

"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

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ABSTRACT. *This article discusses the impact of social representations of ageing, such as breakdown, inevitability of illnesses and unfitness, on chronic illness experience of elderly people in Latvia. The qualitative study is based on theoretical framework of symbolic interactionism and uses grounded theory methodology. The results of the study lead to the conclusion that in Latvia certain social representations of ageing have a negative impact on chronic illness experience of elderly people, decreasing health-related quality of life and hampering reception of required medical assistance, adaptation of environment to the needs of elderly people with chronic illnesses and successful incorporation of the chronic illness in the context of biography.*

KEYWORDS: *illness experience, health-related quality of life, chronic illness, ageing, social representations of ageing, illness metaphors.*

RAKTAŽODŽIAI: *ligos patirtis, gyvenimo kokybė, susijusi su sveikata, senėjimas, socialinės senėjimo reprezentacijos, ligos metaforos.*

Demographic forecasts show that due to the changing age group proportion in society in the next decades we will inevitably need to reassess the attitude towards elderly people and address the social problems related to the ageing of society. Research conducted in various countries shows that particularly many problems are associated with health-related quality of elderly people's lives (Bowling 2005; Poon, Gueldner and Sprouse 2004; Mollenkopf and Walker 2007). Accordingly, the avoidance of illness as well as the preservation of physical and cognitive functions is some of the most important factors that significantly improve the quality of life in the elderly age. Different studies also conclude that health is one of the most prized values for elderly people (Bowling and Gabriel 2007). Poor health is associated with the loss of control, autonomy and independence, and it makes people aware of the approaching death.

One of the most significant research studies on the quality of life in Latvia in recent years is the study “Quality of Life in Latvia” by the Strategic Analysis Commission (Tisenkopfs 2006). In this study, the elderly as a group are described as stepchildren of life, “who still ‘survive,’ pinch and scrape, cannot make both ends meet, face continuous difficulties and cannot enjoy a fully valuable life” (Tisenkopfs 2006a, 28). Research data show that 77% of respondents rate retired life in Latvia as bad (Bela 2006, 49). The same study also found that people of the retirement age often stress that they have “difficulties in dealing with health problems – visiting doctors, buying medicines or hospital treatment are often too expensive, even if it is necessary” (Bela 2006, 54). The report “Quality of Life Index of the Population of Latvia” by the Latvian Strategic Analysis Commission concludes that the low assessment of life quality by elderly people “is closely related to the increase of the importance of health care and social programs for them and the existing problems in these areas” (Stratēģiskās analīzes komisija 2006).

As a result of the increasing proportion of elderly people in society, the number of people with chronic illnesses will inevitably increase in the coming decades. One of the essential concepts related to the quality of life of elderly people, which so far has not been sufficiently analyzed in Latvia, is a chronic illness experience and social representations affecting it.

Conceptual and Theoretical Framework

Sociology of health and illness and medical anthropology use three different terms – disease, illness and sickness. Each of them indicates a separate meaning of ill health. H.T. Engelhardt, describing the separation of these concepts, talks about three essential elements of the life-world of an ill person – illness as suffering, disease as an explanation and sickness as a social role (Engelhardt 1982). In the conceptual field of a *disease*, a doctor is the one who is able to objectively discern, describe and correct faults that have arisen in the human body by metaphorically “seeing through” the patient (this metaphor is strengthened by the possibilities of modern diagnostic equipment). However, the epistemological framework of the concept *disease* is quite narrow, because it offers only one particular perspective on the ill health – biological causes and consequences but excludes the subjective aspects of illness experience. From a wider perspective, the biomedical paradigm and the concept of *disease* is closely related to the values of rationality and control in the Western culture. In this perspective, the key is to obtain objective empirical information on the disease that is the most important data from a medical point of view (Eisenberg 1977). *Illness* is ill health as a deeply individual emotional experience. A. Frank, explaining the meaning of illness, writes: “If disease talk measures the body, illness talk tells of the fear and frustration of being inside a body that is breaking down. Illness begins where medicine leaves off, where I recognize that what is happening to

my body is not some set of measures" (Frank 1991, 13). Thus, illness is directly felt in personal experience but the scientific knowledge of the illness experience is provided by sociological and anthropological analysis.

