Clinical conditions and perceived well-being of the patients suffering from chronic diseases: An application to Multiple Sclerosis

Alexis Belianin[1], Lev Brylev[2], Elena Kashina[2], Olga Isupova[3], Maria Radionova[4] and Ekaterina Lishchenko[1]

[1]ICEF NRU HSE (*icef-research@hse.ru*)

[2]Institute for Neurology RAMS

[3]Institute for Demography, NRU HSE

[4]City institute for psychology and pedagogy, Moscow, Russia

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General description

- The project aims at multidisciplinary investigation of clinical and psychological determinants of the well-being of patients suffering from chronic diseases, in an example of Multiple Sclerosis (MS).
- It combines efforts of economists and sociologists from NRU HSE and physicians, clinical and cognitive psychologists based at the Institute for Neurology of the Russian Academy of Medical Sciences, based in Moscow, which approved it as a research initiative.
- The project is empirical: Data shall be collected from repeated observation of the patients at the various stages of the disease, and will consists of a battery of sociological socio-demographic questionnaires, psychological tests and measurements of subjectve well-being, together with clinical observations

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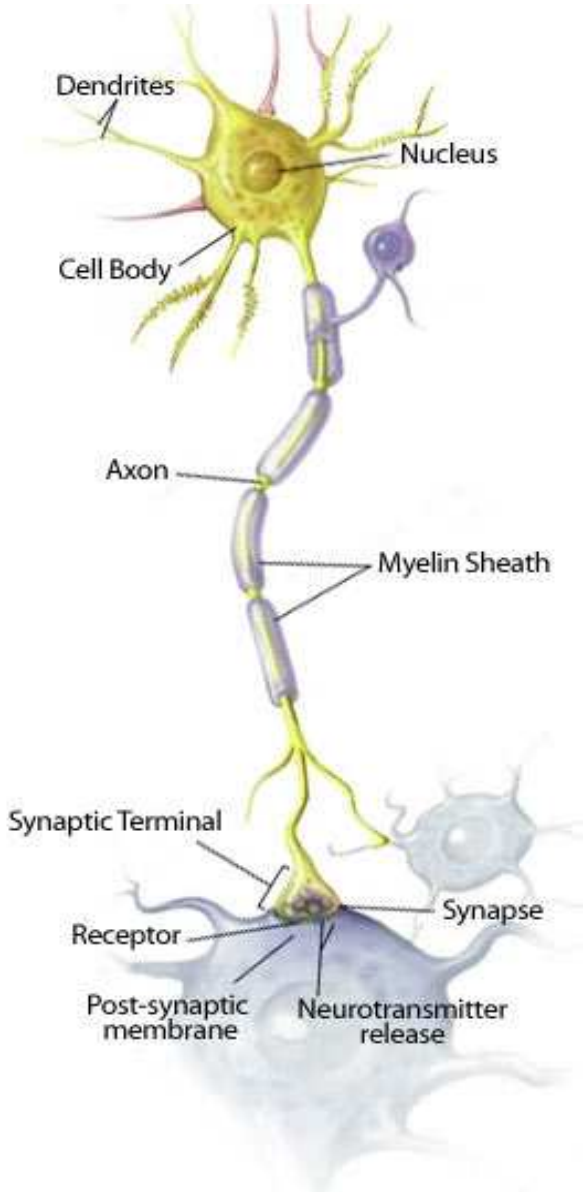
- ultimately, build a taxonomy of optimal treatments conditional upon physical and psychological state of the patient and affecting the degree of health decay through patient's attitude towards her treatment.
- Methodology is based on MS, but can be adjusted to other chronical diseases.

