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RIGA STRADINS UNIVERSITY

Signe Mežinska

# CHRONIC ILLNESS EXPERIENCE AND QUALITY OF LIFE OF RETIREMENT AGE PEOPLE

Summary of Doctoral Thesis

Riga 2010

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Summary of Doctoral Thesis

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The Doctoral thesis and its summary are available for reading in the library of Riga Stradins University.

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## 1. Topicality of the Doctoral Thesis

Many processes of a human body, including illness, can be characterised by various terms and explanations other than biological, chemical or medical. Illness also represents the subjective experience that forms part of a person's life and has a major impact on the quality of life. At the same time illness is a certain status with social meaning that is interpreted within social interaction and influenced by cultural values, events and processes. When forming social interpretations about illness and health, people and societies tend to develop a link between biological and social order. In individual perceptions about illness and health, the ideas on biological causes and consequences are intertwined with the impact of social processes and cultural values, as well as the person's biographical context. Certainly, in modern medicine disease is characterised by analyses, measurements and other data, however, well-being and the quality of life in social environment of an ill person to a large extent is determined by values, stories, interpretations and metaphors related to the illness and social interaction with the surrounding people.

Over the last decades in sociology of health and illness more and more attention is paid to illness as subjective experience that is a much wider notion than the objective, medical diagnosis. This is proven by a number of significant researches in this area (Anderson & Bury, 1988; Calnan & Williams, 1996; Charmaz, 1991; Frank, 1997; Toombs, 1992; Karp, 1996; Price, 1996 etc.). In these researches the viewpoints of experts and personal illness experience are treated as equal, each of them carrying its social meaning.

Interest in the experience of retirement age people with chronic illnesses is important due to several reasons. The theme of the Doctoral thesis is socially important if we take in account the development perspectives of demographical situation. In Latvia and around the world the over-60 age group constantly grows. Examinations of the World Health Organisation forecast that from 1970 till 2025 this group could increase by 694 million people or 223% (WHO, 2002, p. 6). It means that in 2025 there would be 1.2 billion people over 60 years of age. Demographic forecasts convincingly demonstrate that over the coming decades the number of retirement age people in Latvia will grow rapidly. The significant increase of the number of retirement age people also means a fast increase of the number of chronically ill elderly people. There will be more senior citizens who will have to learn how to live with the chronic illness experience, find its meaning in one's autobiography and cope with and adapt to restrictions caused by chronic illnesses.

In the Doctoral thesis the author applies a new methodological approach in Latvia towards research on the illness experience. Up to now more comprehensive research on the illness experience in Latvia was carried out by Vieda Skultans (Skultans, 1998; Skultans, 1999; Skultans, 2003; Skultans, 2007) and Agita Lūse (McKevitt, Luse, & Wolfe, 2003); A. Lūses's Doctoral thesis explores the experience of mental disorders. However, the author's approach of this Doctoral thesis is different as the illness experience is explored on the basis of the theory of symbolic interactionism and the application of the grounded theory methodology. V. Skultans uses the method of narrative analysis, thus investigating the history of illness within the historic and socially-political context. Therefore V. Skultans' viewpoint is more directed towards the past by searching for the historic factors that have influenced the history of illness. The author's perspective, without excluding the historic aspects of the illness experience, focuses more on the connection of the illness experience with the quality of life. A. Lūse has applied the phenomenological approach for the analysis of the illness experience and she has profoundly researched the experience of one disease (cerebral thrombosis) (McKevitt, Luse, & Wolfe, 2003), as well as the experience of mental disorders. The author of this Doctoral thesis applies a different theoretical approach and covers a wider spectrum of chronic illnesses and examines the common and distinct themes in various individual experiences. Another novelty is the analysis of illness in relation to the quality of life; there has been no in-depth research on this aspect so far in Latvia.

The Doctoral thesis contributes to the development of theoretical ideas and empirical investigations of sociology of health and illness in Latvia by expanding the scope of thematic issues and the range of methodological approaches in several aspects. The theoretical part of the Doctoral thesis provides in-depth analysis of the notions of illness and health, as well as proposes new translations of particular terms into Latvia. The theoretical part of the Doctoral thesis comprises the most comprehensive analysis of research on the illness experience in Latvia at present.

The topicality of the research refers to the selected methodology and the theoretical substantiation, as well as the choice of the research subject. Up to now there are no studies in Latvia that would profoundly examine the experience of an individual illness in relation to the quality of life. Similarly, in researches of other countries more attention is focused on various social and economic factors: how such factors as income level, gender, age etc. influence the quality of life. The Doctoral thesis expands knowledge on the illness experience in Latvia by highlighting its connection to the quality of life. The author analyses aspects of chronic illnesses that till now have not been broadly examined in Latvia and their relation to the quality of life of the elderly: problems of bodily identity, the influence of employment on the chronic illness experience, subjective explanations for causes of illnesses, possibilities to improve and change the experience of a chronic illness, as well as ethical considerations of the chronic illness experience.

## 2. Objective and Tasks of the Doctoral Thesis

The **objective** of the Doctoral thesis is to analyse the chronic illness experience of retirement age people in relation to their quality of life.

The following tasks are put forward in order to attain the objective:

1. To do theoretical analysis of the notion of the chronic illness experience on the basis of the existing research in philosophy and sociology of health and illness.
2. To analyse researches on the illness experience that have been carried out within the theory of symbolic interactionism.

3. To study the connection of the chronic illness experience of retirement age people and their quality of life by applying the grounded theory methodology.
4. To examine the influence of the chronic illness experience of retirement age people upon the perception of their identity and body.
5. To analyse how the chronic illness experience influences the understanding of the notion of health.
6. To analyse how individual meaning of the illness experience develops and how biographical work is performed.
7. To analyse metaphors and symbolic meanings related to the notions of illness and health that were mentioned in interviews of this research.
8. To identify individual, cultural and social factors promoting successful inclusion of the chronic illness experience into one's autobiography and identity.
9. To identify individual, cultural and social factors hindering successful inclusion of the chronic illness experience into one's autobiography and identity.

## 3. Scope and Structure of the Doctoral Thesis

The Doctoral thesis is written in Latvian, its structure includes introduction, 4 chapters, bibliography and 2 appendices. The text includes 6 figures and 2 tables. The scope of the Doctoral thesis is 174 pages without appendices. The bibliography lists 161 sources.

The introduction substantiates the choice of the theme and its novelty, as well as the importance of this research for the modern sociology of health and illness, it outlines the object, objective and tasks of the research.

In Chapter I the author provides the analysis of theoretical aspects of the chronic illness experience. Subchapters 1.1 and 1.2 outline the most significant interpretations of the notions of disease and the illness experience in modern philosophy, sociology and medical anthropology. Subchapter 1.1 also analyses the importance of the narrative approach in the examination of the illness experience and the use of metaphors in narratives of the illness experience.

Subchapter 1.2 examines the interaction of the illness experience with the quality of life at the retirement age on the basis of previous investigations on the experience of chronic illnesses of the elderly and the quality of life in Latvia and other countries. A separate analysis is devoted to sufferings in the illness experience and their relation to the quality of life, as well as the meaning of a patient's activity during the improvement of one's quality of life.

Subchapter 1.3 analyses the most significant notions and theories that have been used in sociological researches on the illness experience insofar, a special emphasis is put on concepts and theoretical considerations that are based on the theory of symbolic interactionism. The themes covered in this chapter cover the history of researches on the illness experience, the search for the self and identity during the chronic illness experience, a chronic illness as a biographical event and the problems in the management of a chronic illness trajectory.

Subchapter 1.4 features definitions of health and their relation to the illness experience and the quality of life.

Chapter II of the Doctoral thesis focuses on the description of the methodology and the course of empirical research. It describes the methods for the acquisition of empirical data and the process of research, provides the demographical characteristics of respondents and outlines the method of data analysis.