There is no single definition of the concept of illness experience in sociological and anthropological literature; it is used in a wider context and the operational definition of the illness experience depends on the design of each individual study. However, these different applications have common research questions: What meaning is given to the fact of the illness? How does the illness affect a person's daily life and his/her relations to others? How does the ill person understand and explain the possible causes and the course of illness? What is being done to affect the illness situation? How does the illness affect the person's identity? Once a person is ill, he/she, together with the others, starts to interpret the meaning of symptoms. The severity of symptoms, possible causes of the illness, possible reaction and action, etc. are being assessed. The specific illness experience is affected by the person's previous illness experience, age, sex, knowledge, attitudes, beliefs, personality, language, religion, marital status, etc., as well as a cultural, social and economic context. In different cultures, societies or society groups, these interpretations are formed in the context of very different normative frameworks and cultural symbolic systems.

The theoretical perspective of this study is the theory of symbolic interactionism, especially the studies of illness experience conducted by K. Charmaz (Charmaz 1983; Charmaz 1991; Charmaz 1995). In the theory of symbolic interactionism, "human beings act toward things on the basis of the meanings that the things have for them" (Blumer 1998, 2). However, what specifically characterizes the view of symbolic interactionism is the understanding of meaning formation process – the meaning of a thing develops through interaction with other persons, so it is a social product: "The meaning of a thing for a person grows out of the ways in which other persons act toward the person with regard to the thing" (Blumer 1998, 4). This means that for any experience, including illness experience, to gain meaning, interpretation performed in interaction is required. Interaction creates common symbols that become reference points for further interactions. These symbols are constantly validated, reviewed and redefined. Thus, the range of interests of symbolic interactionism includes the interpretative processes through which a person develops the situation definition in illness and ageing conditions.

Methodology

Aims of the Study

The study was carried out under the grant of Riga Stradins University entitled "Factors Affecting the Lifestyle and Quality of Life of Residents of Latvia at Retirement Age." The study consisted of two parts – the qualitative and the

quantitative, and the main aim of the study was to analyze the factors affecting the health-related quality of life of elderly people in Latvia. This paper focuses exclusively on the qualitative part of the study. The aim of this sub-study is to analyze the impact of social representations of ageing on chronic illness experience and health-related quality of life of elderly people in Latvia.

Data Collection and Analysis

The qualitative part included 28 semi-structured interviews with elderly people in various Latvian cities and rural areas. Three interviewers from the project's work group conducted the interviews. Within the framework of the study, people aged from 62 to 91 were interviewed. Respondents living at home rather than institutionalized care institutions were selected. The sample of respondents was made using the maximum diversity strategy. It was assumed that the quality of life of elderly people was significantly affected by sex, the place of residence and age. Chronic illness was not taken into account as an initial respondent selection criterion, however, during the analysis of the first interviews (according to the methodology of grounded theory, the analysis was started immediately after first interviews were conducted), it became evident that in most interviews chronic illness experience was an important factor affecting the quality of life of elderly people. This fact motivated us to focus on the analysis of chronic illness experience.

Twenty-three of the interviewed persons stated that they were suffering from a chronic illness that lasted more than a year and caused serious functional disturbances. The analysis is based on the interviews with these respondents. However, in some cases the interviews with respondents whose self-assessment did not include chronic ailments have also been used for comparison. The fact that respondents represented very different chronic illness experiences could raise questions. However, such study design is not uncommon in chronic illness experience studies. Although a part of illness experience research is focused on the experience of a certain illness (e.g., arthritis, diabetes, stroke, etc.), a number of sociologists and anthropologists have studied chronic illness experience on the basis of a universal chronic illness experience concept rather than focusing on a particular illness (Corbin and Strauss 1991; Kleinman 1988; Morse and Johnson 1991).

