correspond to coping strategies – as can be seen, most of these have received about mean scores (14 to 16), with an important upward bias for Family (with mean 20.3) and downward bias for Depression (mean 11). Row 10 summarizes general health status before being diagnosed by MS (abbreviated as HHBEFORE). For this variable, value 1 means "I was already an ill person used to consult physicians", 2 –"Didn't have any serious illness, but consulted physicians at every occasion", 3 – "I considered myself as a healthy person and consulted physicians only in case of necessity", 4 – "I consulted physicians in case of necessity and regularly attended medical examinations", 5 – "I was a healthy person and practically never consulted physicians", 6 – "I treated myself without going to physicians in case of necessity", and 7 – "other", all self-reported by the patient. Inasmuch as this scale is effectively qualitative, statistics for this variable should not be treated literally. However, as categorical measure, it plays an important role of an exogenous instrument of self-assessed health state before the patient got caught by MS.

It may be asked to what extent is this variable truly exogenous to present health of the patient. Indeed, a patient caught by MS could easily extend its present status to previous perceptions of oneself as of a very ill person. However possible (e.g. due to hindsight bias – Fischhoff, 2003), this interpretation does not appear to be valid for our data. First, the distribution of answers to HBEFORE question shows an overwhelming (68%) prevalence of answers in category 3, with further 18% of choices of category 5 – i.e., subjects have viewed themselves as generally healthy people before being diagnosed with MS. At the same time, we have in our disposal two more questions: "what do you do first thing now when you feel unwell", and "what have you done first thing when you felt unwell before you have been diagnosed with MS", again measured at qualitative scales. General tendencies for these questions are the same: specifically, 73% of subjects reported the same strategy before and after the MS diagnosis. This means that almost ¾ of our respondents perceive (and report) their health attitudes to be the same across the MS treatment, implying high correlation between their coping strategies.

Similar considerations can be applied to psychological characteristics given by the EPI tests. Test statistics for the two scales, Extraversy and Neurotism, are provided in the last two rows of Table 1. Neutral values for both scales are about 12. Value over 15 on an extraversy scale characterizes an individual as an extravert, and value below 9 as an introvert. Similarly,

value below 15 on the Neurotism scale are treated as high, values below 7 – as low. EPI tests are important because, unlike most other psychological tests, they are known to be robust to temporal variation in subject's experiences and perceptions, in particular under MS treatment (Lin e.a., 2009). In other words, individual temperament remains relatively constant across MS, and also may be highly correlated with her coping strategy.

5.4. Coping strategies

Results of Section 4 suggest estimation of an empirical model of the form $y_i=f(x_i,z_i)+e_i$, where y_i is measure of severity of disease, z_i is coping strategy (CS), x_i is objective measurement of patient's state and other covariates, and e_i is the error term.

The main limitation for our study is sample size, which is quite small (51 valid observation), effectively precluding estimation of the effect of all 7 CSs. In view of this, we reduce the dimensions of individual decisions by means of principal component analysis whose results are provided in Table 2. We retain 4 principal components which account for over 3/4 of the total variation in the CS. The first principal component captures Denial, Work and Hedonism, i.e. in general, reflects patients' **rejection** of one's disease as a new state of health and life stage. The second component reveals high Dependence, Depression and Recovery. This attitude is opposite to the former: it is typical of patients who are centered on (**obsessed** by) the disease, and are desperately concerned about it. The third component reveals Family and Depression, which is symptomatic of a person who **focuses** her mind and family resources on the disease, even if at the expense of openness to the world. The fourth component is in Depression and Hedonism – these are people who **grieve** and feel very depressed by their diagnosis, as it denies them the chance to enjoy life to the extent they would like. Given the data restrictions, we limit attention to the first four components, denoted *pca1* through *pca4*.