Chapter III describes the results of the empirical research and the most important categories and their interrelation obtained as a result of coding of empirical data. The main categories include: body exposed to sight; interpretations of the cause of illness; illness as a 'norm' of ageing; active action to improve health; coping with a chronic illness, age discrimination in the illness experience; decrease or change of goals; control and lack of control; the meaning of the notion of health in the illness experience.

Chapter IV summarizes the conclusions that have been obtained as a result of the research.

## 4. Theoretical Substantiation of the Doctoral Thesis

The theoretical substantiation of the Doctoral thesis is the theory of symbolic interactionism (Blumer, 1998). This theory forms a united entirety with the grounded theory methodology that is applied in the research part of this Doctoral thesis (Glaser & Strauss, 1967; Glaser, 1992; Charmaz, 2006).

Herbert Blumer, the founder of symbolic interactionism mentions three statements as the main premises of this theory: "*human beings act toward things on the basis of the meanings that the things have for them*"; "*the meaning of such things is derived from, or arises out of, the social interaction*"; "*these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters*" (Blumer, 1998, p. 2).

From the premises of symbolic interactionism it follows that the meanings of things are formed during interaction with actions of other persons, therefore they are "*social products*" (Blumer, 1998, p. 5). This means that in order any experience, including the illness experience, could gain meaning, there should be a disclosure of the contents of experience that is carried out in social interaction.

In the theory of symbolic interactionism things can be physical objects, social objects, other people, as well as abstract cultural objects. In this understanding illness is also a thing, and its meaning and experience develops during the process of social interaction. Representatives of symbolic interactionism emphasize that the objective of sociology is to search for answers to the question "what does it mean to be ill from the point of view of the ill person?" To take into account the illness experience means to recognize that disease is not only a certain biological state of the body, but also a tense biographical event that not only refers to particular organs or part of the body, but to a person as entirety, his/her autobiography and relationships.

The main notions, on which the Doctoral thesis is based, include the chronic illness experience and the quality of life as subjective satisfaction. In the 70s of the 20th century a major turn about the understanding of the notion of disease took place in social sciences. Sociologists and anthropologists defined patients' sufferings and narratives as a voice that is strong enough to object against the biomedical viewpoint about a disease as objective and measurable condition (Frank, 1997; Kleinman, 1988). In order to differentiate various meanings of the notion 'disease' in British and American sociology of health and illness, as well as in the tradition of medical anthropology, three separate terms were introduced: *disease, illness* and *sickness. Disease* denotes a pathological process that can be described objectively, a "*deviation from a biological norm*" (Marinker, 1975, p. 82) in a human body or psyche. It is characterised by a medical diagnosis that outlines a clinical status, somatic or psychic changes and a cause of the disease. *Illness* is personally experienced unhealth as a deeply individual experience, a person's reaction to a disease or trauma as a biological process in his/her body. "*Illness is a feeling, an experience of unhealth which is entirely personal, interior to the person of the patient.*" (Marinker, 1975, p. 83), sickness is "*the external and public mode of unhealth*" (Marinker, 1975, p. 83). It describes sickness as a social role, status and it is related to the social identity of an unhealthy person.

Taking into account the above-mentioned differentiation of terms, in the Doctoral thesis the author has chosen to apply the definition of the chronic illness experience elaborated by Lennart Nordenfelt. In the article "On Chronic Illness and Quality of Life: A Conceptual Framework"

(Nordenfelt, 1995), the author analyses the differences between notions '*chronic disease*' and '*chronic illness*'. On the basis of this analysis L. Nordenfelt defines a chronic illness: "*A person A is chronically ill, if and only if A is in a bodily or mental state which is such that A is disabled and has, at least, intermittent pain or other kind of suffering. This state must have existed for a minimal period of time (say 6 months) and the subject cannot foresee that this disability of suffering will terminate.*" (Nordenfelt, 1995, p. 291)

This definition of a chronic illness does not require a diagnosis approved by a medical professional, but the main characteristics of the chronic illness experience is provided by the patient's own suffering.

The relation among the health condition, the illness experience and the quality of life is neither simple, nor direct. One of the ways how to examine the subjective assessment of the quality of life in the chronic illness experience and ageing is to regard it as a contradiction between an individual's ideals, hopes and his/her actual experience. The bigger the difference between the person's expectations in relation to his/her body and health and the actual illness experience, the lower is his/her subjective assessment about the quality of life.

## 5. Research Methodology

The application of qualitative methods as the main instrument of empirical research logically derives from the theoretical substantiation and the choice of the subject of the Doctoral thesis. For the data acquisition and analysis the author used the grounded theory approach (Glaser & Strauss,

1967) that is based on the theory of symbolic interactionism in sociology. For the first time the grounded theory method was laid out in the research by B. Glaser and A. Strauss "The Discovery of Grounded Theory. Strategies for Qualitative Research" that was published in 1967 (Glaser & Strauss, 1967). In the following decades the method was explained, developed and advanced by several researchers, including B. Glaser and A. Strauss themselves (Strauss & Corbin, 1998; Wuest, 1995; Glaser, 1992; Glaser, 1998; Stern, 1994; Charmaz, 2006).

The central methodological principle in the grounded theory approach is the fact that the data acquisition and analysis are carried out in parallel during the course of research with an aim to develop the theory. The theory is not formed before the commencement of empirical research, but it arises directly from the empirical data. Notions and categories emerge when a researcher collects, codes and analyses the data. Sometimes the grounded theory method is characterized as a method that uses constant comparison of coded data, at each level of the formation of the theory. The data are continuously compared with other data and notions during the data acquisition (Charmaz, 2006). The objective of the method is to establish a theoretical framework and verify its expediency, not statistic testing of logically deducted hypotheses.

The substantiation of such methodological principle is rooted in rapid social changes and consequential variety of human lives that reveal more and more new aspects of social phenomena and make us search for alternative viewpoints towards as if explored situations. The traditional deductive methodology where the formation of hypotheses derives from theoretical models that are approved with the help of practical examinations is not suitable for such changeable and inconsistent objects. Therefore, researchers need to turn to inductive methods more intensely where notions and theories are derived from empirical experience, namely, from a specific social environment. With the help of qualitative methods the researcher finds out individuals' knowledge and practices, analyses social interaction, for instance, the manner how they get along with illness on a day-to-day basis, how the illness experience influences their relationships with relatives, how the illness experience affects the perception of one's body etc. In each particular case the social interaction is described and explained by referring to particular features of this case. In addition, the researcher takes into account the fact that in this area various opinions and practices can exist that arise from diverse individual viewpoints and attitudes and social differences.

By applying the grounded theory methodology, the examination begins with an assumption that all people involved have a common (conscious or unconscious) problem situation (Schreiber, 2001, p. 62). The first task of a researcher is to find out what each subject of the study thinks about this common social problem and how each of them attempts to solve it. The grounded theory method is based on the assumption of symbolic interactionism that people are active agents, not passive receivers of social events and processes.

For the research's qualitative part the form of a semi-structured interview was chosen as it provides an insight into respondents' life situations and everyday life. A semi-structured interview as a method allows the inclusion of those elements of individual experience from which other research methods usually abstract from and disassociate. This type of interviews directs respondents towards a certain problem, at the same time it leaves enough freedom for the disclosure of personal opinions and motives. In case of necessity the interviewer can change the sequence of questions, as well as formulate *ad hoc* questions that are related to the particular case and that cannot be foreseen in advance (Flick, 2005, p. 143). Therefore, the invaluable advantage of a semi-structured interview as a qualitative research method is its flexibility that fosters the adjustment to the specific needs of the research's object and the peculiarities of the research process (for instance, to have a closer focus on a certain category that appears during the research). Only due to in-depth analysis of individual experience, by searching individual meanings with the help of qualitative methods, it is possible to understand and examine individuals' subjective experience.