The data analysis began, according to the methodology of grounded theory, with the coding to create the theoretical categories. The coding of the interviews was not performed according to a pre-prepared code; the categories were created through the course of the coding. The coding was started at an early stage of the study, simultaneously continuing data acquisition. The interviews were transcribed verbatim and imported into a qualitative software package NVivo 8 to facilitate the thematic coding, evaluation and analysis. Based on coding results, the following categories characterizing chronic illness

experience were developed: body exposed to the sight; interpretations of the cause of illness; illness as a "norm" of ageing; active action to improve health; adaptation to chronic illness, age discrimination in illness experience; reduction or change of goals; control and lack of control; and lay definitions of health. This article will analyze some of these categories, particularly illness as a "norm" of ageing and age discrimination in illness experience.

Results

An essential category that appeared in illness experience of the interviewed persons was "normality" of illness in old age. In spite of chronic illness or even several chronic ailments, respondents considered their health to be normal – appropriate for their age. Pain, movement restrictions, weakness, etc. caused by the illness were characterized as normal features of the age; the respondents perceived the impact of chronic illness on the quality of life as an unalterable and logical part of the biography of an ageing person. A 64-year-old man suffering from high blood pressure characterized his health status as follows: "You should complain if you can't get out of the bed. But, as long as you can move and do something, it is normal – no problem." An 82-year-old man, who had chronic health problems related to low blood pressure, also considered the possible deterioration of the situation in the future as normal: "I think that it would be normal."

Suffering caused by the illness can be perceived very differently. Nevertheless, the reconciliation with the suffering without hoping for the improvement was characteristic of most respondents with the chronic illnesses in this study. There are different possible explanations for such attitude – both the statistically broad prevalence of chronic illnesses among elderly people which makes them seem a self-evident feature of ageing and cultural symbols and meanings that associate age with breakdown and diseases and represent illness as a normal condition in old age.

How did the fact that pain and other symptoms associated with chronic illnesses were viewed as normal in old age affect the illness experience and quality of life of elderly people? Some interviews showed that the symbolic meaning of the illness as a norm might act as a barrier preventing the reception of assistance that could improve the quality of life, especially the adaptation of the living environment to the needs of an ill person. Serious chronic illness experience changes the meaning of objects in the surrounding space. According to K. Toombs, "The bookcase outside my bedroom was once intended by my body as 'a repository for books,' then as 'that which is to be grasped for support on the way to the bathroom,' and is now intended as 'an obstacle to get around with my wheelchair'" (Toombs 1995, 10). Lived illness experience changes the perception of the living space and requires adaptation of the surrounding space to the changed needs of the body. As movement limitations develop and

the abilities of an elderly person to take care of himself/herself decrease, it is very important to adapt the apartment and a wider environment. If the apartment – bathroom, toilet, bed and kitchen – is not suited to the changed needs, the body constantly reminds of its limited capabilities. A 75-year-old woman suffering from rheumatoid arthritis tells: “When my husband is away, I am afraid to move away from home. Once in the winter (we don’t have a bathroom inside, we have to go outside) the temperature was 28 degrees, I went out and fell. My husband was watching television and he didn’t hear me shouting So I scuffed to the door. I leaned on my hands – little by little”

Due to various reasons in Latvia such necessary adaptation of living spaces takes place quite rarely. None of the visited respondent residences had such amenities and transformations. There are various reasons these needs are being ignored in Latvia – the lack of money for such reconstruction, the lack of information on various auxiliaries, as well as conservatism, reluctance to change the living environment and the mentioned “normality” of illnesses and difficulties in old age. Another reason which emerged in the interview with the above respondent is the meaning assigned to various auxiliaries (in this specific case – crutches) and special amenities – a perception that in the eyes of others they directly indicate the weakness and helplessness of the ill person that is shameful:

I. Do you also leave home for anyplace further?

R. No, not while I’m on crutches – nowhere anymore, nowhere. . . . I want to but I feel ashamed. I’d want to... Once I went but now I’m like this Awful, it’s awful

Reconciliation with the suffering is also caused by a number of other factors – difficult previous life experience, religious beliefs, etc. Some researchers stress that it is the war experience that makes the older generation reconcile with difficulties and become passive (Bowling 2005). In the coming decades, there will be an increasing number of elderly people born in the postwar period who have not experienced serious critical situations and a sudden deterioration of the quality of life (war and deportation). This could increase the expectations of the elderly as a group and create greater dissatisfaction in the domain of health-related quality of life.