Component	Eigenvalue	Difference	Proportion	Cumulative
Comp1 (rejection)	2.132	0.783	0.304	0.304
Comp2 (obsession)	1.348	0.310	0.192	0.497
Comp3	1.038	0.129	0.148	0.645

(focus)

Comp4 (grief)	0.908	0.105	0.129	0.775
Comp5	0.803	0.365	0.115	0.889
Comp6	0.437	0.103	0.062	0.952
Comp7	0.334	.	0.047	1.000

Variable	Comp1 (pca1)	Comp2 (pca2)	Comp3 (pca3)	Comp4 (pca4)	Comp5	Comp6	Comp7
recovery	0.1947	0.3785	-0.6392	-0.3572	0.4377	0.1367	0.2692
depression	-0.2166	0.4948	0.3973	0.4785	0.4110	0.3350	0.2007
hedonism	0.4834	0.3207	-0.2329	0.3845	-0.1825	0.1687	-0.6322
dependence	-0.0935	0.6671	0.0740	-0.1574	-0.6041	-0.3089	0.2359
family	0.2928	0.1649	0.5715	-0.6426	0.1784	0.1497	-0.3053
denial	0.5476	-0.1920	0.1191	0.0673	-0.3353	0.4853	0.5447
work	0.5359	-0.0043	0.1818	0.2311	0.3114	-0.6981	0.2051

Table 2. Principal components for CS.

These components reveal proper correspondence with clinical characteristics as captured by the major psychological tests. Correlation coefficients and their significance are provided in Table 3.

	reject	obsess	focus	grief	SF36-1	SF36-2	MSIS	HADS1	HADS2	Hard	ASS	EPI1
rejection	1.00											
obsession	0.10	1.00										
focus	0.05	0.28	1.00									
grief	-0.38*	-0.06	0.00	1.00								
SF36 1	0.46*	-0.40*	-0.16	-0.07	1.00							
SF36 2	-0.04	-0.18	-0.17	-0.16	0.07	1.00						
MSIS	-0.23	0.39*	0.16	-0.08	-0.68*	-0.34*	1.00					
HADS1	-0.02	0.25	0.14	-0.09	-0.31*	-0.44*	0.42*	1.00				
HADS2	-0.05	0.22	0.23	-0.10	-0.32*	-0.46*	0.37*	0.67*	1.00			
Hardiness	0.31	-0.17	-0.17	-0.23	0.30*	0.41*	-0.37*	-0.34*	-0.37*	1.00		
ASS	-0.19	0.47*	0.17	-0.03	-0.37*	-0.47*	0.40*	0.38*	0.40*	-0.39*	1.00	
EPI1	0.29	0.14	-0.20	0.04	0.14	0.21	-0.22	-0.14	-0.28*	0.22	-0.07	1.00
EPI2	-0.06	0.48*	-0.05	-0.08	-0.31*	-0.35*	0.39*	0.46*	0.37*	-0.34*	0.48*	-0.09

Table 3. Correlation coefficients of coping strategies (rejection through grief) with psychological characteristics.

Abbreviations: SF36-1: physical health, SF36-2: mental health, HADS1 – worry, HADS2 – depression, EPI1: Extraversy, EPI2: Neurotism. Starred (*) correlations are significant at 5% level.

This table confirms two sets of our prior expectations: first, CSs are rather uncorrelated with each other, revealing differences in CS. By contrast, most of psychological characteristics, including MSIS, HADS, Maddi's Hardiness, ASS and EPI-2, are highly correlated with each other, as well as with coping strategy 2 (obsession). This suggests that most of these measures are affected by the diseases – a fact which is confirmed by other studies (Yousfi e.a., 2004). Hence they also are likely to be correlated with unobservable factors of the disease, alongside with coping strategies.

This leads to another empirical problem: CS is of course dependent (endogenous) to the disease, hence its effect cannot be identified directly by means of an OLS regression. In order to instrument for it, we need a set of variables that are correlated with patient's CS, but uncorrelated with the unobservables - error term in the main equation. Our earlier discussion suggests a proper route: one instrument for this would be general health before the disease, HBEFORE, and another, EPI Extraversy (EPI-1), as a psychological measure unaffected by the disease, which we use as instrument for time-invariant psychological characteristics of the individual.

Altogether, our empirical model takes the form

$$\text{EDSS}_i = \beta_0 + \beta_1 \text{ AGE}_i + \beta_2 \text{ GENDER}_i + \beta_3 \text{ PCA(j)}_i + \varepsilon_i,$$
$$\text{PCA(j)}_i = \alpha_0 + \Sigma_k \gamma_k \text{ HBEFORE}(k)_i + \alpha_1 \text{ EPI1}_i + \eta_i$$

where j=1,2,3,4 refers to the number of the principal component for the CS, which are instrumented by the exogenous levels of health assessment before the MS, and PSY are the two EPI indicators taken as proxies for the IID taken from psychological questionnaires; ε_i and η_i are uncorrelated iid error terms.