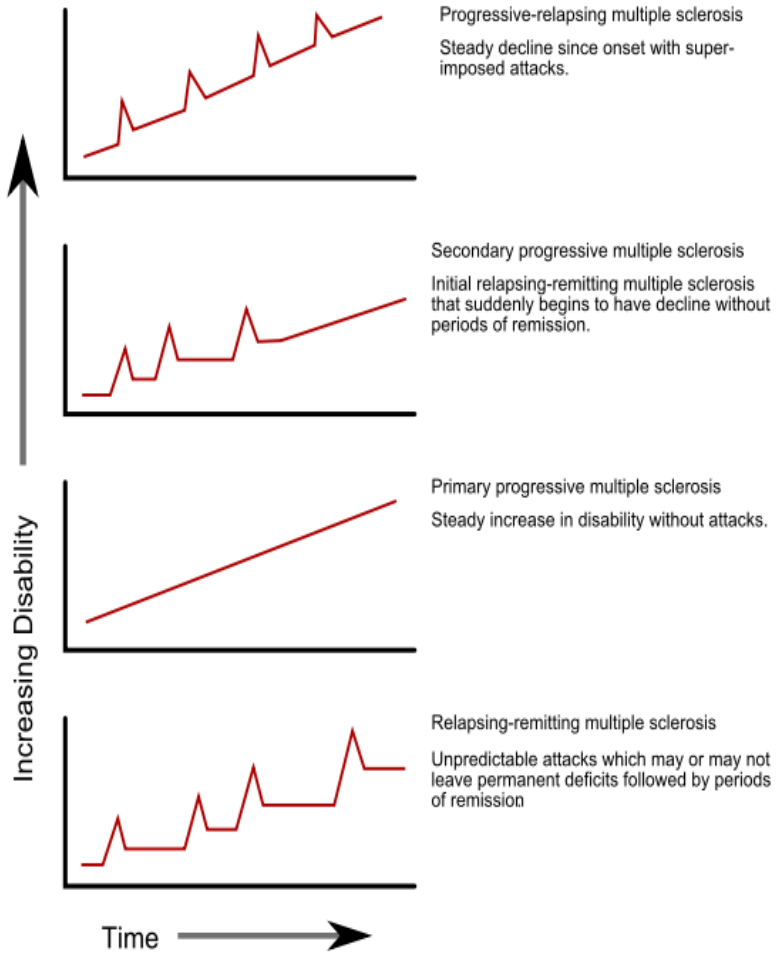
Multiple Sclerosis (MS) as chronical disease

- Autoimmune disease caused by deficit of myelin (prothein responsible fo isolating axones)
- Unexpected arrival, unknown causes, no known cure (at best, can be slowed down through medication)
- Symptoms include loss of visual fields or entire vision, blurred or double vision, muscle weakness, loss of balance, fatigue, memory disorders, and urinary incontinence



Multiple Sclerosis (MS) II

- Results in premature decay lasting from years to decades, develops in waves
- Early symptoms may be mixed with other diseases, and has to be confirmed by a set of tests (incl.fMRI) in 6-month time
- About 2 mln. patients worldwide, about 200,000 in Russia (1.4 per 1,000), 83,000 covered by state program (7 nozologies) with annual budget of about 10 bln RuR.