Furthermore, others such as doctors and social workers do not think it is necessary to provide quality medical assistance to old and sick people, believing that age reduces the importance of the illness making it less noticeable and thus not worthy of assistance. Sometimes doctors also strengthen the view that illness is a “normal” phenomenon at a certain age. An interviewed 81-year-old woman included, as an abusive experience, a story about neglect and age discrimination during her visit to a doctor:

I had to go to a skin doctor to get a prescription for some kind of ointment for this [points to a skin defect on her temple] and I left just like I

came . . . So I went to her, went in and asked if I could get some kind of ointment because I have this fungus or something like that. She was sitting at a table; she looked at me and said – the old age. I asked again if she could still prescribe something. Visit an oncologist, – she said. . . . She was sitting at the table and didn't pay attention to me, she was talking on the phone, and when she finished she looked at me and said – the old age.

The unequivocal label "old age" suggested by the doctor and clearly associated with illness as a norm leaves no opportunity for debate possibilities. The doctor's attitude clearly demonstrates the view that from a certain age only very severe health problems are worthy of attention ("visit an oncologist"). All other symptoms that seem insignificant to her (and probably to the larger social conventions too) are labeled as "old age." This episode of the interaction made the respondent deeply mortified and doubting the attitude towards the older generation among doctors, the health-care system and society as a whole.

A 67-year-old woman shares similar observations in the interview. In response to the question: "How do you assess the health care available to you?" she talks about her experience of her husband's illness: ". . . here the one can really feel negligence towards elderly people. If you are retired you are overlooked. That's why I don't go to them."

The division of society into the age groups – children, adults and elderly people – is a usual but somewhat artificially constructed model that can promote the emergence of stereotypes and prejudices. Instead of focusing on a particular person during the interaction at the moment, the person is labeled as "old," meaning "collapsed," "invalid" and "not worthy of attention." Such a breakdown of the society into the groups that hide the individual person's problems seems unfair and unsuitable. The attitude towards illness as a "norm" in old age becomes the cause for discrimination against the older generation. The quantitative research data also demonstrate it. According to the 2008 Eurobarometer survey data, 52% of Latvian respondents say that age discrimination is widespread in Latvia (Eurobarometer 2008b, 59). In the 2009 Eurobarometer survey, this figure increased to 67% (Eurobarometer 2009, 10). Older respondents are more likely to say that age discrimination is widespread (Eurobarometer 2008, 60). In the context of illness experience, a particularly significant indicator is the attitude towards elderly people in the health care system. Additional study (Eurobarometer 2008a, 18) shows that age is the most common cause for discrimination in the health care in European Union. 30% of Latvian respondents in this study believe that age discrimination in the health care is "very widespread" or "fairly widespread" (Eurobarometer 2008a, 21). This figure is above the average figure in the European Union.

It should be noted that the superficial and discriminatory attitude towards health problems of retired people is not only a personal resentment but can also lead to much more specific problems. One of these problems is the irrational use of medication. If due to the doctor's attitude and prejudices a trust-

based relationship between the patient and the doctor does not develop, there is an increased possibility that decisions regarding the use of medication will be made without consulting an expert. In this case, people will medicate themselves and the compliance with the treatment strategy ascribed by the doctor will decrease.