5.5. Results

Estimations of models for the four CSs derived from our data are presented in
Table 4. All estimates were performed in Stata 11 with ivregress command using
GMM estimator with robust standard errors.

Dependent variable: EDSS

	EPI Extraverson/Intraversion (eysextraversy)			
age	0.0264	0.0270	0.0495*	0.0364
	(1.22)	(1.63)	(2.03)	(1.87)
gender	0.904*	1.832**	1.076**	1.139**
	(2.17)	(2.87)	(3.01)	(3.15)
relapse	0.0919*	0.168***	0.164**	0.185***
	(2.10)	(3.35)	(2.94)	(3.47)
rejection	-0.465*			
	(-2.56)			
obsession		0.679		
		(1.41)		
focus			-0.641***	
			(-3.81)	
grief				0.485**
				(2.94)
_cons	2.113*	1.362*	0.611	1.009
	(2.48)	(2.21)	(0.72)	(1.42)

Table 4. Estimates of the main equation. t statistics are provided in parentheses,
p<0.001***, p<0.01**, p<0.05*.

This Table shows that number of relapses as a summary variable for objective
seriousness of the disease, is a significant explanatory factor for EDSS in all models, implying
general validity of the questionnaire data. Variables of our main interest are CSs, suggest that
rejection of disease generally negatively affects EDSS – in other words, if the patient at early
stages of the disease behaves as if she is not mortally ill, her deficit is lower. Similar in sign is
the effect of **focus** of one's own and family resources on the disease, which helps fighting its

progression. By contrast **grief** at the end of one's enjoyable life, which implies some neglect of one's healthcare, results in acceleration of deficit accumulation. The only variable without significant effect is the second component, **obsession**. This can be explained by the somewhat messy character of this component, as well as by its correlation with some psychological characteristics of the individual. However, its marginally significant coefficient suggests as well that excessive preoccupation of one's status of trapped ill also leads to faster progression of the disease.

These findings may also be given the following interpretation. CSs that imply patients' *openness* to the world, as captured by strategies `Family' and `Work', tend to support patients in relatively good state. This is in sharp contrast with strategies that negatively affect patients' health (grief and, to a lesser extent, obsession): these patients primarily focus on *their own* fate and feelings, which tends to aggravate their situation. In other words, external anchors, however limited they might be in case of MS, are of good service to the patients, whereas focusing on personal feelings and emotions proves to be detrimental.

6. CONCLUSION

Results of our analysis are limited in time and data sample – yet even they seem to warrant some conclusions. Our main working hypothesis was that attitude towards MS, or coping strategy towards it, does affect the progression of disease, has been confirmed in a natural way. Patients who are positively minded, and do not exaggerate the state of their health, are have generally lower progression of the disease, and thus ensure longer years of relatively healthy life. By contrast, concentration on the negative aspects of the disease, obsession by its negative consequences or grief at one's lost life opportunities tend to aggravate the situation.

These results are of course preliminary, and should be extended to a longitudinal study with the direct measurement of IID. Instead of, or in addition to psychological tests, these would require larger dataset, and should be captured by measurement of instantaneous well-being (experienced utility) by means of DRM or ESM analysis.

REFERENCES

1. Aikens, J. E., Fischer, J. S., Namey, M., & Rudick, R. A. (1997). A replicated prospective investigation of life stress, coping, and depressive symptoms in multiple sclerosis. *Journal of Behavioral Medicine*, 20, 433−445.

2. Arnett, P. A., Higginson, C. I., Voss, W. D., Randolph, J. J., Grandey, A. A. (2002). Relationship between coping, cognitive dysfunction and depression in multiple sclerosis. *The Clinical Neuropsychologist*, 16, 341−355.

3. Bénabou, Roland, and Jean Tirole (2002). Self-Confidence and personal motivation. *Quarterly Journal of Economics*, MIT Press, vol. 117(3), 871-915.

4. Benabou, Roland, and Jean Tirole (2004). Willpower and personal rules. *Journal of Political Economy*, vol. 112(4), 848-886.

5. Clark, Andrew, Ed Diener, Yannis Georgellis and Rich Lucas. (2008a). Lags and Leads in Life Satisfaction: A Test of the Baseline Hypothesis. *Economic Journal*, Vol.118, no.529, F222-F243.