## 6. Criteria for the Selection of Respondents and their Demographical Characteristics

The research carried out within the framework of the Doctoral thesis is part of a wider research performed by a team of researchers of the Department of Humanities of the Rīga Stradiņš University (RSU) on the quality of life of retirement age people. The research was executed within the framework of the RSU grant "Factors Influencing Lifestyle and Quality of Life of Retirement Age People in Latvia" (No. RSU–ZP 07–6/15). The ultimate objective of the research was the identification and analysis of factors influencing the quality of life of retirement age people in Latvia.

The research consisted of two parts: qualitative and quantitative. The qualitative part of the research comprises 28 in-depth semi-structured interviews with retirement age persons from 62 to 91 years of age. At the time of interviews the age of 62 was chosen as the official retirement age for men that will not be increased in the near future. Respondents who live at home, not institutionalised care establishments were selected. This Doctoral thesis is based on the empirical material obtained only during the qualitative part of the research. Within the quantitative part of this research an inquiry of retirement age people was also carried out. 400 persons from 65 to 94 of age were questioned in telephone interviews. Questions for the interview were formulated on the basis of categories obtained in the interview analysis carried out in the qualitative part of the research.

As the ultimate objective of the research was the identification and analysis of factors influencing the quality of life of retirement age people, respondents were selected by using the strategy of maximal comparison: cases that demonstrate maximally many differences. When choosing respondents for the interviews, initially the statistical method was applied by setting the main criteria for the selection of respondents (Flick, 2005, p. 99). It was assumed that the quality of life of retirement age people is mostly influenced by such factors as gender, place of residence and age; these were chosen as the main criteria for the selection of respondents.

Chronic illness was not taken into account as the initial criteria of selection as the common objective of the grant's research was a wider exploration of the quality of life of retirement age people. Nevertheless, during the course of research when the first interviews were coded, it turned out that the major part of respondents have at least one chronic illness and this experience has a significant impact on their quality of life. Due to this reason, in further interviews particular attention was paid to the subjective experience of illness, however during further course of research chronic illness did not become a criterion for the selection of respondents. In 23 out of total 28, interviews respondents asserted that they had the experience of one or several chronic illnesses. This research uses those interviews of respondents who have chronic illnesses, although in some cases, for the reason of comparison, the author has included those interviews where respondents themselves declared that they had no chronic illnesses.

Appendix 2 of the Doctoral thesis summarises the demographical data of respondents and outlines the characteristics of chronic illnesses; this description is based on the information provided by respondents themselves and it has not been compared with medical data. All respondents are Latvian by nationality, from the total of 28 persons 19 are women and 9 are men. 19 respondents do not work, 7 persons have a full-time job, and 2 persons have odd jobs. Former and present professions represent a wide range of employment. The education level of respondents is as follows: 2 persons have education of 4 grades; 2 persons have primary education, 2 persons have unfinished secondary education, 14 respondent have secondary or secondary professional education, 6 persons have higher education and one respondent has not mentioned the level of education.

13 respondents are married, 8 persons are widowers and widows, 2 persons have never been married, and 5 respondents are divorced. 12 persons live together with a spouse/partner, 6 persons live alone, 5 persons live in a three-generation family together with children and grandchildren, one respondent lives together with her sister, one respondent lives together with a tenant, one persons lives together with grandchildren.

When analysing the selection criteria of respondents, a question could be posed why respondents have different experiences of a chronic illnesses. However, such design of research is not uncommon in researches on the chronic illness experiences. Although a great part of these researches have focused on one particular disease (for instance, the experience of arthritis, diabetes, depression etc.), many sociologists and anthropologists have explored the experience of chronic illness on the basis of a universal notion of 'experience of chronic illness' without turning to a particular disease (Corbin & Strauss, 1991; Kleinman, 1988; Morse & Johnson, 1991).

In interviews questions about the overall quality of life were posed to respondents, by putting a special emphasis on the issues of health-related quality of life. 3 interviewers of the project task group carried out the interviews (Vents Sīlis, Ainārs Kamoliņš and Signe Mežinska). One part of interviews were executed by two interviews (especially at the beginning of the research), and this fact helped to improve and advance the interview strategies. The length of interviews ranged from 1 to 2 hours. All interviews were recorded in a digital format and transcribed.

When performing the initial analysis of data according to the grounded theory methodology, it was revealed that the subjective experience of chronic illness is a significant category. This served as ground for the decision to have in-depth focus on this research object. In the most part of the group's interviews on the quality of life of retired persons the experience of chronic illness was the main theme that intertwined the interview as the leading issue and all other factors influencing the quality of life were subjected to this one. Questions that are related to processes of everyday life include the following: how illness has changed the relationships with friends and members of the family; in respect of the financial situation: how it affects the quality of life and the possibilities to receive medical treatment; in respect of mobility: how difficult it is to get to a doctor or whether the restrictions caused by an illness hinder the possibility to go to cultural events etc.

As any research, this research also has certain restrictions that should be identified. Taking into account the specific features of the qualitative research methods and the number of respondents, nationality, it cannot be considered that the qualitative part of the research represents the situation in Latvia in general. In addition, the length of interviews (1-2 hours) certainly leaves out significant biographical data. However, the validity of research compensates the lack of representativeness.

## 7. Methods of Data Analysis

The data analysis in accordance with the grounded theory approach started with coding; its purpose was to establish theoretical categories. The coding of interviews was not performed according to a previously prepared code, but by forming the categories during the coding. The coding was commenced at an early stage of the research alongside with the acquisition of data. Interpretations of each code were verified by returning to the collected data by rereading the transcripts of interviews.

The qualitative data analysis programme Nvivo 8.0. was used for the processing and analysis of interviews. The application of this programme in researches that use grounded theory approach has been analysed by several authors (Bringer, Johnston, & Brackenridge, 2006; Hutchison, Johnston, & Breckon, 2009; Siccama & Penna, 2008). With the help of Nvivo 8.0 all types of coding described by theorists of the grounded theory approach can be applied. The use of the data processing programme Nvivo increases the validity of the qualitative research (Siccama & Penna, 2008, p. 91).

In the grounded theory approach a three-level coding is usually applied: the first-level codes are described as notions; the second-level codes – as categories; and the third-level codes are describes as relations. The analysis was begun with the first-level coding where information is structured with the help of notions used by respondents. A mixed approach was applied as part of interviews' texts were coded, using "incident to incident" coding, whereas in those parts of texts that were saturated with essential notions related to the illness experience, "line-by-line" coding was chosen (Charmaz, 2006, p. 50). When coding the data notions was mostly coded as actions, not themes, as K. Charmaz suggests it in the description of the grounded theory methodology (Charmaz, 2006, p. 48). The substantiation for such coding strategy is the need to avoid from shaping a theory before the analysis is performed. A special attention was paid to typical notions used by respondents. These are notions that respondents use in a special way: metaphors, innovative notions and concepts that characterise their experience, words peculiar to a certain group of people etc.

Based on the results of the first-level coding, the focused coding (the second level) was executed; its objective was the selection of codes that feature the ability to form categories. The second-level coding was started at the moment when similarities in notions occurred in the process of the first-level coding.

At the next level of analysis the theoretical coding was also performed; its objective was to search for a relation between codes. The relation between codes is established as, for instance, the relation of one code with another code in time or space and by searching for the approval for a repeated relation of codes in such aspects. The third-level coding includes the formulation of hypotheses and their verification for further data acquisition processes, as well as the identification of one or several core categories or the basic social process (Glaser, 1992).

## 8. Review on the Research Results

### 8.1. Chronic Illness Experience in the Social and Cultural Environment

By analysing the interview results of the second level coding, four categories of the experience of the central illness were outlined (body exposed to sight; an illness as a 'norm' of old age; old age discrimination; the decrease and change of goals) that described the chronic illness experience in the social and cultural experiences. When the theoretical coding was set, a relation between these categories and the categories of the quality of life were determined and 'the narrowing of the living-space' was identified as the main social process.