The use of language in illness experience statements and social representation analysis plays a very important role because there is an essential relationship between language and the meaning formation process. L. Kirmayer points out that there also exists an indissoluble and reciprocal link between the physical experience and language: "Past infancy, bodily experience is most conspicuously elaborated and communicated through language. Language, in turn, is grounded in bodily experiences that provide common referents for a lexicon and in the organization of bodily action that provides a prototype for syntactic structure" (Kirmayer 1992, 324). One of the objectives of illness experience studies is to identify and analyze the hidden, concealed, undisclosed or unconscious meanings of illness manifested in the social interaction by the use of illness metaphors. One of the most notable works analyzing the use of illness metaphors in language is the book "Illness as a Metaphor" by S. Sontag (Sontag 1990). S. Sontag argues that, although the signs and symptoms of illness are material and tangible, they also constitute the cultural image, the reality of metaphors and collective representations. Metaphors turn the symptoms from signs into symbols, thus, letting the ill person understand the changes better and assign meaning to them in the biographical context. The symbolic meanings of illness formed by society and culture in addition to the physical manifestations of the illness can also cause stigma, rejection, fear or exclusion. Thus, the illness affects the patient with the double force.

One of the most significant groups of metaphors in the context of illness experience that also emerged in the interviews was related to the military field. Military metaphors that originate in the biomedical paradigm include the idea of illness as an enemy and describe illness treatment and life of an ill person as a struggle. The doctor and the patient in this interpretation form an alliance that protects the patient and attacks the enemy by using medical weapons (Jennings, Callahan and Caplan 1988, 9). This use of metaphors puts the ill person in the background, bringing the illness in the foreground. The metaphor of an enemy alienates the person from the illness and makes the person view it as an external, hostile and disturbing force. The illness is considered as the other, strange and evil. In the case of chronic illness, this metaphor may impede the acceptance of illness and ability to cope with it.

Another important group of metaphors is related to the collapse and loss of orientation. This group of metaphors appears in several interviews that describe the ill body as a "slum." An 81-year-old respondent in the interview said: "I am a slum, a slum, I take one medicine after another to treat my leg, the veins, and thus the blood pressure rises, and then I take a medicine for the

blood pressure and circulation of blood, and sclerosis and things like that, as one doctor told to me – it's the age. That's it"

The metaphor of the "illness as a neighbor" that characterizes reconciliation and getting on with the illness is also used in the interviews. A 65-year-old woman suffering from rheumatoid arthritis tells:

Yes, it is hard indeed. But if you don't think about it and accept it as, say, your neighbor with whom you have to cope and from whom you can't go away, you get used to it and reconcile yourself with it. The only thing perhaps is that in old age something constantly arises and when it happens, it takes some time for you to accept the way it will now be for you, and you can't get rid of it, but when you have accepted it everything is fine again.

A metaphor that one of the interviewees attributes to ageing is "leaving the stage." Age is seen as a resignation from visibility. In another interview, a 68-year-old woman used the metaphor of invisibility to describe her ageing experience: "In your youth you are still noticed, you are something but old people are not even noticed. People pass them by as if they were an empty space. That's the way it is. . . . It is also insulting that in old age you are no longer considered a human being. It is really so. You're something disturbing, ugly, old, and . . . useless. People don't even talk to you" In this fragment of the interview, the respondent remarks that being elderly means to be unnoticed, invisible and unheeded. A 77-year-old man describes the attitude towards elderly age briefly and concisely: "Well, a retired person is considered to be someone who has been discarded."

Discussion and Conclusions

Ageing, like gender, is closely related to the symbolic meanings assigned to it on individual, interaction and institutional level. As long as sex is a culturally determined social differentiation criterion, a person cannot avoid developing a gender. Similarly, as long as age is a social differentiation criterion, a person cannot avoid assignment of a symbolic meaning to age and interpretations of these meanings. Although age is not an equally important criterion in all social interaction situations, it certainly functions as a part of self-formation and interactions. Consequently, by engaging in interactions, individuals assign a symbolic meaning to both their and others' age.