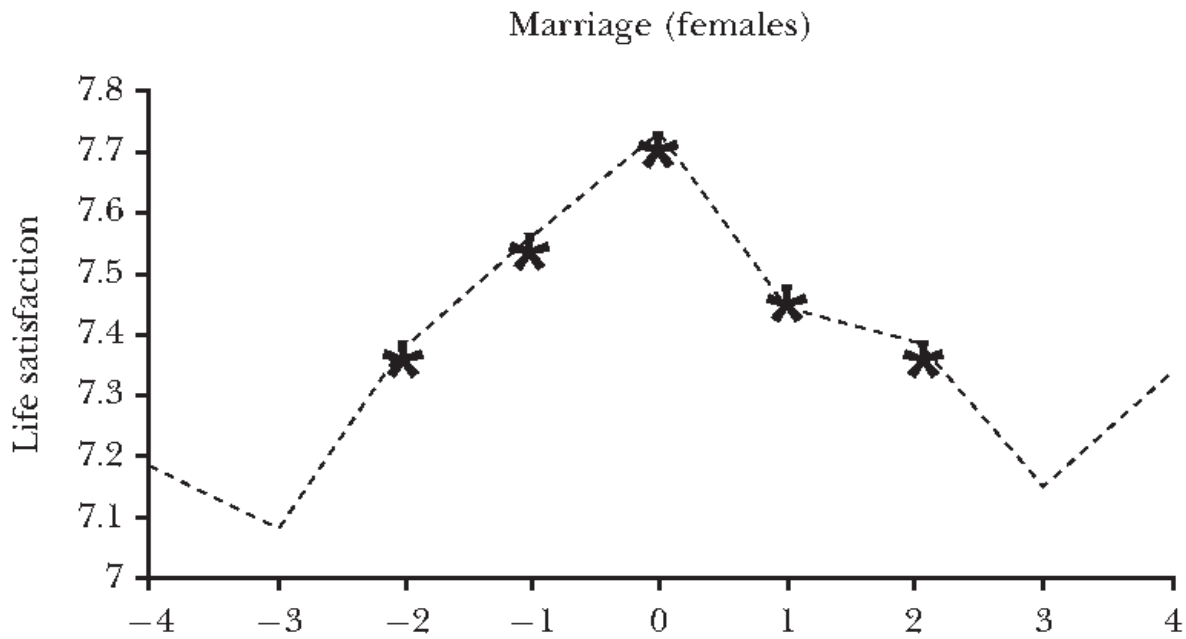


Multiple Sclerosis (MS) III

- Early start of the treatment is shown to be very important for the progression of the disease, as is patient's attitude towards own treatment (Ebrecht et al., 2004; 2008; Grant et al., 2009; Hamer et al., 2009; McNulty, et al., 2004; Wineman et al., 1994).
- Subjective perception of one's health status (internal image of disease, IID) affects one's coping strategy, and hence the efficiency of cure.
- Recent studies in cognitive psychology suggest that people's perceived well-being is not constant conditional on an event.

Subjective well-being across time: an example

Average Life Satisfaction for a Sample of German Women
(by year of marriage $t = 0$)



Source: Clark, Diener, Georgellis and Lucas (2003), using data from the German Socioeconomic Panel.
Note: An asterisk indicates that life satisfaction is significantly different from the baseline level.

Subjective well-being: Measurement

- As shown recently by Daniel Kahneman and his colleagues (Kahneman Wakker Sarin QJE 1997; Kahneman e.a., Science, 2006) as well as others (Oswald and Powdthavee, 2007; Clark e.a, JEL, 2007), 'utility' can be empirically measured as

  experienced , perception-based, or Benthamite: how do you feel here and now?

  evaluated : judgment about inner satisfaction, aggregated across moment utilities, but not identical to its integral, assessed through

- **Experience Sampling Measurement (ESM)** (Csikszemtmihalyi, 1994): self-reported well-being at a scale 1-10 through electronc transmission devce ('pager') at random times of the day.
- **Day Reconstruction Method (ESM)** (Kahneman and Rijs, 2005): self-reported remembering of the previous day by episodes.