**Body exposed to sight.** A significant part of the interview analysis regarding chronic illnesses and ageing experience was related to changes in the body's appearance and its assessment by oneself and other people. Persons who suffer from chronic illnesses are at risk to face major changes, losses and threats that might influence and affect their identity (Charmaz, 1995). In the theory of symbolic interactionism one of the main types of self-definition is bodily identity. The formation of bodily identity is a process with the help of which a person differentiates oneself from the surrounding world and at the same time assigns meaning to one's body.

When speaking about changes in their bodies, the respondents used several characteristic contrasts: 'I versus the body'; 'the former body as opposed to the current body'; 'the social identification versus self-definitions'. In summary, during the interviews the respondents revealed their thoughts and opinions about bodily changes and identity problems resulting from them in three aspects: the contraposition of the body and the self, "the looking-glass self", and the comparison of appearance of the former and the current body.

In the interviews several female respondents spoke about themselves as the self that has remained as non-affected by the illness and ageing and they opposed it to the ageing body, altered by the illness as the changed shell of the self. They mentioned that the illness experience and the ageing process permit looking at one's body from aside and feel it as something alien, by pointing out "I versus the body". The illness and ageing tear apart the normal unity of the body and "I" thus creating the need to renew it again and search for a new identity.

When speaking about the bodily experience of the illness and ageing, the looking-glass self is frequently mentioned in the interviews. Glancing at the looking-glass during interviews presented evidence about the presence of "the looking-glass self" in the formation of identity and self-assessment (Cooley, 1983). Glancing at the looking-glass is looking at oneself from aside with the eyes of another person and imagining how the body looks from the point of view of other people; moreover, the looking-glass and "the looking-glass self" makes us reflect more about the value of this image in the eyes of the surrounding people rather than think about the image itself. Reflection in the eyes of others is an unavoidable part of embodiment: bodies are looked at and observation creates thoughts. By watching other bodies, a person interprets those things that he/she sees them. Alike, the persons who are observed image what their observers see and feel thus making this process similar to glancing at oneself in the looking-glass.

The mentioning of a looking-glass image and "the looking-glass self" in respect of the appearance was more typical of women. In the interviews men named changes in their appearance more seldom, in a simpler manner or with humour. It is possible that traditionally a woman's look has been regarded as a much more important capital in comparison with a similar assessment of a man.

One of the reasons why the interviewed respondents believe that the assessment of other people is indirectly important can be related to the uncertain social status of the elderly people in the society of Latvia nowadays. In many countries in traditional societies the elderly people have a stable, strictly determined place in the social system that determines the attitude to this social group. A clearly defined status makes the process of identity formation much easier. In Latvia the place and role of the elderly people in the social hierarchy has not been set clearly, therefore the identity of senior citizens to a less degree is moulded by the social order. This uncertainty of identity is one of the reasons why the recognition of other people is so essential during the formation of identity or the renewal process.

When analysing the category of body exposed to sight, it became obvious that this category is also related to the narrowing of the respondents' living-space. In general two aspects of the narrowing of the living-space appeared in the chronic illness experience. In addition to bodily restrictions that are created by the illness (movement difficulties, inability to leave home or to cover distances that were habitual previously); there are major restrictions due to the glances of the surrounding people and "the looking-glass self". Indisposition to expose the body that has been altered by the illness to the bodies of others, as obvious in several interviews, was related to shame about one's body. Although the respondents would have a wish to go out, they refuse to do it because of their bodies and glances focused on them. For instance, a 77 years old respondent whose chronic illness is manifest as movement restrictions problems assumed that the surrounding looks might perceive his movement disorders as a social deviance: the expression of alcoholism. In this case the loss of control over one's body simultaneously becomes the loss of control over one's identity. This respondent also mentioned shame of his illness, and he named his image in the eyes of others as one of reasons for the feeling of shame: "the looking-glass self". In another interview a 65 years old women told us about her unwillingness to leave home as she can move around only with the help of crutches, and movements obviously cause difficulties for her. This interview also showed that shame of one's appearance and things that symbolise bodily changes and weakness of old age (crutches) actually significantly narrows the respondent's world, in such a manner also affecting the quality of life essentially.

**Illness as a 'norm' of old age.** This category appeared in the interviews in two intermingled meanings:

1) Illness as a phenomenon that is inevitably related to ageing in the assessment of respondents themselves;
2) A wide-spread opinion, expressed by the surrounding people and the society, that an illness is a normal and relevant characteristic feature for old age.

In the opinion of the respondents the normality of an illness mostly was manifest as conciliation with the illness and a positive self-assessment of the health status and the quality of life. However, the belief that an illness is a self-evident characteristic of old age in the society and the attitude of the surrounding people was evaluated negatively. A negative assessment particularly referred to events in which illness as a 'norm' of old age was related to the category of ageing discrimination.

When speaking about the first understanding of illness as a norm in old age, several respondents, despite a chronic illness or a number of chronic illnesses, admitted that their health is normal, that is correspondent to their age. Pain and sufferings caused by the illness, movement restrictions, weakness of old age and other features were described as a norm, a feature of ageing, by perceiving the influence of a chronic illness upon the quality of life as an unchangeable and logical part of a lifestory of an ageing person. There can be various explanations for the 'normality' of an illness in the experiences of the senior generation: both the statistically widespread distribution of chronic illnesses among people of retirement age that make them a natural characteristic feature of old age and cultural symbols and meanings that associate old age with collapse and illnesses, as well as various historical and social conditions. Another function of 'normalising' the illness among the senior citizens in the chronic illness experience is the adjustment to the illness.

The analysis of interviews reveal that in particular cases the acceptance of illnesses as a 'norm' of old age works as an obstacle that hinders to accept help in order to improve the quality of life. Such an attitude towards illnesses, for instance, had deferred a respondent's decision to look for the help of professional doctors in a case of an illness.

The other group of cases, obtained as a result of coding, spoke about situations where the 'normality' of illnesses was perceived as the attitude of the surrounding people towards ageing people, and not seen from the point of view of the ill person him/herself. In the communication process, instead of addressing a particular person in a specific moment, the person is sealed with a stamp "an old person" and its meaning is "not worth the attention", "ill", "incapable". The author is convinced that such stereotypes behind which the particular person with his/her individual experience of illness and problems becomes invisible are unjust and useless. The attitude of other people is based on the opinion that old age decreases the meaning of an illness, makes it less visible, therefore it is not worth rendering assistance. When speaking about this problem, respondents metaphorically described their situation with the following expressions: "*no-one notices old people*" or "*I am an empty space*". Doctors also sometimes share the opinion that an illness is a 'normal' thing in a certain age. Stories about several cases were included in the interviews where the respondents have felt a discriminating attitude from doctors towards themselves due to the symbolic meanings of old age. In one of the described cases the doctor's attitude expressed an opinion that with a certain age it is worth paying attention only to very serious health problems and all the other, in her opinion (and, perhaps, in the view of a wider social agreement), insignificant symptoms were labelled with the word "ageing". This kind of attitude can also foster irrational use of medicine as the patient's request for help is being ignored and the patient needs to search for a solution him/herself.

Consciously or unconsciously a person's age influences communication and interrelation with other people. Depending on the person's age (or the age attributed to the person), in social interrelation conclusions are made about the person's physical and mental abilities and opinions. However, in order to avoid stereotypisation and discrimination it is essential to evaluate critically the symbolic meanings related to certain age groups and, in case of necessity, to change them. The 'normality' of senior citizens in culture is closely linked to the experience of social exclusion that in interviews was marked with the above-mentioned notions of "*invisibility*" and "*an empty space*". In case the identity problems are not solved, help from other people is not received and if persons avoid communication, sick persons develop the experience of exclusion.