The social representations of the old age have a long history offering different models of meaning. "Normalizing" attitude towards chronic illnesses of elderly people is closely related to the "deficiency model" in geriatrics (Schmid 1991) in which an ageing person is mainly viewed from the perspective of gradual deterioration of mental and physical abilities. Geriatric literature that is based on medical and biological point of view regards ageing as a gradual

exhaustion of the body's resources and activities. Compared to children and adults, the elderly are seen as a part of the society with serious deficiencies. The deficiency model does not take into account the significant individual differences between elderly people. However, there are large differences between the personal attitudes of elderly people with chronic illnesses, the development of illness trajectory, their motivation and other areas. The deficiency model can cause serious difficulties in the integration of the growing group of elderly people into society since problems related to the identity, meaning and self cannot be solved with the help of a biomedical understanding of health and illness and the concepts of validity and activity.

If we looked at it superficially it would seem that the old age as the end of a life is a time characterized by restrictions, collapse and the lack of capacity. However, it is very limited view because elderly people are also able to enjoy an adequate quality of life. The negative age-related social representations have largely created the situation where discretion regarding the end of life is a dogma in the Latvian society. Elderly people are invisible in political, social and cultural fields. In the study "Quality of Life in Latvia," this situation was described from a point of view of a representative of the older generation, a 67-year-old woman:

Our society believes that the old age is comparable to mental and physical collapse, weariness and uselessness. But Socrates at the age of 70 began to learn several musical instruments, Goethe completed "Faust," and Konrad Adenauer at the age of 74 took the wheel of German post-war politics in his hands and guided it for 14 years. Here a retired person is an outcast (Bela 2006, 55).

One can see the bitterness this woman feels about the attitude of society towards the older generation and symbolic meanings assigned to the old age.

From the interview analysis and compilation of the most important categories in the illness experience of elderly people, it is possible to conclude that there is a mutual interaction between the illness experience and social representations of ageing. Social representations of ageing, such as collapse, normality of illness or uselessness, negatively affect the elderly people's illness experience. The health care system does not assume responsibility for solving this problem, and within the biomedical model it is not considered a problem to be addressed in medicine. However, from a social point of view, the fact that at least some of the negative social representations can be influenced and changed is the most significant. Categories that can be influenced on the social level are the overall public attitude towards the elderly and ill people as well as the meaning assigned to the old age in interaction. It is also necessary to change the attitude of health-care workers towards the chronically ill and elderly people as patients and to reassess biographical aspects of chronic illness experience in the relationship between the patient and the doctor and the interaction between the ill person and his/her relatives.

As for the incorporation of the illness into the biographical context, it is important for "successful illness" narratives of retired people to appear in the public space because active ageing scenarios place more emphasis on a healthy and active image of a pensioner. If the elderly people who successfully coped with the illness and continued to actively build their lives without making the illness a center of their lives became more visible and audible, it would possibly form new interpretations of the old age and illness in society.

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„Tada ji pažiūrėjo į mane ir pasakė: senatvė!”
Socialinių senėjimo reprezentacijų įtaka senyvo
amžiaus žmonių chroniškų ligų patirčiai Latvijoje

Santrauka

Straipsnis analizuoja socialinių senėjimo reprezentacijų, tokių, kaip išsekimas, ligos neišvengiamumas ir netinkamumas, įtaką senyvo amžiaus žmonių chroniškų ligų patirtims Latvijoje. Ši kokybinė studija remiasi teoriniais simbolinio interakcionizmo teiginiais ir grindžiamosios teorijos metodologija. Tyrimo rezultatai leidžia daryti išvadą, kad tam tikros socialinės senėjimo reprezentacijos Latvijoje turi neigiamą poveikį

tam, kaip senyvo amžiaus žmonės patiria chroniškas ligas. Tai savo ruožtu neigiamai veikia senyvų žmonių gyvenimo kokybę, siejamą su sveikata, trukdo jiems kreiptis į sveikatos apsaugos įstaigas reikalingos medicininės pagalbos ir sėkmingai inkorporuoti chroniškas ligas į savo biografijas. Kartu neigiamos socialinės senėjimo reprezentacijos neskatina pritaikyti fizinę aplinką senyvo amžiaus žmonių, sergančių chroniškėmis ligomis, reikmėms.