Subjective well-being: an emotional map

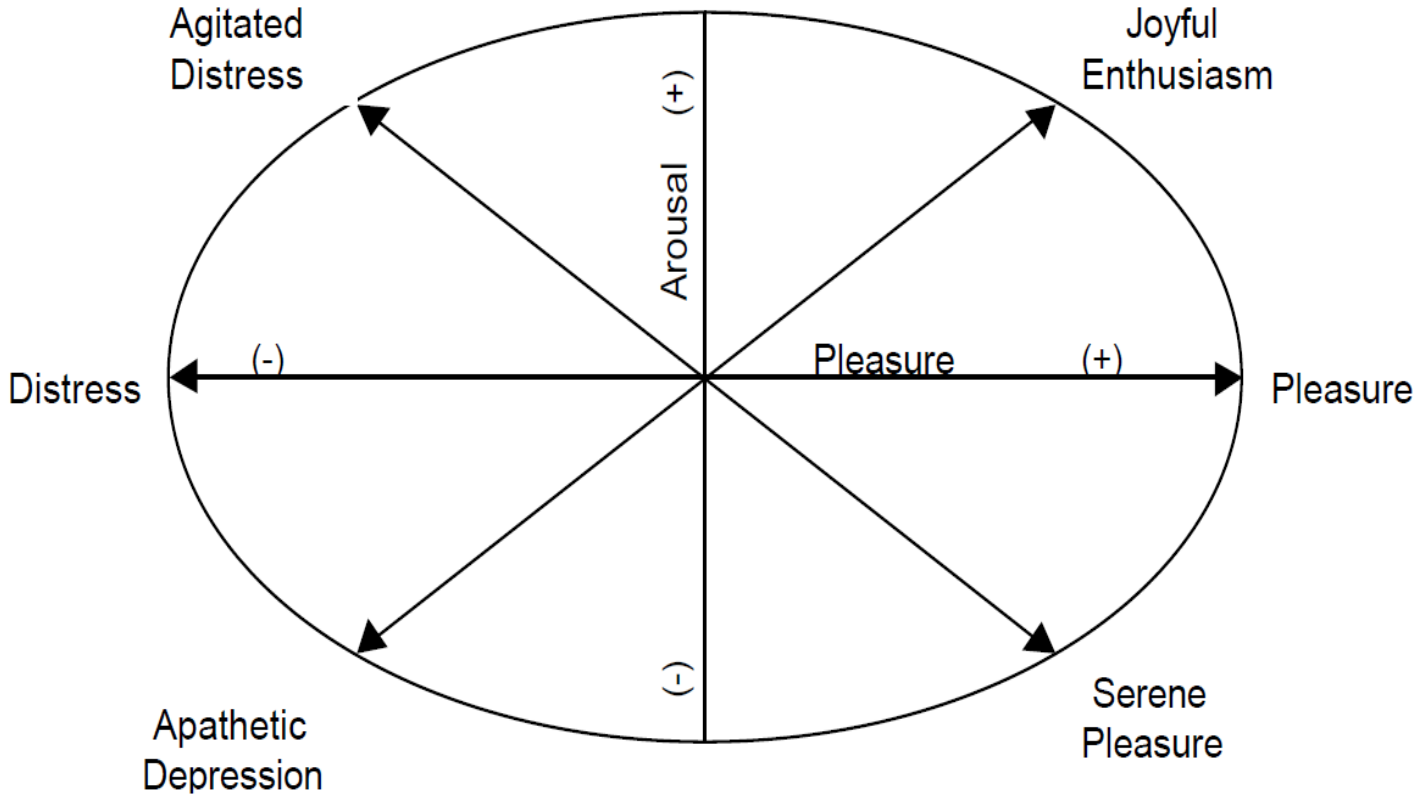
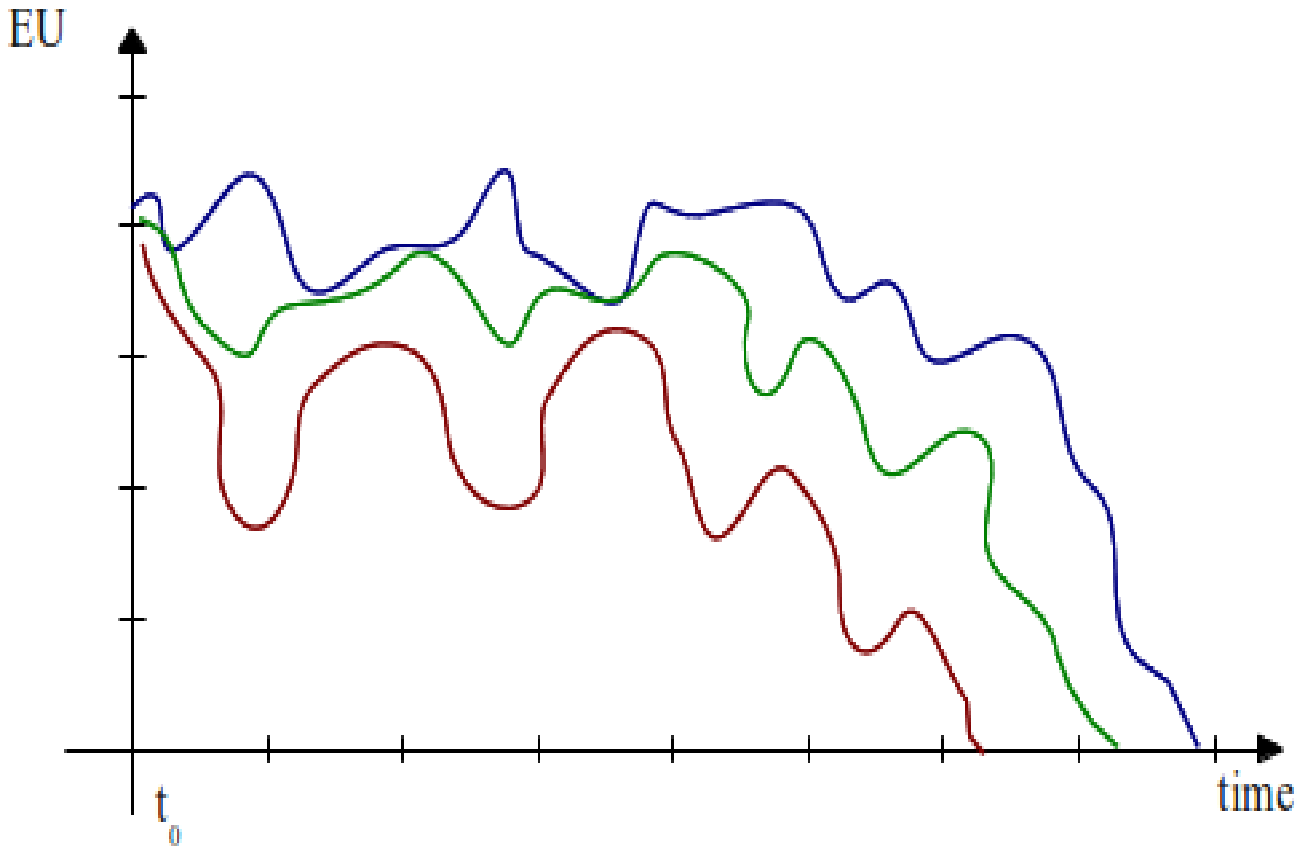