**Employment and decrease of goals.** An essential aspect for the chronic illness experience is the decrease of goals and activities that to a large extent ease the illness experience and improve the quality of life. In many situations the fact of an illness releases the person from certain social duties, including the duty to go to work as the sociologist T. Parson has proven in his model of the sick role (Parsons, 1997). Similarly, reaching of a certain age boundary is a socially justified reason to decrease goals. However, in the same way as criticism about the theory of the role of a sick person in sociology, interviews that were carried out within the scope of this research have also demonstrated that the decrease and change of goals is not an unequivocal and simple task as outlined by the ideal sociological models.

Professional activities are one of the most important biographical aspects that are closely related to the identity of a person. Experience expressed in the interviews confirmed that in many cases paid employment during the retirement age has a positive impact upon the chronic illness experience and ageing, thus helping to maintain self-esteem, social contacts and improve the financial situation. In several interviews the respondents who were working pointed out that the professional identity is an essential part of their self. Work is the one that makes a person significant, visible and needed in the eyes of other people thus essentially improving the person's self-image. In addition, work substantially improves the living-space and sets important goals outside the narrow private life. The necessity to dress up, get ready and set one's body according to the expectations of other people and social norms makes people feel belonging to a wider group of people – the employees, instead of the retired people as a social group. The inclusion of oneself into another social group does not allow attributing other negative meanings towards oneself that are related to ageing people as a group. Employment was also motivation to bring health to the forefront, regardless the chronic illness experience.

However, during the analysis of interviews there were situations when persons of the retirement age had to work despite the chronic illness and the necessity to decrease goals. Those were cases when due to financial, social and household problems, as well as the attitude of other people, the sick person was put in a situation when he/she had to do more than it is possible and more than he/she wished as there was no other way how to take care for oneself and provide the minimum quality of life. In such situations a gradual and natural harmonisation of goals with the decrease of physical abilities was practically an impossible task. The research has shown that one cannot unequivocally declare that work always improves the quality of life of people of the retirement age. Within the context of the illness experience a significant role can be attributed only to the decrease of goals. Unfortunately, in Latvia the financial situation is a major reason why, when and how people want or do not want to decrease or change their goals.

A situation when a person has to work despite a serious chronic illness creates contradictions between the desire to fulfil oneself in the professional sphere, the need to provide for oneself financially and the sufferings caused by a serious illness. A story told by one of the respondents was a clear illustration for a situation when work could have a negative impact upon the person's identity: the need to work as the only way how to provide the minimum quality of life despite the fact that she has cancer for a long time.

In general the research results demonstrate that work can have both a positive and negative role in the process of regaining of one's identity and the chronic illness experience. In a positive sense work serves as a means for the maintenance of one's identity (it is applied in "active ageing" strategies) and it provides additional financial support. Employment expands the person's social communication space, thus strengthening self-consciousness and increasing the possibilities of interrelation. In a negative sense work in the illness experience appears as the only possibility to sustain a minimal quality of life and this promotes additional sufferings in the chronic illness experience. The social system should provide a realistic way how to decrease goals and leave work in case it is necessary for the sake of a chronic illness and ageing experience.

## 8.2. Possibilities to Improve and Change the Chronic Illness Experience

The analysis of interviews disclosed several categories and their connections that point to the possibilities how to improve and change the illness experience. One of such categories is control over the illness that is related to capacity to act, autonomy and satisfaction with the quality of life. Other important categories within this context were adjustment to the chronic illness and activities in order to improve one's health that was related to a higher assessment of one's quality of life. A significant role in the improvement of the chronic illness experience is played by biographical work that in interviews was revealed as explanations of the reasons for the illness.

**Control over the illness.** One of most important preconditions in respect of a high quality of life is the conviction that the person is able to control the situation to a certain extent. In the case of a chronic illness the control of the illness means the control of self-image, as far as possible not to allow the illness to come to the foreground of the lifestory, to change the person's identity and the desired order of life. Moreover, the control of the illness also means the control of space physically and the control of one's movements and body.

In the interviews carried out within the framework of the research an important category related to the control over the illness and autonomy was the planning of the future. The ability and desire of the respondents to plan their future was linked with a positive experience of the illness and health, not bringing the illness to the foreground. The research also proves that there exists a mutual connection between the sense of control over the illness and bringing health to the foreground of the illness experience. The control over a chronic illness allows the sick person to put forward health, while putting health in the foreground increases the possibilities to control one's life and the symptoms of the illness.

When analysing the individual health definitions included in the interviews, the conclusions made in an earlier research (Mežinska, 2006a) were confirmed once again. Although in Latvia the definitions of health, expressed by people, represent the negative type of health definitions (they define health as the non-existence of illness), nevertheless senior citizens mostly speak about health as a value and potential. This can be explained with the fact that in most cases the transfer from the use of negative health definitions to other types of health definitions based upon the experience of a serious illness. Only after facing a serious illness people begin defining health as a value.

An increasing inability to control one's body usually threatens the status of the sick person as an autonomous person that is closely linked with the notion of an agency. Dependence on other people both symbolically and practically outlines the refusal from the agent's position. The lack of control in the future caused by a possible illness or fear from it was demonstrated in the interviews as an important category. In relation to ageing and illnesses almost all respondents, both men and women, mentioned the fact that they would not be able to take care of themselves. Coercive refusal, caused by the illness, from the agent's position to act marks the beginning of a justified dependence from the surrounding people and release from the necessity to act energetically (Coupland, Coupland, & Giles, 1991) that in a situation of a serious illness can also provide a major relief. However, the refusal from the agent's position unavoidably leads to partial or full loss of the rights to make decisions.

Another significant precondition for the provision of the quality of life is control over the space. Interviews confirmed that the chronic illness experience that includes movement disorders, pain, fatigue or loss of strength increasingly narrows the living-space and reduces the control over it. The illness experience changes the perception of the space by demanding the adjustment of the surrounding environment to the body's altered needs. When movement restrictions occur and as an elderly person has fewer abilities to take care of oneself, it is important to adjust the flat and the wider surrounding environment to new needs. In case the flat – bathroom, toilette, bed, and kitchen – are not suitable the body persistently reminds about its restricted possibilities and the inability to control the situation.

In Latvia, due to various reasons the adjustment of the living-space and its possibilities for the improvement of the quality of life are not used efficiently and fully. None of the visited respondents' places had such kind of improvements and changes. There are various reasons for ignoring these needs in Latvia: lack of money for transformations and reconstruction; lack of information about different auxiliary means, as well as conservatism and no desire to change the surrounding environment. Emotional aspects also refer to the transformation of the space. Visible changes in the surroundings symbolise "*permanent change in [..] mode of being-in-the-world*" (Toombs, 1995: 16), as well as changes in the body's existential possibilities and the level of control.

**Coping with a chronic illness.** The analysis of interviews demonstrates various strategies that the respondents have applied in order to cope with and adjust to situations of a chronic illness. One of the most successful among such strategies was the inclusion of the illness into person's identity. This strategy means living with the illness, but not living just for the illness: to carry out all the necessary illness work, and at the same time successfully manage all other sides of the person's life. Such strategy corresponds to B.L. Paterson's theoretical perspective "health in the foreground" that was analysed in the theoretical part of the research: the identity is formed by bringing forth the self, not the sick body (Paterson, 2001). The sick body is the one that has been taken care of; however, it does not control the person's life. Nevertheless, this strategy needs a longer time and it is more successful if the chronic illness has begun in the youth. When it appears for the first time, a chronic illness is metaphorically described as an unwanted invader but gradually it becomes a part of the self with which a person has to learn to live with.

If we look at the illness experience as a part of the social process, it also includes activities of the family and the social network. The research discloses that the influence of the illness experience upon the quality of life depends on the stability of the social network; in the case of the elderly persons it mostly means help and support from their children, grandchildren and other relatives. Those respondents who had children pointed out that support from them was the most important factor; moreover, the relations with children were assessed in direct connection with the children's desire to offer the needed help and support. Advice from children is highly appreciated; therefore in the interviews those respondents who had children indicated that they consulted with their children before making major and significant decisions about health and treatment.