6. Clark, Andrew, Paul Frijters, Mike Shields (2008b). Relative Income, Happiness and Utility: An Explanation for the Easterlin Paradox and Other Puzzles. *Journal of Economic Literature*, Vol.46, no.1, 95-144.

7. Csikszemtmihalyi M. (1994). Flow: the psychology of optimal experience. NY: Harper Collins.

8. de Ridder, D., Schreurs, K., Bensing, J. (2000). The relative benefits of being optimistic: Optimism as a coping resource in multiple sclerosis and Parkinson's disease. *British Journal of Health Psychology*, 5, 141−155.

9. Dennison, Laura, Rona Moss-Morris, Trudie Chalder (2009). A review of psychological correlates of adjustment in patients with multiple sclerosis. *Clinical Psychology Review*, v.29, 141-153.

10. Ebrecht M, Hextall J, Kirtley LG, Taylor A, Dyson M, Weinman J. (2008). Enhanced wound healing after emotional disclosure intervention. *British Journal Of Health Psychology*, Vol.13, Part 1, 95-102.

11. Ebrecht, M, Weinman, J, Hextall, J, Kirtley, L, Taylor, A, Dyson, M. (2004). Perceived stress and cortisol levels predict speed of wound healing in healthy male adults. *Psychoneuroendocrinology*, Vol.29, issue 6, 798-809.

12. Fischhoff, B. (2003). Hindsight ≠ foresight: the effect of outcome knowledge on judgement under uncertainty. Quality and Safety in Health Care, 12, 304-312.

13. Fournier, M., de Ridder, D., Bensing, J. (2002). Optimism and adaptation to chronic disease: The role of optimism in relation to self-care options of type I diabetes mellitus, rheumatoid arthritis and multiple sclerosis. *British Journal of Health Psychology*, 7, 409−432.

14. Grant, N., Wardle, J., Steptoe, A. (2009). The relationship between life satisfaction and health behavior: A cross-cultural analysis of young adults. *International Journal of Behavioral Medicine*, 16, 259-268

15. Hamer, M., Stamatakis, E., Steptoe, A. (2009). Dose response relationship between mental health and physical activity: The Scottish Health Survey. *British Journal of Sports Medicine*, 43, 1111-1114.

16. Hoeffler, Steve, Dan Ariely, Pat West (2006). Path Dependent Preferences: The role of early experience and biased search in preference development. *Organizational Behavior and Human Decision Processes*, Vol. 101, no. 2, 215 − 229.

17. Kahneman, D. (1999). Objective happiness. In D. Kahneman, E. Diener & N. Schwarz (Eds.), *Well-being: Foundations of hedonic psychology*. New York: Russell Sage Foundation Press.

18. Kahneman, D. (2000). Evaluation by moments: past and future. In: D.Kahneman, A.Tversky, eds. *Choices, values and frames*.

19. Kahneman, D. (2003). Maps of bounded rationality: Psychology for behavioral economics. *American Economic Review, 93*, 1449-1475.

20. Kahneman, D. (2011). *Thinking fast and slow*. New York: Farrar, Strauss, Giroux.

21. Kahneman, D., Fredrickson, B.L., Schreiber, C.A., RedeImeier, O.A. (1993). When more pain is preferred to less: adding a better end. *Psychol. Science*, v.4, 401-405.

22. Kahneman, Daniel, Alan B. Krueger, David A. Schkade, Norbert Schwarz, Arthur A. Stone. (2004a). A survey method for characterizing daily life

experience: The Day Reconstruction Method. *Science*, 3 December, Vol. 306. no. 5702, 1776 – 1780, DOI: 10.1126/science.1103572.

23. Kahneman, D., Krueger, A.B., Schkade, D.A., Schwarz, N., Stone, A.A. (2004b). Toward national well-being accounts. *American Economic Review*, 94 (2), 429-434.

24. Kahneman, Daniel, Alan B. Krueger, David Schkade, Norbert Schwarz, Arthur A. Stone. (2006). Would you be happier if you were richer? a focusing illusion. *Science*, 30 June, Vol. 312. no. 5782, 1908 – 1910, DOI: 10.1126/science.1129688.

25. Kahneman D., and Riis J. (2005). Living, and thinking about it: Two perspectives on life. In F.A. Huppert, N. Baylis & B. Keverne (Eds.). *The science of well-being*. Oxford: Oxford University Press.