Figure: Source: D.Kahneman and A.Tversky, eds. Choices, values and frames, Ch.37, CUP, 2000

Subjective well-being: MS



Over lifetime, objective state and evaluated utility of a healthy person is superior to that of an MS patient prone to biased perception of current health state, which is yet lower than that of an MS patient with optimal coping strategy.

Theoretical framework

- s_a — experienced utility of activity a
- $f(s_a)$ — evaluated utility of activity a
- $R_A = \int f(s_a)da$ — total evaluated utility of the set of activities
- θ, $\tilde{\theta}(= \theta - z)$ — *actual* and *perceived* health state (IID)
- $x^* = \arg\max_x \sum_t \int f(s_{at}(x_t, \theta_t, \varepsilon(t)))dF(\varepsilon_t) = \arg\max_x \sum_t \int R_{At}(\theta_t, \varepsilon_t)dF(\varepsilon_t)$ — optimal coping strategy for a person with perceptions based on true state of one's health. But in general,
- $\tilde{R}_A = \int f(s_a(\theta, x(\tilde{\theta})), \varepsilon)dF(\varepsilon)$ — total evaluated utility of the set of activities at period t with perceptions $\tilde{\theta}$ and random perturbations ε, and
- $d\tilde{R}_A = \int \frac{\partial f}{\partial s_a}\left(\frac{\partial s_a}{\partial \theta} + \frac{\partial s_a}{\partial x^*}\frac{\partial x^*}{\partial \tilde{\theta}}\right)da$ — effect of distorted perceptions on evaluated utility in period t.

Coping strategies of (MS) patients

On the basis of the preliminary interviews and reviews, we conjecture the following coping strategies of MS patients:

Family	Cope with disease through family orientation
Work	Cope with disease through work orientation
Recovery	Aspiration for recovery through own behaviour or medical advancements
Hedonism	Take most of the remainder of one's life
Ignorance	Live as if nothing happened
Consommation	Everybody has the duty to support me in my disease
Desperation	Giving up, and losing control of one's life and cure

Survey tests

These strategies are revealed through a specially designed questionnaire (about 50 questions), together with a battery of psychological tests:

1. Monthreal Cognitive Ability test (MOCA, 10 questions) — to assess subjects' cognitive competence
2. Life quality scales (clinical tests SF-36, FAMS, MSIS-29, 50 questions)
3. Bechterew Institute Personality Questionnaire for Types of Attitude towards Illness (TOBOL, 12 questions)
4. Hospital Anxiety and Depression scale (HAD, 14 questions)
5. Self-assessment, Activity, Mood (SAM, 30 questions), patient's current mood and self-assessed ability to cope with life tasks.
6. Hardiness test by S.Maddi (45 questions), evaluating commitment (to life actions), control (over one's life), and challenge (willingness to accept).
7. Heims questionnaire of coping strategies (26 statements)
8. Asthenic State Scale (30 questions) to estimate self-assessed level of asthenia and fatigue
9. Eyseneck test of character, emotional stability and personality (57 questions), to measure emotional state and neurotism, robust to MS progression.

Research design

- These tests are to be performed bi-annually, complemented by clinical tests and monthly DRM questionnaire.
- At first stage (starting Spring 2012) — questionnaire, clinical and psychological tests carried out for 70 patients of the Institute for Neurology, in order to test/ramify taxonomy of coping strategies leading to a structural model.
- Data analysis: multilevel latent mixed model.
- Subsequent longitudinal analysis with pecuniary motivated subjects who agree to participate in the project for 2 years.
- Aimed sample size: 80 subjects: at the stage of initial diagnosis, new patients with confirmed diagnosis, patients with deficit and healthy people.
- Possible issues: sample selection and size, duration of study.

Thank you for your attention!