Some interviews indicated ignorance of the illness as an important strategy that brings forth the idea about the relativity of health as a value. Traditionally, especially within the framework of the biomedicine paradigm, health and avoidance of illness is regarded as the main goals. However, many interviews showed that gaining of health as a goal is measured and balanced with many other competing goals that might lead to ignoring of the illness.

The third coping strategy was the adjustment of the usual life and order to the illness.

**Active actions for the improvement of health.** Regular work is needed for the trajectory management of a chronic illness that J. Corbin and A. Strauss have characterised as three types of work in the chronic illness trajectory model: illness work, everyday work and biographical work (Corbin & Strauss, 1991). In the interviews respondents spoke about all three types of work. Most frequently people mentioned visits to doctors, the use of medicine and healthy nutrition as the main constituents of illness work; while fitness, active lifestyle and preventive measures were mentioned less frequently.

Taking into account that the use of medicine and visits to doctors form a very significant part in illness work of the interviewed retirement age persons, it is not surprising that the respondents mentioned the lack of money as the major obstacle for changing the chronic illness trajectory and improving one's health. This position coincides with the overall outlook about the quality of life and the quality of life related to health issues in the country: under the circumstances of survival and poverty that are typical of retirement age persons as a group, the main indicator of the quality of life is material provision. The research results of the quantitative questionnaire also testify that the lack of money is considered to be the main factor that influences the illness and the overall situation. 48% of the retirement age respondents who were sick with a chronic disease responded that they would need more money for the improvement of their health status (Sīlis, 2010: 148). Undoubtedly, the society and the policy makers play a significant role in the protection of chronically ill persons; the provision of income and sufficient financial support frequently has a decisive role in the provision of the quality of life for the elderly people with chronic illnesses. However, based on the data obtained during the research's quantitative part, 42% of retirement age persons with chronic illnesses believe that they would need more willpower and initiative in order to live with their illness better (Sīlis, 2010: 148). This tendency was supported by the fact that the majority of the interviewed retirement age persons mentioned visits to doctors and the use of medicine as the main types of illness work. Fewer respondents spoke about such types of illness work that would require more initiative and willpower and that is related to an active lifestyle.

Nevertheless, several interviews highlighted attempts to do something in order to improve health despite various unfavourable conditions and the lack of money. These respondents spoke of themselves as the agents of their own actions and they searched for various resources for the management of their chronic illness trajectory. In addition to visits to doctors and the use of medicine they mentioned fitness activities, walks, the use of folk-medicine, strengthening one's body and swimming.

Undeniably, such types of active behaviour and actions are possible only if a person has certain abilities to move around and take care of oneself. For lying patients the ability to influence their illness is fundamentally restricted therefore the illness work and the trajectory formation is mostly delegated to relatives and health care professionals. The activity of a sick person and the ability to influence the illness trajectory depend on the development phase of the chronic illness. However, the majority of the interviewed respondents, in accordance with the illness trajectory model of J. Corbin and A. Strauss, were in the stable phase of the chronic illness. Only three respondents characterised their health status at the time of the interview as corresponding to the downward trajectory or the unstable phase. Exactly in the stable phase of the chronic illness trajectory there are more possibilities to take additional actions in order to improve one's health and manage the illness trajectory.

It is typical that additional activities, mentioned by respondents, for the change of their illness were mostly individual; it was illness work that most frequently people did alone. At the same time the interviews disclosed the fact that group activities provide greater motivation to improve one's health and offer the feeling of security. Therefore, the research uncovers unused possibilities that are available for retirement age people in Latvia, public organisations and health promotion programmes in order to establish initiative groups for chronically ill people. Such programmes are formed in many European countries, for instance, walking clubs with an aim to promote physical activities of retirement age people in parks close to their places of residence.

The research of the Doctoral thesis confirm the relation analysed in the research "The Quality of Life in Latvia" (2006) between subjective types of health definitions and the respondents' understanding of their capacity to act (Mežinska, 2006a). The research approves that three typical points of view exist: health depends on success; health is something that is affected by a doctor; health is something that the person can affect himself/herself. People who have accepted negative health definitions most frequently express the first and the second position: in the case of an illness health depends on success and the professional activities of a doctor. If health is defined as a value or a holistic status of balance, there is an opinion that the health status to a large extent depends from the actions and attitudes of the person, including the cooperation with the doctor. Those persons who define health as something that is related to their choice and believe that they can influence their health are more conscious to choose a healthy lifestyle. Those persons who feel helpless to influence their health are active to follow suggestions of a healthy lifestyle.

V. Skultans, by analysing the influence of culture and historical conditions on the illness experience, concludes that in some cases the attitude towards a chronic illness was strongly affected the experience of the health care system during the Soviet period, that is, the fact there was no family doctor practice, the patient had restricted possibilities to express one's autonomous choice, define the essence of one's illness and get involved in the plan of one's treatment and recreation (Skultans, 1999: 315).

**Biographical work in the illness experience: explanations for the causes of illness.** The notion "explanatory models of illness" that denotes explanations for the causes of an illness was introduced in medical anthropology by A. Kleinman (Kleinman, 1988), and later it was also taken over by sociology of health and illness. Explanations for the causes of illnesses can have a polysemantic meaning. Anthropologists affirm that the explanations for the causes of illnesses primarily function as the group's relation with cultural values as they demonstrate the dominating models for the explanations of illness and health, as well as the values upon which these models are based. Secondly, these explanations are linked to the requirement of normality in social interaction (Foster, 1976; Kleinman, 1988; Kleinman, Eisenberg, & Good, 1978). By explaining the causes for an illness, the patient outlines his/her situation as meaningful and justifies one's being in a certain status both in the eyes of oneself and others. Individual explanations of the causes for an illness help to include the illness experience into the lifestory, while in many cases the biomedical causal explanations fails to do it.

As the most important explanations for the causes of illnesses respondents mentioned the following groups: work and historical conditions; traumatic biographical events; inheritance; ageing; lifestyle and supernatural causes.

When analysing the explanations for the causes of illnesses, it is important to pay attention to the terms and notions, as well as the flow of narration. In several interviews the part of narration that explained the causes for illnesses or described a particular event as the reason for the illness was outlined by a fluent narration. It is particularly interesting that in order to explain the illness, the respondents used ready stories that seemed to be told over and over several times. Details of the story and nuances already indicate that it is important in the person's lifestory and biographical work has been performed earlier.

In the interviews one of the most significant groups of explanations for the causes of illnesses was related to hard work life and poor employment conditions. Interviews showed elements of criticism of the Soviet political and social system by pointing out that the origin of the illness, to a large extent, could be sought in historical conditions. Similarly, V. Skultans in his research outlines that narrators closely link the history of their individual illness with the social environment by substantiating it with historical events and the political system (Skultans, 1999: 314). Another significant group of the causes in the eyes of the respondents was unexpected, sudden and severe turning-points in their lifestory: in two interviews such a reason was the death of the respondent's spouse.

An important group of the causes of illnesses were explanations of supernatural things. The significance of this group of causes differed from the data obtained in the quantitative questionnaire where only 1% of the respondents chose supernatural causes as the main reason for one's illness (Sīlis, 2010: 147). Some of the respondents searched for a supernatural cause for the illness as they felt the lack of control over their illness. In total, a chronic illness, at least some of its expressions, make the person feel his/her body as weak and out of control, sometimes even unacceptable and loathsome. In such a situation the explanations of the illness assign meaning and sense to the events that are related to the illness; it allows the person to perceive, analyse and understand oneself as ill by reducing the negative illness experience. When a person explains the causes for the illness, the sick person makes his/her status meaningful. At the personal level the explanation of the causes for the illness is a way how to approach, move closer and get introduced with one's changed life and body. At a social level it brings closer the sick body and makes it more acceptable for the surrounding people. Biomedical explanations about the origin of the illness are not always sufficient from the point of view of the sick person; therefore they are expanded or made anew, when persons speak about social, historical, supernatural or other reasons for the illness.