26. Kahneman, D. and Sugden R. (2005). Experienced utility as a standard of policy evaluation. *Environmental and Resource Economics*, 32, 161-81.

27. Kahneman, D., Wakker, P.P., Sarin, R. (1997). Back to Bentham? Explorations of experienced utility. *Quarterly Journal of Economics*, 112,375-405.

28. Koczegi, Botond and Matthew Rabin (2006) A Model of Reference-Dependent Preferences. *Quarterly Journal of Economics*, 121(4), 1133-1166.

29. Korostil, M. and Feinstein, A. (2007). Anxiety disorders and their clinical correlates in multiple sclerosis patients. *Multiple Sclerosis*, 13, 67−72.

30. Kroencke, D. C., Denney, D. R., Lynch, S. G. (2001). Depression during exacerbations in multiple sclerosis: The importance of uncertainty. *Multiple Sclerosis*, 7, 237−242.

31. Kutzke J.F. (1983). Rating neurogical impairment in multiple sclerosis: an expanded disability status scale (EDSS). *Neurology*, v.33, no.11, 1144-1152.

32. Leibenstein, Harvey (1966). Allocative Efficiency vs. X-Efficiency, *American Economic Review*, 56 (3): 392–415.

33. Liu X.J., Ye H.X., Li W.P., Dai R., Chen D., Jin M. (2009). Relationship between Psychosocial Factors and Onset of Multiple Sclerosis. European Neurology, 62(3), 130–136.

34. Lynch, S. G., Kroencke, D. C., Denney, D. R. (2001). The relationship between disability and depression in multiple sclerosis: The role of uncertainty, coping, and hope. *Multiple Sclerosis*, 7, 411−416.

35. Maddi S. and Hightower M. (1999) Hardiness and optimism as expressed in coping patterns. *Consulting Psychology Journal*, 51, 95-105.

36. McCabe, M. P. (2002). Relationship functioning and sexuality among people with multiple sclerosis. *Journal of Sex Research*, 39, 302−309.

37. McCabe, M. P., and De Judicibus, M. (2005). The effects of economic disadvantage on psychological well-being and quality of life among people with multiple sclerosis. *Journal of Health Psychology*, 10, 163−173

38. McNulty, K., Livneh,H., Wilson, L.M. (2004). Perceived uncertainty, spiritualwell-being, and psychosocial adaptation in individuals with multiple sclerosis. *Rehabilitation Psychology*, 49, 91−99.

39. Oswald, Andrew and Nattavudh Powdthavee (2007a). Obesity, unhappiness, and the challenge of affluence: theory and evidence. *Economic Journal*, v.117(521), p.F441-454.

40. Oswald, Andrew, and Nattavudh Powdthavee (2007b). Death and the calculation of hedonic damages, Mimeo, University of Warvick.

41. Patten, S. B., Metz, L. M., Reimer, M. A. (2000). Biopsychosocial correlates of lifetime major depression in a multiple sclerosis population. *Multiple Sclerosis*, 6, 115−120.

42. Rabe-Hesketh, S., Skrondal, A., Pickles, A. (2004). Generalized multilevel structural equation modelling. *Psychometrika*, 69 (2), 167-190.

43. Reid, D. (2004) Utility theory from Jeremy Bentham to Daniel Kahneman. Working Paper No: LSEOR 04-64, London School of Economics.

44. Rumrill, P. D., Jr., Roessler, R. T., Fitzgerald, S. M. (2004). Vocational rehabilitationrelated predictors of quality of life among people with multiple sclerosis. *Journal of Vocational Rehabilitation*, 20, 155−163.

45. Schwartz, C. and Frohner, R. (2005). Contribution of demographic, medical, and social support variables in predicting the mental health dimension of quality of life among people with multiple sclerosis. *Health and Social Work*, 30, 203−212.

46. Stanton, A., Revenson, T., Tennen, H. (2007). Health psychology: Psychological adjustment to chronic disease. *Annual Review Psychology*, 58, 565−592.

47. Wineman, N., Durand, E., Steiner, R. (1994). A comparative analysis of coping behaviors in persons with multiple sclerosis or a spinal cord injury. Research in Nursing and Health, 17, 185−194.

48. Yousfi S., Matthews G., Amelang M., Schmidt-Rathjens C. (2004). Personality and Disease: Correlations of Multiple Trait Scores with Various Illnesses. Journal of Health Psychology, 9, 627-647.