### 8.3. Ethical Aspects of the Chronic Illness Experience

A chronic illness and sufferings related to it is a direct bodily experience, as well as a personal and social event that can be attributed a certain moral assessment. Within the framework of the Doctoral thesis two ethical aspects of a chronic illness were analysed; they appeared as significant themes during the coding process of the interviews: the relationship of a doctor and a patient and the problems of human dignity.

In the view of social sciences the relationship of a doctor and a patient as social interaction undoubtedly is placed in the centre of medicine. The patient's health status, the quality of life and subjective satisfaction depend on the type of this relationship, as well as the overall quality of the whole health care system. In the view of social sciences and ethics significant preconditions for the relationship of a doctor and a patient are mutual trust, respect and interest and involvement of the doctor.

When assessing their relations with medical staff, the respondents expressed rather diverse opinions in their interviews. Several respondents valued their relationships with doctors, especially the family doctor, positively. One of important assessment criteria in the interviews was the doctor's desire and possibilities to reduce the patient's financial burden that is related to financial provision as one of the main criteria for the quality of life.

However several respondents pointed out and criticised negative features in their relationships with doctors. Insensitivity and indifference were mentioned as attitudes that hindered the relations of a doctor and a patient. The sociologist A. Frank outlines that the narration and listening to the patient's illness experience is a major constituent part of the treatment process: "the wounded storyteller" simultaneously heals oneself (Frank, 1997). Telling of stories of the illness experience is based on the sick person's need to lay out his/her experience, as well as the requirement of the medical staff to listen to such stories in order to understand the patient's situation in a better way.

The data of quantitative researches demonstrate that the problems of doctors' attitudes (superficiality, unkindness, rudeness, indifference, bureaucracy etc.) is regarded by patients as the second most important group of problems in Latvia; in the first place is the problem with the accessibility of doctors (Veselības obligātās apdrošināšanas valsts aģentūra, 2008: 39). Listening to the illness experience is one of the ways how to improve the relations of the doctor and the patient. Both the medical anthropologist A. Kleinman and A. Frank believe (Kleinman, 1988; Frank, 1997) that in medicine the narration of the illness experience and listening to it decreases the asymmetry in medicine and forms a basis for trust between the doctor and the patient. In the relations of a narrative dialogue the expressions of power from the medical staff that are typical of instrumental, technical situations decline.

In one interview, when substantiating the positive assessment of the relations between the doctor and the patient, the respondent mentioned respectful partnership relations between the doctor and the patient and the readiness to listen to and cooperate with the patient. These criteria prove that the understanding of the relations between the doctor and the patient significantly differ from the Soviet paternalistic relations and they demonstrate a modern perception of the doctor and the patient as cooperation partners.

The assessment of the relations between doctors and patients in the interviews show that there are still many problems to be solved in the relations between the doctor and the elderly person: patients do not trust doctors, doctors are inconsiderate and superficial in respect of the patient's needs. These problems create subjective dissatisfaction, but they also cause wider health problems in the society: irrational use of medicine and deferment of visits to doctors.

## 9. The Main Conclusions

1. The theoretical analysis of the notion of the illness experience outlined in the Doctoral thesis leads to a conclusion that illness as experience is a relatively new notion, based upon normative health definitions that substantiate investigations of the subjective illness experience in sociology of health and illness. Up to now in the research carried out in Latvia on the quality of life, particularly the quality of life of retirement age persons, no particular attention has been paid to the notion of the illness experience, thus excluding a significant characteristic aspect from the field of research in sociology of health and illness. In the Doctoral thesis the analysis of the notion and the theoretical substantiation of the research from the basis for further investigation on the illness experience of the retirement age persons in Latvia.
2. In Latvia there is still no established tradition for the translation and differentiation of the notions *disease, illness* and *sickness.* The options for translations that have been offered so far have several shortcomings. In the Doctoral thesis the author offers a new translation for the notions *disease, illness* and *sickness.*
3. In the analysis of the interviews four central categories of the experience of the illness include: body exposed to sight; an illness as a 'norm' of old age; old age discrimination; the decrease and change of goals; and as the main social process 'the narrowing of the living-space' was identified.

4. The analysis of interviews disclosed several connections between the categories that point to the possibilities how to improve and change the illness experience. One of such categories was control over the illness that was related to capacity to act, autonomy and satisfaction with the quality of life. Other important categories were adjustment to the chronic illness and activities in order to improve one's health that were related to a higher assessment of one's quality of life. Also biographical work plays significant role in the improvement of the chronic illness experience.
5. By analysing the category of the body exposed to sight, a relation with the narrowing of respondents' living-space became obvious. In addition to direct bodily restrictions caused by the illness (movement difficulties, inability to leave home or to cover distances that were habitual previously), there are major restrictions due to the glances of the surrounding people and "the looking-glass self". Although the respondents would have a wish to go out and carry out former activities, they refuse to do it due to the problems of the bodily identity. The respondents' choice to avoid social and cultural activities is also determined by visible things (for instance, the crutches) that are related to the illness experience and in the eyes of other people approve the bodily changes and weakness.
6. The category 'illness as a 'norm' of old age' appeared in the interviews in two intermingled meanings:

a) illness as a phenomenon that is inevitably related to ageing in the assessment of respondents themselves;

b) a wide-spread opinion, expressed by the surrounding people and the society, that an illness is a normal and relevant characteristic feature for old age.

The first meaning of the 'illness as a 'norm'' was connected with higher self assessment of the health state; however in particular cases the acceptance of illness as a 'norm' of old age works as an obstacle that hinders to accept help in order to improve the quality of life. The second meaning of the category 'illness as a 'norm'' in many cases becomes the cause for discrimination of representatives of the older generation.

7. A mutual interaction exists between the illness experience and social representations of ageing. Such social representations as collapse, the normality of the illness or uselessness negatively influences the illness experience of the elderly persons. The interviews disclosed situations when, instead of focusing on a particular person in a certain moment, the persons is attributed a label "old" that means "not worth the attention", "ill", "incapable". As the symbolic meanings can be affected and changed in a longer period of time, it is important to change these meanings in culture in order to avoid from their negative influence on the illness experience of the senior generation. At the social level the categories that should be influenced include the following: the society's overall attitude towards chronically ill elderly persons, as

well as the meaning that is attributed to old age in social interaction.

8. In many traditional societies the older generation has a stable and strictly established place and role in the social system, forming a basis for a positive attitude towards this group in the society. Such a clearly defined status significantly eases the formation of bodily identity within the context of ageing and the illness experience. In Latvia the place of the elderly persons is not firmly set, therefore the identity of the older generation representatives to a less degree is formed by social order. This uncertainty also influences the chronic illness experience and its related problems of identity.

9. Analysis of the interviews confirmed that in many cases employment during the retirement age has a positive impact upon the chronic illness experience and ageing, thus helping to maintain self-esteem, social contacts and improve the financial situation. Work is the one that makes a person significant, visible and needed in the eyes of other people thus essentially improving the person's self-image. In addition, work sets important goals outside the narrow private life and makes people feel belonging to a wider group of people – the employees, instead of the retired people as a social group. Employment is also motivation to bring health to the forefront, regardless the chronic illness experience.

10. At the same time the analysis of the chronic illness experience, carried out in the framework of this research has shown that one cannot unequivocally declare that work always improves the

quality of life of the retirement age persons. Within the context of the illness experience a significant role can be attributed only to the decrease of goals. Unfortunately, in Latvia the financial situation is a major reason why, when and how people want or do not want to decrease or change their goals. The social system should provide a realistic way how to decrease goals and leave work in case it is necessary for the sake of a chronic illness and ageing experience.

11. The analysis of interviews disclosed a relation among the capacity to act, active actions in the improvement of one's health and the satisfaction with the quality of life. Those respondents who highlighted external conditions (financial, social, and political) as the major conditions that influence the illness trajectory mostly were more dissatisfied with their quality of life. Those respondents who were confident about their capacity to act, showed the desire and ability to affect their illness trajectory, mostly were satisfied with their quality of life.

12. Among different coping models included in the interviews one the most successful models was the inclusion of the illness into person's everyday life, life story and identity. This strategy means living with the illness, but not living just for the illness: to carry out all the necessary illness work, and at the same time successfully manage all other sides of the person's life.

13. When speaking about various factors that influence the quality of life in relation to the chronic illness experience, the research has

disclosed that several major factors exist that the elderly persons are not aware of or they do not regard them as significant. For instance, one of the factors that was not mentioned was the adjustment of the environment for the needs of chronically ill elderly persons. Due to various reasons, such as financial problems, the lack of knowledge, conservatism etc., the retirement age persons fail to use these possibilities sufficiently. The society has to change its way of thinking and attitude by attaining that the change of environment for the elderly persons becomes as self-evident as the adjustment of environment for the needs of small children.

14. In the interviews the assessment of the relations between the doctor and the patient demonstrates that there are many problems to be solved in the relations of the doctor and the elderly persons: the patients lack of trust in the doctor, negligence of the doctor and no interest about the patient's needs. These problems create the patients' subjective dissatisfaction, but they also cause wider health problems in the society: irrational use of medicine and deferment of visits to doctors. In situations when the doctor approaches the illness as a biological dysfunction and pays little attention to the patient's subjective illness experience, a risk exists that there might be a discrepancy between things that a patient expects and things the patient receives from the doctor.

15. The understanding of respondents about the causes of chronic illnesses is wider than the explanations of causes offered by the

professionals of medicine. The significance of individual explanatory models of illness is affirmed by the fact that a part of respondents included specially developed narrations on the social, historical or metaphysical reasons for their illness. In the biomedical paradigm no special attention is paid to the individual explanations of causes of illnesses as the main value is attributed to the explanations of a doctor as an expert. However, these alternative explanations help the sick person to include the illness experience in the lifestory and assign meaning to it, thus making the illness situation more meaningful and acceptable.

16. In order to decrease the impact of a chronic illness on the quality of life of the retirement age persons, new approaches to health care and social assistance should be established that would also take into account the diversity of individual illness experience. Such approaches possess the potential to improve the quality of life of the older generation, as well as to reduce the problems in the relationships of a doctor and a patient.

17. In Latvia the possibilities to promote mutual initiatives for the improvement of health and the management of the chronic illness trajectory for the retirement age persons have not been used in full. One of such possibilities is to establish patients-experts programmes that are based on the research of M. Barry. In addition, it is necessary to promote and support events that popularise active lifestyle and that are organised by the elderly persons themselves.

18. It is important that positive narratives of the illness experience of the retirement age persons appear in the public space, as they would provide an example for a successful management of the chronic illness trajectory and the inclusion of the illness into the person's identity and biography.

## 10. List of Publications Related to the Subject of the Thesis

**Publications in peer-reviewed journals and edited books**

1. Mezinska S. (2010). „Then She Looked at Me and Said – the Old Age!": The Impact of Social Representations of Ageing on the Elderly People's Chronic Illness Experience in Latvia. *Culture and Society: Journal of Social Research*, 1 (1), 29–41.
2. Gefenas E., Dranseika V., Cekanauskaite A., Hug K., **Mezinska S.,** Peicius E., Silis V., Soosaar A., Strosberg M. (2010). Non-equivalent Stringency of Ethical Review in the Baltic States: A Sign of a Systematic Problem in Europe? *Journal of Medical Ethics*, 36, 435-439.
3. Mežinska S. (2010). Ķermenis, slimība un biogrāfija: hroniskas slimības pieredze pensijas vecumā. Grām.: *RSU Zinātniskie raksti 2009. Ekonomika. Komunikācija. Politika. Socioloģija. Sociālā politika un sociālais darbs. Tiesības* (131. – 141. lpp.). Rīga: RSU. *(In Latvian)*
4. Mežinska S. (2009). Pensijas vecuma cilvēku subjektīvā slimības pieredze Latvijā. Grām.: *RSU zinātniskie raksti. 2008. gada sociālo zinātņu pētnieciskā darba publikācijas* (141. – 151. lpp.). Rīga: RSU. *(In Latvian)*

5. Mežinska, S. (2006). Nespeciālistu priekšstati par veselību un to saikne ar dzīves kvalitāti. Grām.: *Dzīves kvalitāte Latvijā* (217.–237. lpp.). Rīga: Zinātne. *(In Latvian)*
6. Dranseika V., Gefenas E., Cekanauskaite A., Hug K., **Mezinska S.**, Peicius E., Silis V., Soosaar A., Strosberg M. 20 Years of Human Research Ethics Committees in the Baltic States. *Developing World Bioethics. (Forthcoming).*
7. Mežinska S. Pensijas vecuma cilvēku aktivitātes nozīme hroniskas slimības trajektorijas vadīšanā (*Accepted for publication in Riga Stradins University Collection of Scientific Papers 2010*)

**Published conference abstracts**

1. Mezinska S. (2010). The role of medical ethics in chronic illness experience of older adults: Latvian case. In *„Is Medical Ethics Really in the Best Interest of the Patient? ”* (pp. 25). Uppsala: Uppsala University.
2. Mezinska S. (2007). Lay health beliefs in the context of public health. In *XXI European conference on philosophy of medicine and health care „Ethics, philosophy and public health”* (pp. 64.–65). Cardiff: Cardiff University.
3. Mežinska S. (2007). Hroniskas slimības subjektīvā pieredze pensijas vecuma cilvēkiem Latvijā. Grām.: *Konferences "Sabiedrība. Veselība. Labklājība." tēžu krājums* (61.–62. lpp.) Rīga: RSU.
4. Mezinska S. (2007). Public bioethics debates and policy outcomes in Latvia. In *XXII European conference on philosophy of medicine*

*and health care „European bioetics in a global context"* (pp. 52.–53). Tartu: Tartu University.

**Other publications**

1. Mežinska, S. (2007). Slima ķermeņa dzīve. *Kentaurs XXI*, 43, 113–120.
2. Mezinska, S. (2007). The concept of quality of life and bioethical argumentation. *Ethically speaking,* 7, 39–41.

## 11. Presentations at Scientific Conferences

1. International conference „Is Medical Ethics Really in the Best Interest of the Patient? ", 14 – 16 June 2010, University of Uppsala, Sweden. Presentation title „The role of medical ethics in chronic illness experience of older adults: Latvian case".
2. International conference „Life and Evolution", 27–28 November 2009, University of Latvia, Riga. Presentation title „Darwinism and definition of the notion of disease". *(In Latvian)*
3. XXIInd European Conference on Philosophy of Medicine and Health Care „European bioethics in a global context", 20 – 23 August 2008, University of Tartu, Estonia. Presentation title „Public bioethics debates and policy outcomes in Latvia"
4. International conference „Baltic Futures".23 – 24 November 2007, University of Latvia, Riga. Presentation title „Chronic Illness Experience of Elderly People in Latvia"
5. International conference „Society. Health. Welbeing." 8 – 9 November 2007, Riga, Riga Stradins University. Presentation title

„Chronic Illness Experience of Elderly People in Latvia". *(In Latvian)*

6. XXIst European Conference on Philosophy of Medicine and Health Care „Ethics, Philosophy and Public Health", 15 – 18 August 2007, Cardiff, United Kingdom. Presentation title „Lay health beliefs in the context of public health".
7. International conference „Bioethical Aspects of Human Life". 5 – 6 October 2006, Riga. Presentation title „The concept of quality of life and bioethical argumentation"
8. International conference „Expanding Borders: Communities and Identities". 9 – 12 November 2005, University of Latvia, Riga. Presentation title „Lay concept of health – its relation to quality of life"

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